



Touch of Courage . . . Connection

April 2014

TAKING ACTION – EDUCATING – ADVOCATING – MAKING A DIFFERENCE

IN THIS ISSUE

Life – During and After Cancer

A Personal Testimony by Jake Schaefer L.M.H.C., N.C.C.
of Inspire Hope Consulting

Diagnosed with Leukemia at the age of 5 (now 35 years old), I was very fortunate with the treatments available. I went into an early remission and medically never looked back. However, mentally cancer is something that remains with me in a variety of ways.

People often ask me if I remember anything about my cancer treatments. I used to respond, "How could I not". This was until I realized that it is impossible for someone without cancer to realize how intrusive cancer is. So for those of you who thankfully have never experienced cancer this is what I remember . . .

The feelings of isolation in the hospital, or if I was stuck inside to avoid infection – seeing the rest of the world go by without me – the huge pill regiment every day – walking into kindergarten bald – feeling like an idiot in math because of chemo brain – the piercing needles going through my bones during bone marrow aspirations – the thousands of sticks I had from blood draws, chemo treatments, and various other procedures – the anxiety I had driving to Iowa City knowing the next day I would have needles shoved in me – feeling jealous that no one else around me had to deal with this – feeling lonely that although death haunted me I had no one

to talk to about it – the pain of hearing I may not be able to have children – the guilt when I lost my friends to cancer – the isolation I feel when I'm around people that can't understand – finally, everyday I remember the anxiety about it coming back.

These are small accounts of my cancer experience. They have stayed with me for a very long time. For a while I avoided being a cancer survivor. I tried to live my life like everyone else. However, cancer never left me. It hung around no matter how hard I tried to ignore it. I tried to push cancer out of my life. I stopped going to events. I stopped talking to people about cancer. I stopped telling people I had cancer. The problem was I still had all of the feelings, worries, fears, etc., but now I had buried them and cut myself off from my support system.

I needed to learn to take charge of my survivorship and stop letting cancer dictate the rest of my life. The first big step I took towards improving my life as a survivor was going to counseling to move past my post-traumatic stress symptoms. I was having difficulty with depression and anxiety. I was highly

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Living with Cancer -

Evelyn Gardner's survivor story

On September 15, 2011 at age 28 I was diagnosed with breast cancer and it was the scariest day of my life, so I thought at the time. Days after I was informed that the cancer had already started to spread to my bones. I was beyond scared and all I could think about was my husband Corey and our three children Vaneia (8), Corey Jr. (3), and Valarie (2).

I started chemotherapy right away, Adriamycin, Cytosan followed by Taxol, a very aggressive treatment. I was on that treatment until October 31, 2011 and then I was placed on Tamoxifen. In February 2012 I decided to have a double mastectomy and that was painful both physically and mentally. I thought I would never recover but I did. Just when I was starting to be okay with things I got more bad news.

At my monthly doctor's appointment I was told my incision where not healing correctly and I was given a pet scan. The results showed new spots in my bones and I was told I would be doing chemotherapy again. In November of 2012 I started Abraxane and things seemed to be going fine. But after a couple of months I started noticing numbness in my fingers and toes. I was in the beginning stages of neuropathy one of the side effects of this new treatment. So I continued with this treatment for a little while longer until my tumor markers started to rise and I was then placed on Havalen, another type of chemotherapy. Since it was stronger than the last one, I would be getting a low dose. At that point and time in my life I was just plain tired of everything that had to do with me having cancer but I knew I had to be strong for my family.

As though that wasn't hard enough the neuropathy was getting worse. It was starting to make my legs numb and slowly moving up. My treatment dosage was then lowered. That worked for a short while, but in the middle of October it was becoming hard for me to walk. So after discussing it with the doctor we decided I needed to stop

the treatment and start receiving fosciladex a hormone suppressant. So after getting

another pet scan and making sure I didn't have any new spots and the spots I already

had were under control I started the fosciladex in November of 2013.

In January 2014 at a routine appointment I was told my hormone leveled had become extremely high over a matter of weeks because my ovaries were working overtime to replace the hormones the fosciladex were destroying and I would need to have them removed. So on February 3rd I had my ovaries and tubes removed and I am happy to say they were cancer free.

With the support of my husband, Corey, my family, in-laws, friends, the Beyond Pink TEAM and Splash of Color, I will continue to fight this on-going battle with cancer and enjoy each day I am here with my family.

Continued from page 1

embarrassed about this and was to the point I could not handle things on my own. Through the process I learned how reactions I had were associated with the intensity of what I went through. The simple act of talking about my experiences with someone who would be there just to listen was wonderful. It took this huge weight off of my shoulders. I slowly began to learn how to manage my problems, and it helped me put things in context. I have worked to get connected with other survivors through different causes and organizations.

In my late 20's, I received a gift to attend a young adult survivors camp in Montana. It was like coming home. I was in a group of complete strangers, but we all had one thing in common – cancer. It was an instant bond. I didn't have to hide or censor myself. I didn't have to worry about people not understanding. It also helped me take my survivorship more seriously. It was great being around other cancer survivors because simply put we were "family". The Livestrong Summit taught me to take charge of my survivorship and medical care. I got over being embarrassed being followed up in pediatrics. I went and had cognitive testing done to understand the effects chemo and radiation had on my brain. I began working on living a healthy lifestyle. I stayed involved in the cancer community to honor those who went before me. Finally, I have learned how to keep the anxiety of possible second cancers at bay.

I'm lucky enough to have a great life. I found a terrific woman who worked to understand what cancer is like for me. I'm blessed to have an 8-month-old son. I'm an independent consultant with Inspire Hope Consulting. I'm also a licensed mental health professional with Cedar Falls Counseling Associates.

"Going Green"



By Cindy Harris, a breast cancer survivor

Organic Foods the Best!

There are some foods that no matter how much we love them we need to stop eating them unless they are organically grown. Strawberries, though good for you, are one of the worst and probably one of our favorites.

When the Food, Inc. program tried to film the workers in the strawberry fields they weren't allowed. They weren't even allowed to take still pictures. This is because of the huge protective suits and masks the workers wear to protect themselves while applying the 13 different pesticides put on the strawberries. Washing the strawberries can't get all this off. Even if they are a bit more expensive organic strawberries should be the only ones you eat.

These chemicals are also killing our bees, which is critical to the future of our food supply.

Above & Beyond Cancer

Dr. Deming, Medical Director-Mercy Cancer Center, Des Moines, will be the guest speaker at the **YOUNG CANCER SURVIVORS - Meet, Mingle and Learn with Other Young Women** on Tuesday, April 15, 2014 from 4:30 – 7:00 p.m. at the Unitarian Universalist Society, 3912 Cedar Heights Drive, Cedar Falls, IA (*just south of AEA267*).

Dr. Deming, known in the community for the compassionate care he provides cancer patients and their families, is involved in many national, state and community organizations and is the recipient of numerous awards. He was awarded the Lane Adams Award by the American Cancer Society for excellence and compassion in patient care. He is the recipient of “the one hundred” Award by Massachusetts General Hospital for his work with cancer survivors. He was awarded the Iowa Cancer Champion Award for his tireless efforts in the field of advocacy. He is dedicated to the principals of human dignity, social justice, and compassion. He is inspired by the courage and compassion of his patients and their families. He is also an athlete and adventurer

His greatest ambition is to encourage others to pursue lives of meaning, purpose, passion and compassion. Dr. Deming is the Founder and Chairman of Above & Beyond Cancer.

Young Cancer Survivors
is a **FREE EVENT** and
Open to **ALL** persons living with
cancer.

Agenda

4:30–5:30pm – Refreshments and social

5:30–6:30pm – Dr. Deming – **“Above and Beyond Cancer”**

6:30–7:00pm – Wrap up and final questions

Refreshments provided by Panera Bakery and Cafe.

Event sponsored by **Beyond Pink TEAM** –
Contact Gabbi DeWitt with questions at
319-292-2225



Dr. Deming with baby in Nepal – 2000



National Breast Cancer Coalition (NBCC) was founded in 1991 with the mission to end breast cancer through the power of action and advocacy.

On September 20, 2010, NBCC launched a plan of action to reach their mission. Breast Cancer Deadline 2020 is a call to action for policymakers, researchers, breast cancer advocates and other stakeholders to know how to end breast cancer by January 1, 2020.

Breast Cancer Deadline 2020® has gained tremendous support since its inception. From scientists and researchers who are working with us on our innovative Artemis Project® to bipartisan cosponsors of the Accelerating the End of Breast Cancer Act to consumer advocates who review research proposals for the Department of Defense Breast Cancer Research program, NBCC is not alone in our efforts.

Recent scientific progress has created an unprecedented opportunity to development of a preventive vaccine.

The Deadline has two primary areas of focus: **(1) to prevent breast cancer in the first place** and **(2) to prevent metastasis**. Three seed grants have been awarded to support research in these areas.

NBCC has a great plan, solid leadership and dedicated supporters. In fact, 2013 was one of the most successful years so far in the Breast Cancer Deadline 2020 campaign. But we need your help to surpass last year's achievements. Each year we need to build on the momentum that we achieved the year before. Your support in this effort is critical. To learn more how you can support Breast Cancer Deadline 2020, visit: www.breastcancerdeadline2020.org/get-involved.

Fear of Recurrence – Practical Tools for Coping

From “Living Beyond Breast Cancer”

- Give yourself a break.** Let yourself experience scary feelings and fears, but limit your “worry time”. Reflect on and address your worries by writing in a journal or talking with a friend about your concerns.
- Focus on things you enjoy.** Take time to process your emotions, but stay busy at other times to take your mind off cancer. Taking part in activities you enjoy helps you to focus on the present and improve your mood.
- Avoid stress.** Don't take on things you don't have to take on, and try to accept help when you need it. Allow yourself to say “no.”
- Get the facts.** Your healthcare team can help you review your personal risk for recurrence.
- Journal.** Direct your emotions onto paper or a computer.
- Enjoy your creativity.** Channel your emotions into a creative outlet like crafts or movement.
- Use physical activity.** Moving your body will help improve your mood and can decrease anxiety and improve sleep, mood and energy.
- Make lifestyle changes.** Exercising, getting enough sleep, eating a well-balanced diet and working to maintain your physical and mental health can help you cope.
- Explore your spirituality.** Being spiritual or learning about spirituality is a coping tool for many women. Being outdoors helps connect with nature and appreciate the vastness of the universe.
- Find meaningful ways to help others.** Getting involved in the community, volunteering your time or engaging with organizations can be a great way to stay busy and develop a new sense of meaning in life.



Each year, more than 4 million people in over 20 countries raise much-needed funds and awareness to save lives from cancer through the Relay For Life movement. During a Relay event, participants and survivors Celebrate what they've overcome. Attendees Remember people lost to the disease, and honor people who have fought or are fighting cancer. The event inspires Relay participants to Fight Back by taking action against a disease that has taken too much.

Area Relay For Life events are:

Relay For Life of UNI (Cedar Falls) – April 11, 2014 at McLeod Center

Relay For Life of Chickasaw County (New Hampton) – June 6, 2014 at Mikkelson Park

Relay For Life of Buchanan County (Independence) – June 7, 2014 at Lyle Leinbaugh Football Field & Track

Relay For Life of Bremer County (Waverly) – June 13, 2014 – Waverly-Shell Rock High School

Relay For Life of Grundy County (Grundy Center) – June 13, 2014 – Grundy High School

Relay For Life of Tama County (Tama) – June 14 at South Tama High School

Relay For Life of Fayette County (Oelwein) – June 14 at Oelwein High School

Relay For Life of Black Hawk County (Waterloo) – June 20, 2014 at Hawkeye Community College

Relay For Life of Butler County (Allison) – July 11, 2014 at Butler County Fairgrounds

To find Relay events in your area,
Call 1-800-22702345
or visit www.relayforlife.org

Celebrate – Remember – Fight Back

Support Group Meeting Dates

April 1, 1:30 p.m.

Care & Share Cancer Support Group

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

April 7, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

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

April 14, 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

April 15, 4:30-7:00 p.m.

Young Cancer Survivors

Meet – Mingle and Learn

Unitarian Universalist Church
3912 Cedar Heights Drive, Cedar Falls
Gabbi – 319-292-2225

May 5, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

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

May 5, 4:45-6:45 p.m.

Grundy Area Cancer Support Group

Support for ALL cancers

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

May 6, 1:30 p.m.

Care & Share Cancer Support Group

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

May 8, 5:00-7:00 p.m.

Splash of Color – Women of Color

Breast Cancer Support Group

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

June 2, 1:30 p.m.

Touch of Courage

Breast Cancer Support Group

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

June 3, 1:30 p.m.

Care & Share Cancer Support Group

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

June 9, 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

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

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.

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

Volunteer for BPT . . .

If you are interest in volunteering for the Beyond Pink TEAM, please visit our website at beyondpinkteam.org or contact Jessica Miller at jmiller1321@gmail.com

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

Sunday, June 15, 2014 – Pretty in Pink Horse Show – Silver Spur Saddle Shop Arena, 3574 W Shaulis Road, Waterloo

Waterloo Bucks "Breast Cancer Awareness" at the Ball Park – **Tentatively Monday June 16, 2014** – River Front Stadium, Waterloo – First Pitch 6:35 p.m.

Beyond Pink TEAM 2013 Year End Report

October 2013 marked the 25th Anniversary of the first meeting of the Beyond Pink TEAM. At that first meeting, our organization was called the Cedar Valley Committee for Breast Cancer Awareness. The focus of this collaborative group of volunteers was to raise breast cancer awareness, increase utilization of screening mammography, provide affordable mammography, and provide a breast cancer support group. We continue to be a diverse group of dedicated volunteers, representing many health, service, and educational organizations, without the benefit, or expense, of an office and staff.

The past 25 years have seen much growth in our organization along with a name change to better reflect who we are today. Beyond Pink TEAM represents that we have gone beyond awareness and pink ribbons to Take action, Educate, Advocate and Make a difference (TEAM). And we do live up to our name.

When the Beyond Pink TEAM sees a need, we Take action. Uninsured and/or underinsured women were getting free screening mammograms through Care For Yourself. Several women had abnormal findings on their mammograms but refused biopsy when told not all biopsy charges would be covered by the Care For Yourself program. In 2006, we established the Beyond Pink Fund at the Northeast Iowa Community Foundation. This fund is used to pay breast medical expenses, including breast biopsy charges, and some living expenses for women in breast cancer treatment. In 2013, the fund paid \$51,726.77 towards bills owed by 76 women.

The Beyond Pink TEAM Educates women through speakers at support groups, interacting with the community at health fairs using our version of Jeopardy, presentations to organizations and church groups, and our breast cancer newsletter. We have been writing, printing and distributing free newsletters for 17 years. Current

and past issues are available on our website at www.beyondpinkteam.org. We also teamed with the Cedar Falls and Waterloo Fire Departments to make the July 7, 2013 Pink Fire Truck an inspirational and educational event.

As an organizational member of the National Breast Cancer Coalition, the Beyond Pink TEAM Advocates for women and men living with breast cancer. We support NBCC's Breast Cancer Deadline 2020, bringing awareness to NBCC's goal to eradicate breast cancer. By the year 2020, they are on target to have a vaccine to prevent breast cancer and drugs to stop metastasis so women can live with breast cancer as a chronic disease. These breakthroughs will in turn help research for all types of cancer. The Beyond Pink TEAM is currently serving a three year term on the NBCC board. Christine Carpenter serves as the NBCC field coordinator for Iowa as well as serving as our representative on the NBCC board along with Lori Seawel.

On October 17, 2013, the Beyond Pink TEAM held a 25th Anniversary Celebration of Accomplishments at the Gallagher Bluedorn Performing Arts Center. The reception and program were open to the public, breast cancer survivors, and Beyond Pink TEAM members and donors.

Our accomplishments over the past 25 years are many and we have Made a difference in the lives of women living with breast cancer in our community. One of the ways we make a difference is by supporting women with a teddy bear and message of encouragement before going into breast cancer surgery. We also provide a packet of information, including contacts for our three support groups. We sponsor a traditional monthly support group (Touch of Courage), a quarterly group focused on young women living with all types of cancer (Young Cancer Survivors), and a quarterly group focusing on women of color (Splash of Color). We also support other support groups in surrounding areas.

The Beyond Pink TEAM could not provide all of this for the Cedar Valley

and surrounding communities without a dedicated team of volunteers. They give countless hours of their time and talents. We have spent the past year reorganizing Our Beyond Pink Fund would not be able to provide financial assistance without the many individuals, businesses, sports teams, and organizations that give donations to the fund. At last count, 45 events were held by you in 2013! You are all amazing and are helping so many women during a stressful time in their cancer journey. Thank you to all of the Beyond Pink TEAM and donors. Together we are making a difference.



Healthy Eating

Lemon Blueberry Muffin Bread

from Hawkeye Community College Health Fair

- 2 cups all-purpose flour
- 1 ½ teaspoons baking powder
- 1 teaspoon salt
- 1 stick unsalted butter, room temp
- 1 cup sugar
- 2 cups blueberries
- 2 teaspoons lemon zest
- ½ cup plain Greek yogurt, regular or low-fat

Preheat oven to 350 degrees. Spray a loaf pan with nonstick cooking spray and set aside. Add blueberries and lemon zest and toss to combine. Cream together the butter and sugar until light and fluffy. Add the eggs, one at a time, beating well after each addition. Add the yogurt and dry ingredients, mixing only until incorporated and being careful not to crush the blueberries. Scoop the batter into loaf pan. Bake for 1 hour and 10 minutes, or until golden brown. Let cool 10 minutes in pan before inverting gently onto a plate.

MISSION – Beyond Pink TEAM is a nonprofit organization whose mission is to provide breast cancer prevention, education, support and advocacy for comprehensive, quality health care for ALL in the Cedar Valley and surrounding communities.

Resources

Information, support, counseling, and educational materials are available from the following:

Beyond Pink TEAM is a local breast cancer organization providing a variety of services. Our website lists services we provide as well as other services available in the Cedar Valley. www.beyondpinkTEAM.org

Living Beyond Breast Cancer includes a helpline, newsletter and information. Survivors Helpline: 888-753-5222 www.LBBC.org

Young Survival Coalition connects with other young women diagnosed with breast cancer. www.youngsurvival.org

Cancer Care is a national nonprofit organization offering counseling, support, financial assistance and education to individuals with cancer and their families. www.cancercare.org

Iowa Cancer Consortium offers cancer information and links to resources in Iowa. www.canceriowa.org

American Cancer Society offers cancer information and services. www.cancer.org. 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

M.D. Anderson Cancer Center, University of Texas offers patient and cancer information. 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

Touch of Courage • • • Connection

Cedar Valley Cancer
Committee
4756 Charolais Dr
Waterloo, IA 50701
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