



Touch of Courage

. Connection

Beyond Pink TEAM

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Breast Care Patient Navigation

By Kelly Flaucher, R.T. (R)(M)

Breast Care Navigators are typically people that have a passion in caring for others. The role of a Breast Care Navigator is varied, often becoming an advocate for our patients and a liaison between the medical providers for each patient. The main goal always remains constant – making sure there are no barriers to care for each and every patient.

The first patient navigation program in the United States was established by Harold P. Freeman, M.D. in a Harlem Hospital. Dr. Freeman found that some people had an inability to access complex and often confusing cancer care services. He found that the poor and medically underserved patients suffered a higher cancer mortality rate. Therefore his goal was to advance access to cancer screenings and address delays/barriers to care. He wanted to make sure that every person with a suspicious finding received a timely diagnosis and treatment disregarding minority and their socioeconomic situation.

Since 1990, there have been studies done that show there is evidence to support the role of patient navigation in breast cancer to improve many aspects of cancer care. The pilot program compared five year survival rates for breast cancer patients who were navigated and those who were not, and found a marked improvement in the navigated patients. Breast cancer is an optimal area for patient

navigation because of known survival benefit of early detection through clinical breast exam, mammograms, and early intervention. It is also important in breast cancer because of documented racial disparity in breast cancer care across the country. In studies they found that even though there were many efforts toward coordination of care for women with early stage breast cancer, there were no consistent methods to track care or receipt of care as well as missed appointments.

When breast cancer patients are diagnosed many patients experience emotional turmoil, they have informational needs, and some have logistical challenges. As a Breast Care Navigator, you have to look at each individual patient and tailor your assistance to their needs. The navigator is the one constant for patients, health care providers, and community partners. They become a liaison between all of the doctors and services a breast cancer patient uses.

It is very important that patients are educated about breast cancer so that they can make an educated decision about their care. The navigator plays a very important role in this by supplying vital information about options available to them. We are often like a “personal assistant” to the patient. A navigator needs to be compassionate, resourceful,

organized, a good communicator, and able to solve problems creatively. When communicating with a patient, they need to be sincere and listen to the patient's wants and needs. The Breast Care Navigator should enlist the patient to become proactive in their care by educating them. They often bridge any gaps to help patients and their families get through the complex healthcare system in a timely manner. We want to make sure the patients do not "fall through the cracks" because of disconnect between health care providers, community services, and cancer centers.

It is important for the Breast Care Navigator to start an open line of communication for the patient at the time of diagnosis and in some cases, suspicious findings. The navigator sets up referral appointments as well as accompanying patients to some or all of their first appointments if possible. They often assist in referring patients to appropriate sources for needed items such as post-surgical compression bras, etc. A navigator should do their best to help streamline appointments for each patient based on their needs.

A Breast Care Navigator should track care from suspicious finding through treatment and survivorship. They monitor a patient's progress and if an appointment is missed they should find out why and get the appointment rescheduled. Navigators want to help patients stay on track with their treatment plan. After treatments, a navigator continues to monitor patients closely and helps the patient in scheduling follow-up appointments. It is equally important to follow both malignant and benign findings to ensure proper follow-up care is being provided. This improves the

quality of care for each patient having suspicious findings.

Breast Care Navigators can help breast cancer patients immensely by providing the following:

1. Save lives for women by scheduling patients with suspicious findings so that they receive a timely diagnosis and treatment.
2. Eliminate any barriers to care by providing access to available services and ensuring patients are not lost in follow-up care
3. Ensure timely delivery of services – moving patients through the complex healthcare system to provide the best patient care possible.

I have had over 20 years of experience in women's health. I take pride in meeting the comprehensive needs of our patients and fulfilling my role as a Breast Care Patient Navigator. I am inspired every day by the strength of women diagnosed with breast cancer and I want to do everything I can to help them along that journey.

Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment
by Sandra Steingraber, Ph.D.
compiled by Christine Carpenter for this newsletter

There was once a village along a river. The people who lived there were very kind. These residents, according to parable, began noticing increasing numbers of drowning people caught in the river's swift current. And so they went to work devising ever more elaborate technologies to

resuscitate them. So preoccupied were these heroic villagers with rescue and treatment that they never thought to look upstream to see who was pushing the victims in. This ongoing column will be a walk up that river.

In the January newsletter we discussed the first trend which is growing acknowledgement that cancer causation is complex. Please see the January newsletter for more information about this first trend.

The second trend in our understanding of the environment's contribution to cancer is an emerging awareness of the importance of epigenetics. The old way of thinking saw DNA - the bricks and mortar of our genes - as a master molecule. Cancer was thought to arise through the inheritance of bad genes or by damage to good genes (mutations). The new thinking acknowledges that cancer can arise through a third route: by changing the behavior of genes. The study of how substances alter gene expression is part of the field of epigenetics. Some chemical exposures appear to turn on and turn off genes in ways that deregulate cell growth and predispose for cancer. From this perspective, our genes are less the command-and-control masters of our cells and more like the keys of a piano, with the environment as the hands of the pianist.

So, how do we have hope? The mounting evidence that our environment is playing a bigger role in the story of cancer than previously supposed is good news because we can do something about it. Check out Breast Cancer Fund's website www.breastcancerfund.org and learn more about the environment and breast cancer and how to reduce your risk.

Beyond Pink TEAM Advocates to Press for the End of Breast Cancer by 2020

On Tuesday, May 3, 2011 in the nation’s capital, the *Beyond Pink TEAM* delegation will join breast cancer advocates from across the country to lobby Rep. Bruce Braley (Democrat, 1st district) and Senators Charles Grassley (Republican-Iowa) and Tom Harkin (Democrat-Iowa) on the National Breast Cancer Coalition’s (NBCC) 2011 breast cancer legislative priorities and NBCC’s Breast Cancer Deadline of 2020. The National Breast Cancer Coalition has set a date and an agenda for ending breast cancer by January 1, 2020.

After three days of extensive training at the National Breast Cancer Coalition Fund’s Annual Advocacy Training Conference, Christine Carpenter and Trish Pedersen of Cedar Falls and Jane Clark, Anne Doyle, Cindy Harris, and Cathy Ketton of Waterloo, members of *Beyond Pink TEAM*, will join breast cancer survivors and other activists working to eradicate this deadly disease. They will discuss NBCC’s breast cancer public policy issues with their elected officials during NBCC’s annual Lobby Day and urge them to support the NBCC priorities. Key priorities covered include implementation of the Patient Protection and Affordable Care Act, the importance of the Department of Defense Breast Cancer Research Program, and Breast Cancer Deadline 2020.

Iowa activists have been participating in NBCC annual Lobby Days and working to forward its agenda for years. This is the 14th time that members of *Beyond Pink TEAM* have participated in NBCC’s Lobby Day and discussed substantive breast cancer public policy issues with members of Congress.

About The National Breast Cancer Coalition

The National Breast Cancer Coalition (NBCC) is dedicated to ending breast cancer by 2020 through the power of grassroots action and advocacy. NBCC increases funding for breast cancer research; monitors how those funds are spent; expands access to quality health care for all; and ensures that trained advocates influence all decision making that impacts breast cancer. Join NBCC, learn more and take action – visit www.BreastCancerDeadline2020.org.

About *Beyond Pink TEAM*

Founded in 1988, *Beyond Pink TEAM* is a nonprofit organization whose mission is to provide breast cancer prevention, education, support, and advocacy for comprehensive quality care in the Cedar Valley and surrounding communities. Join the *Beyond Pink TEAM* – visit www.cedarvalleybreastcancer.org

Beyond Pink TEAM Offers Support

The Beyond Pink TEAM has several options available for you to find the support you need. On the first Monday of each month, we offer a more traditional breast cancer support group. Dawn Colbert facilitates the meetings at 1:30 pm in the Kimball Ridge Center, 2101 Kimball Avenue in Waterloo.

If that doesn’t work with your schedule, we also have Young Cancer Survivor Events held quarterly at the Area Education Agency (AEA267), 3712 Cedar Heights Drive in Cedar Falls. These meet, mingle and learn events are aimed at all young women living with cancer. What is young? Everyone is welcome to attend. The event was started as a way for young women diagnosed with any type of cancer to share their stories and learn from each other how to live with issues unique to the younger woman with cancer. Our next event will be Tuesday, April 19 from 4:30-7:00 pm. They are held the third Tuesday of April, June, September and January. You can visit our website at www.cedarvalleybreastcancer.org to see the flyer.

Our newest option is Splash of Color, a breast cancer support group for women of color. These meetings are held the second Thursday of February, May, August and November at the Waterloo Public Library, 415 Commercial Street from 5:00-7:00 pm. Splash of Color is focused on women of color, however all women are welcomed by Cathy Ketton and her daughters, Shae and Niisha. Their next event will be May 12.

The Beyond Pink TEAM is working on bringing other support options to the Cedar Valley. We are working on a partner/caregiver support group for those who have a loved one diagnosed with breast cancer. We are also working with agencies in counties surrounding Black Hawk to help bring breast cancer support groups to their areas. Our goal is to see that the support is there for every individual affected by breast cancer.

Living Green By Cindy Harris

Sometimes now, I think I can almost smell Spring! I hope everyone has their corn gluten down. Now is also a good time to begin getting supplies you may need for your compost tea, too. If you don't remember what compost tea is, just go on line and look up the easy instructions.

If your compost pile has thawed, this is the time to stir it up so it starts going again. Did you know that a can of beer will give your compost a quick start? It can be flat, old or fresh. The yeast works the same way.

You can start your seeds in starting soil now and place them in a South window. When the days are in the 50's place them outside in the afternoon for awhile. Make sure that they are sitting somewhere the rabbits can't get to them! By placing them outside for this time, the stems grow stronger while the plant adjusts to the outdoors, ensuring some nice plants. I have tulips and daffodils up already and to keep the rabbits from eating them I put blood meal or human hair on them.

And remember! If you are cleaning out the garage or basement, don't just throw chemicals in the trash. This can be detrimental to our environment. Go to earth911.com and put in your zip. You can find a place to take almost anything. Remember, compost, recycle and reuse. It might make a dent in cancer.

WHAT IS RELAY FOR LIFE? By Jill Roberts

Relay for life is the American Cancer Society's signature event. It is a life changing event that brings together people to:

- Celebrate the lives of those who have battled cancer. The strength of the survivors to inspire others to continue to fight.
- Remember our loved ones lost to the disease.
- Fight back. It is a community event to participate in the fight against cancer.

This year's Black Hawk County Relay for Life will be June 17th and 18th. It will be held once again at Hawkeye Community College. Event kick off with the survivor lap will start at 6:00 pm. There will be music, kids' events, food and fund raising.

At relay, teams of people camp out and take turns walking around the path. We ask that there is one person on each team walking and taking their turns on the path for every hour of the night because cancer never sleeps.

If you have never been to a relay, PLEASE come and experience this life changing event. If you would like to be a part of a relay for life team check out the website below and with the additional information or call the local American Cancer Society 319-272-2880.
www.relayforlife.org/blackhawkcountya

Pictures!



Young Cancer Survivor members



Splash of Color members

A Survivor's Story by Kristin Teig Torres

*Think positive, lead a Normal life,
Kick some Cancer Butt...*

These are all mantras I have been saying to myself since December 15, 2009, the day that I had my annual mammogram before going to work. The day that I got a call later in the afternoon saying that something was abnormal and my doctor's office was going to schedule a consultation and possible biopsy with a local breast care specialist. I knew as soon as I hung up the phone that I had cancer. I cried that night as I sat and talked to a friend. I was scared, but I had a peaceful feeling, too. I knew I was going to be okay. I knew what I had to do. Power through the treatment, continue on with my life, and kick some cancer butt!

I am happy to say that I did just that. I continued working full time, continued to stay on top of what my husband and two children (ages 7 and 4) were doing, and continued to study for my graduate degree in Philanthropy and Nonprofit Development at UNI. I traveled to London for 8 days for a work trip I helped plan for my college alumni association, and I played Marian the librarian in a local production of *The Music Man*, all while visiting my oncologist once a week for 12 weeks to received the drug, Taxol.

Why didn't I rest? Why should I?

I was feeling good and was able to keep the schedule I normally would. I saw no reason to stay in bed thinking about my health. I did make sure to get at least 8

hours of sleep each night. I put my health in the hands of my medical team which included a massage therapist and yoga instructor. I made sure I ate well and appreciated positive, supportive comments from my friends and family. I didn't want negative energy around me and if someone began telling a story of how bad treatment would be, or launched into the death of one of their loved ones, I would turn around and walk away.

I had my last radiation treatment on September 16, 2010. I did fairly well; I didn't blister until the very end and though I was tired, I knew this was temporary. My diagnoses and treatment is a chapter in my life that I really didn't want to write and I certainly wouldn't want anyone else to experience. It is a chapter that is now closed. I learned a lot about myself and the people who care about me. I learned I can handle anything – I am in control. Maybe I couldn't control the fact that I had cancer but I could control my attitude towards it.

I kicked some cancer butt with grace and style, if I do say so myself, and it feels good!

Cleaning for a Reason By Jill Roberts

There is a program that provides free housecleaning, once per month for four months, while a woman is in breast cancer treatment. All she has to do is sign up and have her doctor fax a note confirming the treatment. Cleaning for a Reason will have a participating maid service in her zip code area arrange for the service. This

organization serves the entire USA and currently has 547 partners to help women during treatment for any type of cancer. To apply, visit their website at <http://www.cleaningforareason.org/index.html>.

Stuff Etc.

Stuff, Etc is a consignment store that recently opened and is located in the old Office Max building at 1210 Flammang Drive. The Beyond Pink TEAM has set up an account at Stuff Etc so that you can bring in items and have the proceeds go to the Beyond Pink TEAM. Stuff Etc accepts gently-used clothes of recent style and clean household items in working order.

To make an appointment to bring in your items, please call 233-8009. You will give them our account number (2181) and name (Cedar Valley Cancer Committee Beyond Pink Fund).

Thank you for your support!

Save the Date!

Apr 4 1:30 p.m.
Touch of Courage
Breast Cancer Support Group
2101 Kimball Ave., Waterloo
Dawn Colbert 415-6430

Apr 5 1:30 p.m.
Care and Share Support Group
Covenant Cancer Treatment Ctr.
200 E. Ridgeway, Waterloo

Apr 11 1:30-3:30 p.m.
Look Good, Feel Better
RSVP to American Cancer
Society at 866-460-6550

Save the Date! (cont.)

Apr 19 **4:30-7:00 pm.**
Young Cancer Survivors Event
AEA267

3712 Cedar Hts. Dr., Cedar Falls
Emily Hodgins 239-8118

Apr 30-May 3
National Breast Cancer Coalition
Annual Advocacy Conference and
Lobby Day in Washington, D.C.

May 2 **1:30 p.m.**

Touch of Courage
Breast Cancer Support Group

May 3 **1:30 p.m.**
Care and Share Ca Support Grp

May 12 **5:00-7:00 p.m.**

Splash of Color Event
Waterloo Public Library
Cathy 319-493-8857

Jun 6 **1:30 p.m.**

Touch of Courage
Breast Cancer Support Group

Jun 7 **1:30 p.m.**
Care and Share Ca Support Grp

Jun 17-18 **5:30 .**

6:00 p.m. Survivor Lap
ACS Relay for Life
(see article)

Jun 20 **1:30-3:30 p.m.**

Look Good, Feel Better
RSVP to American Cancer
Society at 866-460-6550

Jun 21 **4:30-7:00 p.m.**

Young Cancer Survivor's Event
3712 Cedar Hts. Dr., Cedar Falls

Jul 5 **1:30 pm.**

Touch of Courage
Breast Cancer Support Group

July 11 **1:30 p.m**

Touch of Courage
Breast Cancer Support Group

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.cedarvalleybreastcancer.org

Iowa Breast Cancer Edu-Action is a local advocacy group taking action against breast cancer. www.iowabreastcancer.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.

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.

Connect with us...

A donation for Touch of Courage is both needed and appreciated. All donations go to support the services of the Cedar Valley Cancer Committee and are tax deductible.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

\$_____ amount of donation

General Donation Newsletter Donation NBCC Scholarship Fund

Make checks payable to the Cedar Valley Cancer Committee and send to
1607 Heath Street, Waterloo, IA 50703