



Touch of Courage

Connection Beyond Pink TEAM

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Recipe for Survivorship

By Nancy McHone

“Survivorship” is a “buzz word” in the medical community. It’s not that we have not had any survivors in the cancer world; it’s more an issue of now we have so many survivors! In 2010 there were more than 12 million.

So who is a survivor and what does it mean to be a survivor? Back in 1986, the National Coalition for Cancer Survivorship said a survivor was *anyone* from the time of their diagnosis and for the balance of their life who had been or was diagnosed with cancer. So, welcome to the club to which you never sought membership! In 1992, a physician cancer survivor put a positive spin on the definition when she said, “a survivor who gets good care and lives as fully as possible is a **healthy survivor.**” (Dr. Wendy Harpham)

What does it mean to be a healthy survivor? Basically, it is becoming your own advocate and learning what you need to know for medical management to enhance your quality of life beyond cancer. **Facing Forward**, a publication of the National Cancer Institute, says the first step is knowing what to expect after cancer treatments so you and your family can make plans, lifestyle changes and important decisions as needed.

Some basic tools that are needed for healthy survivorship include:

1. Basic health care

team – oncologist, primary care provider, surgeon etc. – names and phone numbers

2. **Good communication skills** – yours or someone who can speak for you

3. **Knowledge of your treatment** – surgery (what kind?) chemotherapy (what drugs? What dose?) Radiation (what body part and how many rads?) What kind of cancer did /do you have?

4. **Acute and chronic side-effects** from treatment that you need to be aware

5. What kind of **follow up and with whom?**

6. **Daily exercise goals**

7. **Healthy diet** - nutrition counseling if needed

8. **Emotional support**

9. **Financial support planning**

Regarding numbers 1 and 2 above: it is important to have open communication with your health care team. Take notes at visits. Ask questions to be sure you understand what you are being told. Is it something you can and will do? Be honest. If not, ask for alternative ideas.

For numbers 3 and 4: It is very important to know exactly how you were treated for your cancer. Different surgeries and chemotherapy drugs and radiation treatment fields have different side-effects – some that happen during

Recipe, continued on page 5

Senator Charles Grassley



is Breast Cancer Hero

BPT members with Senator Grassley

Great news! On May 25th, Senator Grassley (R-IA) along with Senators Sheldon Whitehouse (D-RI), Senators Collins (R-ME), Brown (D-OH), Murkowski (R-AK), Shaheen (D-NH), Heller (R-NV), and Warner (D-VA) introduced the *Accelerating the End of Breast Cancer Act* (S. 3237) into the Senate. Senator Grassley was the impetus for getting around a Senate road-block. Iowans can be proud of Senator Grassley’s leadership and willingness to step up, be a leader, and do the right thing for women and men with breast cancer.

The *Accelerating the End of Breast Cancer Act* (S. 3237) focuses on the primary prevention of breast cancer and preventing breast cancer metastasis (spread to other parts of the body). It also creates the Commission to Accelerate the End of Breast Cancer. The Commission will be tasked with identifying promising opportunities, tools, technology and ideas not currently being prioritized for breast cancer by the public and private sectors, but which, taken together and applied to this issue, hold true promise in ending breast cancer.

All five Iowa Representatives are co-sponsors of the House version of the **Accelerating the End of Breast Cancer Act**, which currently has 214 bipartisan co-sponsors.

The Beyond Pink TEAM is so grateful for Senator Grassley’s leadership and foresight to do what is right for those with a breast cancer diagnosis and those who are not yet diagnosed.



It’s Time to End Breast Cancer!

Nearly 290,000 women and men will be diagnosed with breast cancer this year. Nearly 40,000 women will die of breast cancer in the US this year and breast cancer will take the lives of almost 500,000 women worldwide.

It’s time to advocate! In May, four ladies from the BPT traveled to the National Breast Cancer Coalition Annual Advocacy Summit in Washington, DC. The focus was on the Breast Cancer Deadline 2020.

“We were informed that currently billions of dollars are spent on breast cancer research, but the focus has not been on prevention and metastasis,” shared Jacque Bakker, BPT member attending the summit. *“Very little has changed in terms of breast cancer incidence and death over the past years. In the US the chance of a woman developing breast cancer in her lifetime was 1 in 11 in 1975. It is*

now 1 in 8! It was said that if we continue progress towards ending breast cancer at the current rate it could take 500 years to end it.”

While a great deal has previously been done to increase awareness of the importance of regular screening for detection of breast cancer, previous research and technology have not had significant impact on reducing breast cancer deaths and diagnoses. Currently there is an Act before Congress, Accelerating the End of Breast Cancer Act which asks for the focus of research to be primarily on prevention of breast cancer and prevention of metastasis. The BPT members visited Iowa Congressmen to ask for their support. We are happy to announce that all signed on in support of the Act.

Summit attendees – Trish Petersen, Christine Carpenter, Lori Seawel and Jacque Bakker



“I am a cancer advocate. I am committed to help end this disease,” states Jacque Bakker. *“When asked, ‘Why breast cancer?’ I answer ‘We have to start somewhere.’ The goal is for other cancers to follow and therefore we will have an end to the disease of cancer.”*

Support “Breast Cancer Deadline 2020”. Sign the petition on-line at www.breastcancerdeadline2020.org and help save millions of lives.

SEE SCAN – PAGE __

SAVE THIS PORTION!

Pick up bulbs on Saturday, October 6, 2012 from 8:00 a.m. to 10:00 a.m. at the parking lot of Covenant Cancer Treatment Center 200 E. Ridgeway Ave. Waterloo, IA 50702

If you are unable to pick up the bulbs by October 6, 2012 and do not notify us, your purchase will be considered a donation.



www.cedarvalleybreastcancer.org
Design and printing donated by Wheaton Franciscan Healthcare www.WheatonIowa.org

Hope Blooms for Breast Cancer

Plant it Pink is a project sponsored by the Beyond Pink Team to honor people affected by breast cancer. Our goal is to have pink tulips blooming throughout the Cedar Valley to show our support. Order your tulips by August 17, 2012 for fall planting on the order form below. If you are unable to pick up the bulbs by October 6, 2012 and do not notify us, your purchase will be considered a donation.



Tulip Angelique



Tulip Innuendo

Name _____
 Address _____
 City/State/Zip _____
 Contact Phone Number _____
 Email _____

Number of Bags	Cost	Type (A / I)
_____ Bag(s) of 12 bulbs at \$10 per bag	\$ _____	_____
_____ Bag(s) of 50 bulbs at \$40 per bag	\$ _____	_____
_____ Bag(s) of 100 bulbs at \$75 per bag	\$ _____	_____
TOTAL:		\$ _____

Send check made out to **BEYOND PINK TEAM**, along with order form to Nancy McHone, Covenant Cancer Treatment Center, 200 E. Ridgeway Ave., Waterloo, IA 50702. Questions, contact Nancy McHone at 319.272.2841 (may leave a message) or Nancy.McHone@wfhc.org.

Win a Chance for Either of These Two Quilts

1 chance for \$5 or 5 chances for \$20 - Raffles tickets available at all BPT Events. Drawing held Friday, October 19th.



Breast Cancer Conference
 To be held at the
Park Place Event Center
 One Technology Drive
 Cedar Falls on
Monday, October 1st
 From 5:30-9:15 p.m.
 With a Mini Health Fair
 From 3:30-5:30 p.m.



Saturday, October 6 - 8:00 am
Pink Ribbon Run
 downtown Cedar Falls



Congratulations to the first ever BPT Dragon Boat Team who "paddled" to first place in their division at the My Waterloo Days Event. Thank you to the Screaming Eagle Team who shared their cash "Spirit Award" with the 3 teams representing cancer supporting efforts.

Thank you!

Various groups, organizations and individuals have held events and donated proceeds to the BPT. We would like to thank the following for their generosity:

- Zumba**
- Cutting It For Cancer**
- Screaming Eagle Dragon Boat Team**

Hakuna My TaTa's – A Survivor's Story from Leanne Schipper

I was diagnosed with breast cancer in August of 2004 at the age of 41. Since the age of 18 I've always been faithful about yearly physicals. That never changed, even after having 4 kids, the youngest being 8. There was no family history of breast cancer at the time.

My family physician found the lump during one of my yearly exams. He ordered a mammogram and ultrasound. The mammogram showed nothing, but the ultrasound showed the lump. A biopsy determined that the cancer was DCIS and lumpectomy followed. A port was put in and then I had chemotherapy, followed by radiation.

During this time, my coworkers were absolutely awesome! They complimented me on my wig and I frequently found little "pink" gifts on my desk. My eyes became extremely dry from the chemo, so my coworkers even helped me put eye drops in my eyes! They also helped me with my work without complaint. Most of all they were my support team with their encouragement, humor and TLC! My employer was very flexible and worked with me around the radiation and chemo appointments.

My cancer came back in February of 2011. After weighing my options, I decided to have a double mastectomy. My coworkers threw a "going Away Party for Leanne's TaTa's" before the surgery. They sold t-shirts and koozies that said "Hakuna my TaTa's" on them. All donations and money made from the party were given to my Relay

For Life of Bremer County, Bosom Buddies.

I am so grateful that they helped me take a bad situation and turn it into a charitable success. My efforts to give back have proven to be labors of love. I participate with a team for Relay For Life of Bremer County and am on the committee for the Relay For Life of Butler County.

Of course, we don't forget the love and support our families give us, but we need the support from our coworkers as well. I was so fortunate to have it from both!

Splash of Color Honored at YWCA Women of Persimmon



Cathy Ketton, Shae Robinson and Nissha Walker are living proof that you can live, work and be happy after breast cancer. This family volunteer team works within their community to provide education, resources and support to women of color about breast cancer. They empower women to receive the care they need with the dignity they deserve. Four years ago this team took a vision and formed a reality, Splash of Color. The group's mission is to assist women of color to care for themselves, get healthy and live life to the fullest. The first Splash of Color Walk brought awareness that there is support for women of color surviving breast cancer. This year's Splash of Color

Walk will be held Saturday, October 27th.

The YWCA of Black Hawk County recognized the Splash of Color as their Women of Persimmon's Business/Organization that Empowers Women for 2012.



Living Green by Cindy Harris

Summer wonderful summer!! How about sunscreen on these great outings for the season? Some of our sunscreens may be causing as much cancer as the sun. We need to stay away from anything that contains oxybenzone as this is supposed to be kept away from kids and pregnant women. It is a hormone disrupter – BAD. Vitamin A and retinyl palmitate are being tested as photocarcinogenics (tumor-promoting when used in sun). That would be why the wrinkle creams with retinyl are only used a night. At this time zinc oxide is also being tested to see if it breaks down in the sun, causing the same tumor-promoting problem. At this time it looks like titanium dioxide may be the best. Most sunscreens, even the ones claiming to be "safe" have at least one of these chemicals in them. There are more chemicals, but these are the worst.

What to do? Get use to wearing a hat and light weight clothing with long sleeves. Limit the time our kids are in the direct sun is a very natural and safe protection. We need to figure something out as the USA has more skin cancer than any other country. But, then, we allow more chemicals in our sunscreen than other countries do. Have a great summer and be safe!!!

Recipe - continued from page 1

treatment and some that can happen years later. You need to know what to watch for and who to see if a problem develops. For example, Adriamycin, a chemotherapy drug, has cardiac toxicities. Should you have an EKG or a MUGA scan on a regular basis? Lymphedema can happen immediately after surgery or years after all treatments have ended.

The follow-up (number 5 above) that you need will be determined by your type and stage of cancer. If you are a breast cancer survivor, how often should you have a mammogram and who will do that for you? Your surgeon or your primary care person, your oncologist? The National Comprehensive Cancer Network (www.nccn.org) does have suggested follow-up for most cancers.

Exercise and a healthy diet are important to everyone. Research has proven that cancer survivors live longer when they maintain a healthy weight and exercise regularly. That doesn't mean that you must train as if for a marathon! Walking with some strength training (weights or resistance exercises) will suffice. Med Fit is a great program that is available to assist people to regain, or maintain strength and mobility. Timi Brown can tell you more about Med Fit (272-1755). Exercise has also been shown to help combat fatigue, a side-effect most survivors deal with at one point or another.

Cancer survivors often face emotional as well as physical challenges. Body image can be affected. The role the survivor played in the family setting can be altered due to treatment side-effects. Sexuality and intimacy

often take a big hit with cancer treatments. It is important to realize that you are not alone in the feelings you may be going through. Please share them with someone whom you can trust and feel comfortable. Support groups are available to try. Feel free to contact the social worker at your local cancer treatment center.

Many times the diagnosis, treatment and aftermath of cancer can take its toll financially. Finding patient financial advocates within the healthcare system or at a place of employment may help alleviate some of this stress. Working with a financial planner can help with budgeting if that is what is needed. Financial assistance for cancer care can be found at www.cancer.gov. If employment issues are causing concerns, a resource found under the Equal Employment Opportunity Commission (www.eeoc.gov) and www.cancerandcareers.org may be helpful. Another resource in this area is the Patient Advocate Foundation (www.patientadvocate.org)

What does one do with all this information that is collected? Good question. With increased emphasis on survivorship has come a document called a "Survivors Care Plan". It is a multi-page document that contains pertinent information to a healthy survivorship. There are several different survivor care plans out there. There has not been any one that has floated to the top as being the best. A free example of one can be found on-line at www.journeyforward.com.

Find a survivor care plan that you like then work to maintain it with current information. Hopefully, one day in the near future, such a document will be part of every survivor's electronic health record.

Then information can be downloaded at the touch of a button and all involved in your care will have access.

SCAN TO SIGN PETITION



Save the Date!

July 2 **1:30 p.m.**
Touch of Courage
Breast Cancer Support Group
2101 Kimball Avenue, Waterloo
Dawn Colbert 415-6430

July 3 **1:30 p.m.**
Care & Share Support Group
Covenant Cancer Treatment Center
200 E Ridgeway, Waterloo

July through August 17

Tulip Orders Taken



July 14
Pretty in Pink Horse Show
Silver Spur Saddle Shop Arena
3574 W Shaulis Road, Waterloo

August 6 **1:30 p.m.**
Touch of Courage
Breast Cancer Support Group

August 6 4:45-6:45 p.m.
Grundy Area Breast Cancer Support Group
Kristi Barnett 319-824-4129

August 9 5:00-7:00 p.m.
Splash of Color Event
Waterloo Public Library
Cathy 319-493-8857

August 13 1:30-3:30 p.m.
Look Good . . . Feel Better
Covenant Cancer Treatment Center
Conference Room
RSVP – American Cancer Society
866-460-6550

August 17
Tulip Order Deadline



September 4 1:30 p.m.
Care & Share Support Group

September 10 1:30 p.m.
Touch of Courage
Breast Cancer Support Group

September 18 4:30-7:00 p.m.
Meet, Mingle and Learn – Young Cancer Survivors Group
Unitarian Universalist Church
3912 Cedar Heights Dr, CF
(just south of AEA267)

October 1 1:30 p.m.
Touch of Courage
Breast Cancer Support Group

October 1 5:30-9:15 p.m.
Breast Care Conference
Mini-Health Fair – 3:30-5:30 p.m.
Park Place Event Center
One Technology Dr, CF

October 2 1:30 p.m.
Care & Share Cancer Support Group

October 6 8:00 a.m.
Pink Ribbon Run
Downtown Cedar Falls

October 8 1:30-3:00 p.m.
Look Good . . . Feel Better

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. www.komen.org

Iowa Breast Resource Guide is available on the Iowa Breast Cancer Education website. www.iowabreastcancer.org

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