



Touch of Courage

. Connection

Beyond Pink TEAM

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Inside this Issue

1	Sleep-Wake Disturbances and Fatigue in People with Cancer
2	Pink Ribbon Run
2	October is a Busy Month
3	Advocate Trish Pedersen Honored
3	A Case for Breast Cancer Prevention
4	Live Green
4	Wow! What a Conference
5	A Survivor's Story
5	Save the Date!
6	Save the Date! (cont)

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Sleep-Wake Disturbances and Fatigue in People with Cancer

By Nancy McHone

Thirty to forty percent of patients with cancer have problems with sleep-wake disturbances. That is more than twice the general population. Sleep-wake disturbance has been defined as a symptom of perceived or actual changes in night sleep resulting in daytime impairment.

Insomnia is the most common form of the sleep-wake disturbance and takes several forms. Insomnia can be difficulty going to sleep, difficulty staying asleep or waking up too early and not being able to return to sleep, or a non-refreshing sleep. Insomnia can result in the following forms of daytime impairment:

- Fatigue or malaise
- Attention, concentration or memory impairment
- Social or vocational dysfunction
- Mood disturbance or irritability
- Daytime sleepiness
- Motivation, energy or initiative reduction
- Proneness for errors or accidents at work or while driving
- Tension, headache, gastrointestinal symptoms
- Concerns or worry about sleep (Berger, 2009)

What can a person do to help themselves if the sleep/wake disturbance is a problem? You can improve sleep habits by making changes. Developing specific “sleep

hygiene” is key. Go to bed at the same time every night and get up at the same time every day. The bedroom is for sleeping and sex only – get rid of those TV’s! Avoid day time napping. If you must rest, limit it to 30 minutes.

Create an environment for yourself that will enhance sleep. Lower the noise and dim or turn off the lights. Sleep ‘cool’ by adjusting the room temperature and using bedcovers for warmth. Wear comfortable, loose fitting clothes to bed and use pillows for support – under your head, between or under your knees if necessary.

Sometimes what you eat can affect your sleep. Avoiding alcohol, caffeine and smoking 4-6 hours before bedtime may help. Replace those spicy, sugary bedtime snacks with a high protein one about 2 hours before bedtime.

Cancer-related fatigue lasts for long periods of time and is unrelieved by a night’s rest or a change in lifestyle. Fatigue is a common side-effect of cancer therapies. It may begin to improve weeks or months after therapies are finished. Some people have long-term fatigue issues even after treatments are done.

There are some interventions you can make to cope with cancer-related fatigue. Try keeping a daily diary of fatigue symptoms,

identifying when they are the worst and best. Once this has been identified then you can begin to make changes. Plan your activities when your energy level is highest. Prioritize those things you *want* to do and *have* to do. Learn to delegate tasks and/or ask for help when your energy levels are low. Exercise lightly or take short walks.

Why exercise? Our bodies work on a 'use it or lose it' principle. When we don't *use* our muscles, we *lose* our muscles! Regular exercise - walking is a favorite - helps our bodies maintain function. Take part in a supervised MedFit program. Exercise often improves mental outlook, too.

If you are having trouble with sleep-wake disturbances and fatigue be sure to let your healthcare professional know. Medicines may be prescribed to help you manage these side-effects. Working together, you can identify what works for you to help manage fatigue and sleep-wake disturbances.

References:

Berger, A.M. (2009). Update on the state of the science: sleep-wake disturbances in adult patients with cancer, *Oncology Nursing Forum*, 36, No.4, pE165-177.
Living Beyond Breast Cancer's Guide to Understanding Insomnia and Fatigue, 2009.
Supportive Solutions, Vo. 3 No.2, April 1999.

Pink Ribbon Run **By Dee Hughes**

The weather was cooler for the 2009 Pink Ribbon Run than it had been the last two years, but it didn't keep the runners and walkers away! About 425 people participated, and the event raised more than \$20,000 for the Beyond Pink Fund. It was a

lot of fun for everyone, and will do so much to help women and men living with breast cancer in our community.



The Beyond Pink Fund was established by the Beyond Pink TEAM in 2006 at the Community Foundation of Waterloo, Cedar Falls, and Northeast Iowa. The Fund is used to pay for expenses not covered by insurance for persons being screened, diagnosed or treated with breast cancer. It has also helped with household expenses when the person in treatment is too ill to work. In 2009, we helped more than 25 women with over \$10,000 in expenses. The need for help has increased greatly each year, and we expect it to continue to increase as we see changes in healthcare and our economy.

The Beyond Pink TEAM is very grateful to the Pink Ribbon Run planning committee and Cedar Falls Community Mainstreet for selecting the Beyond Pink Fund as the recipient of the run proceeds.

Thank you to all the runners, walkers and sponsors for taking part and helping to make a difference in the lives of women and men throughout the Cedar Valley.



October is a Busy Month **By Dee Hughes**

October is a great time of the year for the Beyond Pink TEAM. Breast Cancer Awareness Month brings greater attention to the disease, and prompts many people to take action. A lot of money is donated to national organizations for research.

We all hope to see breast cancer eliminated, and it will take lots of research for that to happen. The Beyond Pink TEAM is so pleased that many people choose to keep some of their donations local. At least 95% of all donations received by the Beyond Pink TEAM go directly to services for our community.



Barb Daniels receives Grundy Center's Girls' Night Out proceeds from Kelli Riskedahl

Thanks to everyone who contributed to the Beyond Pink TEAM. You may have run or walked in the Pink Ribbon Run, bought a Pink Ribbon Bagel at Panera, participated in jeans day at work, bought tulip bulbs, shopped at Girls Night Out in Grundy Center, went to the Black Hawk Hockey game on October 24, had a drink at Smitty's Bar or one of the bars in Fayette County, or bought a pizza cutter at Time 4 Bags. When many people do a little, it results in big benefits for women and men living with breast cancer.

Advocate Trish Pedersen Honored By Christine Carpenter

At the October 16 Beyond Pink TEAM’s luncheon, Trish Pedersen was recognized for all she has done for women and men with breast cancer and the Beyond Pink TEAM. Trish is a breast cancer survivor and advocate at the individual, institutional, state and federal levels.



Trish Pedersen is recognized at the Beyond Pink TEAM’s October luncheon for her advocacy work and support of women with breast cancer.

Trish first became an advocate for herself during treatment for breast cancer. From there she went on to advocate for others as a Reach-to-Recovery volunteer. Trish joined Iowa Breast Cancer Edu-action, working on the second and third editions of the Iowa Breast Cancer Resource Guide, and the translation of breast cancer information into Bosnian. Both projects helped women throughout the state of Iowa.

At the national level, Trish has attended the National Breast Cancer Coalition’s Project LEAD (Leadership, Education, and Advocacy Development) and the National Breast Cancer Coalition’s Annual Advocacy Conference. Trish was also a grant reviewer for the Department of Defense Breast Cancer Research Program. This responsibility takes time, hard work and definitely some chutzpah!

Trish approached her employer’s building and grounds head to ask that they reduce routine spraying of toxic pesticides both inside and outside. Her request was received positively and changes are being made. She is also a member of her employer’s “Go Green” committee.

Beyond Pink TEAM is pleased to honor Trish for her work to support and educate women with breast cancer, her advocacy, and most importantly, her work to prevent breast cancer in the first place!

A Case for Breast Cancer Prevention By Sarah Dunagan, Silent Spring Institute

Each year, the President’s Cancer Panel—a watchdog group of advisors charged with monitoring the National Cancer Program—holds a series of meetings to gather input from experts and the public on a particular theme. This year they are focusing, for the first time ever, on environmental factors. The panel will present a report with its recommendations to President Obama later this year.

At the panel’s meeting on Air Pollution and Water Contamination, Julia Brody, Executive Director of Silent Spring Institute, advocated a new strategy for environmental health sleuthing. Taking the traditional “innocent until proven guilty” approach—requiring definitive proof that a given chemical causes breast cancer before taking action—hasn’t been working as it can take many years after an exposure for breast cancer to develop, women are exposed to a toxic soup of chemicals, and it’s difficult to untangle the many interwoven genetic and environmental factors that can contribute to the disease.

Medical research can dispel some ambiguity by using clinical trials to test, for example, the safety of a given drug. But this model can’t be applied to study the effects of pollutants on women’s health because it’s unethical to test a toxic chemical on women and wait to see if they get sick. So what, then, are we to do?

Instead, we can work to build the case for a “better safe than sorry” approach that would rely on animal and cell studies illustrating how chemicals can contribute to breast cancer, and studies showing humans are exposed to those same chemicals. Taken together, this evidence would create the foundation for preventive action to reduce our exposures to harmful chemicals.

“We see substantial evidence of links between environmental pollutants and breast cancer, enormous knowledge gaps that we can fill immediately, and opportunities for precautionary action,” said Brody. “If we take steps to protect ourselves and our children from chemicals that cause cancer, we will also see benefits for numerous other health endpoints, including diabetes, obesity, neurological disease, and infertility.”

For the full text of Brody’s testimony, see: http://silentspring.org/our-publications/invited_talks/everyday-exposures-and-breast-cancer.

Live Green By Cindy Harris

Winter has found us again! Probably inevitable. I am not fond of having to scrape my windows but here's something to try if you aren't either.

Take a small spray bottle and mix two parts rubbing alcohol (70% works best) with one part water, or just use rubbing alcohol. Spray the mixture on your car's frosted windows. Don't use the wipers right away as the water in the frost will re-freeze. The alcohol will quickly melt its way through the frost/snow and loosen the ice from the windshield. I keep a small bottle in the car because it won't freeze. This is safer than some other chemicals, and easier than the scraper.

WOW! What a Conference by Jane Clark

Thank you Beyond Pink Team for the scholarship to attend the 2009 and 2010 conference. In May, I had the pleasure of attending the National Breast Cancer Coalition (NBCC) Annual Advocacy Training Conference held in Washington DC. Six individuals from the Waterloo/Cedar Falls area attended the conference: four breast cancer survivors, a nurse and a UNI student.

The Conference was awesome! It was the biggest yet, with over 800 attendees from many countries and with representation from all the states. The Conference was inspiring and offered tools in how to be an effective breast cancer advocate. We were encouraged to immerse ourselves in the science, delve into quality care, share our insights, speak out and commit fully to the breast cancer movement.

The first three days were spent listening to several speakers ranging from breast cancer survivors, breast cancer advocates, professors in the medical field, doctors, nurses, surgeons, NBCC directors, researchers and lobbyists. We heard the latest what's working and what's not working in research developments and clinical trials. There were daily workshop sessions where we chose the topics of interest. On the third evening there was a big celebration held for all which was a blast!

The ultimate highlight for me was to listen and meet Dr. Dennis Slamon. He developed the drug Herceptin,

which has been hailed as the first triumph in an emerging wave of new, more effective therapies to fight cancer at its genetic roots. As a Breast Cancer Survivor, infiltrating ductal carcinoma ER/PR positive/HER 2 neu positive, I spoke with Dr. Slamon one-on-one to find answers to questions I had about complications I experienced during treatment. I wanted some clarification on whether the complications were from Herceptin, chemo, and/or a combination of both. I got my answers finally. It was an emotional and ultimate honor to be photographed with Dr. Slamon, the man who has prolonged my life.



Jane Clark with Dr. Dennis Slamon. Dr. Slamon developed the drug Herceptin which Jane took as part of her treatment.

The last day of the conference was Lobby Day on Capitol Hill. We visited each Iowa representative's office to advocate for continued research funding, patient care and access to quality health care for all.

I encourage you to take a trip to Washington DC to attend this conference. Let your voice be heard. You won't be disappointed.

The 2010 Annual Advocacy Training Conference is May 22-25. For more information, you can visit their website at www.stopbreastcancer.org. Hope to see you there!

**Cancer Survivor Event
for Young Women
Tuesday, January 19, 2010
4:30 – 7:00 p.m.
Area Education Agency
3712 Cedar Heights, Cedar Falls**

A Survivor's Story by Jane Clark

My name is Jane Clark and I'm a breast cancer survivor. During my yearly mammogram appointment a lump was found on one of my breasts. EARLY DETECTION saved my life!

I had a lumpectomy on April 26, 2005. The surgery went well and I went back to work. I then had to make a decision whether to have chemotherapy. The results of an Oncotype test showed it was in my best interest to start chemotherapy due to the very aggressive type of cancer I had. It was at this point I decided to take a medical leave from work during my treatment and was off work for nine months.

I started my chemotherapy on June 15, 2005. I received eight treatments of very strong chemotherapy. The treatments were given to me every other week. After each treatment I would go home and sleep for four to six hours, or more. After the second treatment I started losing my hair and within that week, all my dark, thin, fine hair was gone. My appetite was very low, but thankfully I never got sick. By the time I was feeling better and my appetite would come back, it was time for the next treatment.

These treatments were completed and after a month off, I began my second round of chemotherapy plus herceptin (her2neu drug). This type of chemotherapy was not nearly as strong as the first round. In November, however, I developed heart valve damage on my left upper chamber and my doctor stopped all chemotherapy and herceptin treatments. I was

put on two different blood pressure medicines to keep stress off my heart. During this entire treatment program, I had several CT scans, bone scans and echocardiograms to make sure the cancer was not spreading and/or caused heart problems.

Radiation treatments began in December and I had 33 treatments. These were given every day at the same time for 33 days, Monday through Friday. Saturday and Sundays were rest days. I am so thankful that my skin did not get burnt from these treatments. I did get very, very fatigued. The two types of chemo put my body in a fake menopause mode. The hot flashes and not sleeping at night were the worst! My last radiation treatment was on January 31, 2006.

I lost my hair two different times during this journey, and when it grew back for good, it came back thicker, darker and with a little curl. I started back to work part-time in February and full-time in April.

In February of 2006, I began taking tamoxifen. On November 15, 2006, I went to Dr. Singh in regards to some pain in my lower right calf. It was a blood clot. Within two weeks I had eight more blood clots. I immediately stopped the tamoxifen (one of the side affects) and began taking a blood thinner.

I'm very grateful for my wonderful husband, wonderful daughter, family and a whole lot of friends and co-workers, for all their continued support and special care they gave me during this very stressful, scary time in my life. My husband took me to all my appointments and took

care of me at home while running his own business and training a new employee. My daughter was in her last year of college. She was super help! She was there whenever I needed her.

I continue having six month checkups with Dr. Singh and six month checkups (mammogram once a year and MRI once a year) with Dr. Duven, my surgeon, that have all turned out A-ok.

On February 26, 2007 I had a hysterectomy due to blood clot complications. I have been released from taking the blood pressure medicine and blood thinner. I feel great and am looking forward to getting back in shape and LIVING A HEALTHY LONG LIFE!

Save the Date!

Jan. 4 1:30 p.m.
Touch of Courage

Breast Cancer Support Group
2101 Kimball Ave., Waterloo
Dawn Colbert 415-6430

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

Jan. 19 4:30 – 7:00 p.m.
Young Cancer Survivors Event
3712 Cedar Hts. Dr., Cedar Falls
Emily Hodgins 239-8118

Jan. 22 Deadline
Early Bird Registration for
National Breast Cancer Coalition
Advocacy Conference May 22-25

Jan. 28 6:30 p.m.
Iowa Breast Cancer Edu-Action
UNI Center for Energy and
Environmental Education
Corner Campus St & Jennings Dr
Christine Carpenter 266-0194

Jan. 28 7:00 - 8:00 p.m.
Environmental Hlth Wking Group
UNI Ctr for Energy and Envir Ed
Christine Carpenter 266-0194

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

Feb 2 1:30 p.m.
Care and Share Support Group

Feb 25 6:30 pm.
Iowa Breast Cancer Edu-Action

Feb. 25 7:00 p.m.
Environmental Health Working Group

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

Mar. 2 1:30 p.m.
Care and Share Support Group

Mar. 25 6:30 p.m.
Iowa Breast Cancer Edu-Action

Mar. 25 7:00 p.m.
Environmental Health Working Group

Apr. 5 1:30 p.m.
Touch of Courage
Breast Cancer Support Group

Apr. 6 1:30 p.m.
Care and Share Support Group

Apr. 22 6:30 p.m.
Iowa Breast Cancer Edu-action

Apr. 22 7:00 p.m.
Environmental Health Working 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. www.komen.org

Iowa Breast Resource Guide is available on the Iowa Breast Cancer Edu-action 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