



Touch of Courage

Connection Beyond Pink TEAM

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Inside this Issue

- 1** "But I'm Too Young for Breast Cancer!"
- 2** Young Survivors' Conference
- 2** Touch of Courage Support Group
- 3** Banner Year in D.C.!!!
- 3** Beyond Pink TEAM
- 4** What Caused my Breast Cancer?!
- 4** Relay for Life
- 5** A Survivor's Story
- 5** Care and Share Support Group

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"BUT I'M TOO YOUNG FOR BREAST CANCER!"

Excerpts from *Fighting for Our Future*

If you're like most young women, these may have been your first words upon hearing of your diagnosis. The perception that young women can't and don't get breast cancer often leads to an initial misdiagnosis. The average age for a woman diagnosed with breast cancer is 64. Breast cancer is shocking at any age, but if you are under 40, it helps to realize how many women there are out there who are just like you.

There are more than 250,000 women in the United States age 40 and younger diagnosed with breast cancer. Sadly, this year another 10,500 women in this age group will be diagnosed. If you're in your thirties, your chances of getting breast cancer are 1 in 249. If you are in your twenties, the risk is 1 in 2044. It's not surprising that doctors discount the possibility of breast cancer in young women.

If you are like most young women with breast cancer, you may already have discovered a rather disheartening fact: Virtually all of the information on the disease that is readily available is geared to older women. After all, women aged 40 and under make up about 5 percent of the total number of U.S. women with breast cancer. It makes sense that doctors would be more familiar with the needs and concerns of the other 95 percent. You can understand, too, why most of the pamphlets, brochures, and books on coping with cancer

assume that you're in a decades-old marriage, that your children are grown, and that you're at the peak of your career if not actually approaching retirement, instead of being a woman in your twenties or thirties just getting started with your life.

Some of the urgent questions the young woman with breast cancer may have are:

- How do I get the emotional support I need from my friends and family?
- How has breast cancer affected my sexual/dating life?
- What about the effects of pregnancy on breast cancer?
- How do I continue to raise my children?
- How do I manage at work?
- What effects will chemotherapy, radiation, and tamoxifen have on my fertility?
- Will I undergo premature menopause-and if so, what can I expect?
- What kinds of alternative and complementary treatments have been shown to be effective?
- How can I cope with recurrence (the return of cancer) or metastasis (the spread of cancer to other parts of the body)?

In the book, *Fighting for Our Future*, you can find how many young women living with breast cancer have dealt with these issues. For a free copy, visit the Young Survival Coalition's website at www.youngsurvival.org.

Young Survivors' Conference

By Carol Ann Hundley

The 6th Annual Conference for Young Women Affected by Breast Cancer was held February 24 –26, 2006 in Denver, CO. This is the only international educational conference that is dedicated solely to the needs that are unique to young woman with breast cancer. Over 650 women who were diagnosed under the age of 45, gathered at the Adams Mark Hotel in downtown Denver. Women came from 48 states and 10 countries, including Africa and Europe. LBBC (Living Beyond Breast Cancer) & the Young Survival Coalition hosted the conference and provided valuable information for the attendees, their families and providers of healthcare.

Scholarships were available to assist with travel expense and waivers for the \$65 registration fee. The three day conference included breakfast both mornings, lunch and receptions during networking on Friday as well as Saturday. It was announced that they had raised additional funds this year to allow women to attend who otherwise would not have been able due to cost. They made a commitment to not turn anyone away that applied for scholarships.

This conference was created to be a place for young women to gain information and share activities designed to empower and inspire. Young women diagnosed with breast cancer face unique issues such as fertility and building a post-treatment life. World-renowned doctors and researchers spoke about the medical advances regarding young women with breast cancer. Over 20 workshops were offered

that ranged from medical to more personal issues including nutrition, stress management, and medical advances. Other topics were dating, communicating with your children, and sessions specific to living with advanced breast cancer. Special workshops were offered for caregivers.

My favorite workshop was utilizing creative arts to complement your well-being. I learned that creative arts can be used to move through the experience and to rediscover joy through journaling and yoga, for example. They suggested journaling early on in your journey – and explained that journaling is a way to release and move on through the experience, and isn't about perfection. Further suggestions were to create a sacred space and redefine life by picking up something old or trying something new like gardening, for example.

It was stated at the conference that metastatic is not a dirty word. Women had the opportunity to attend workshops focused on their specific concerns or interests. For those living with advanced breast cancer there were treatment updates, resources and methods for living fully with advanced breast cancer. It was a place where, as one speaker said, we gathered for the 3 C's - not cancer, CT, or chemotherapy - but rather, contact, connection, and community.

“Ask the Expert” panel was especially informative. During all of the workshops there was ample time allowed for questions. Another key component to the conference was the opportunity to network with peers as well as visiting the exhibitor hall. Networking with others who share similar situations was aided by the wearing of lei's that correlated to the time frame of

diagnosis. For instance, a white lei signified being diagnosed less than one year ago. Additionally, name tags were designed to highlight the areas of the country people were from so it was easy to connect by location also.

There are several retreats available and contacts can be found at www.bcrf.org or by phoning 608-821-1140. It may be possible to obtain assistance with the cost of the retreat by contacting Infinite Boundaries Retreat.

Websites:

www.youngsurvivorsconference.org
lbbc.org (living beyond breast cancer)
www.youngsurvival.org

Touch of Courage Breast Cancer Support Group

The Touch of Courage Breast Cancer Support Group continues to meet on the first Monday of every month (unless it's a holiday). However, they are now meeting at the **Kimball Ridge Center on 2101 Kimball Avenue**. The meetings are held at 1:30 and 5:30 p.m.



Kimball Ridge Center

The Support Group invites any woman or man who is dealing with breast cancer to attend the support group meetings. Spouses and significant others are also welcome.

Banner Year in D.C.!!!

By Dee Hughes

Iowa Breast Cancer Edu-Action (IBCE) was thrilled to have nine Iowans attending the National Breast Cancer Coalition Advocacy Conference and Lobby Day in Washington, D.C., April 29-May 2, 2006. IBCE President Christine Carpenter, has attended the annual conference for 10 years. Her enthusiasm has rubbed off on her peers and this year's delegation represented three of Iowa's five congressional districts.



Left to Right: Kathy Nelson, Mason City; Jill Moffett, Iowa City; Trish Pedersen, Cedar Falls; Suki Cell, Mt. Vernon; Rep. Jim Leach; Cindy Harris, Waterloo; Dee Hughes, Waterloo; Christine Carpenter, Cedar Falls; Sue Witwer, Cedar Falls, Tina Porter, Waterloo.

Nearly 700 people from across the country attended this year's Advocacy Conference. A variety of panel speakers shared information and views on breast cancer research (what is hope, what is hype), maintaining the integrity and independence of the FDA, and the future of health care (and access to quality health care for all). Each attendee also participated in three different workshops they chose from a variety of topics.

The National Breast Cancer Coalition has selected four legislative priorities for 2006. They are:

- Guaranteed access to quality health care for all
- Funding of the Department of Defense (DDD) Breast Cancer Research Program (BRCP)
- Passing of the Breast Cancer and Environmental Research Act
- Preservation of the Breast and Cervical Cancer Treatment Act.

On Lobby Day, the final day of the conference, the nine Iowa delegates visited all five Representatives and

both Senators. We would normally have to ask them to support legislation for these priorities. However, this year we thanked them for already signing on to support the DODBCRP and the Breast Cancer and Environmental Research Act!

We are fortunate to have the support of the Iowa Senators and Representatives from all five districts on these issues. However, we need to keep asking their help in preserving funding for the Breast and Cervical Cancer Treatment Act and work for healthcare reform that guarantees access to quality care for all. You can do this by contacting your legislators, or by joining the Iowa Breast Cancer Advocacy Network at www.iowabreastcancer.org or email Christine.Carpenter@cfu.net.

Beyond Pink TEAM

By Dee Hughes

There is a new name in town we hope you will soon become familiar with. It is the Beyond Pink TEAM (we Take action, we Educate, we Advocate, we Make a difference). We were formally known as the Cedar Valley Breast Cancer Task Force, which is a mouth full and not easily remembered. After much discussion we chose this name because we go beyond awareness to provide many services for women living with breast cancer.

Besides providing the facilitator for the breast cancer support group and this newsletter, we provide educational materials, educational programs, advocacy work for breast cancer legislation and reduced-price mammograms. We work closely with Black Hawk County to provide free services to women who qualify.

The Beyond Pink TEAM is starting a Support Services Fund to cover medical expenses for uninsured or under-insured women dealing with breast cancer. A donation to the Beyond Pink TEAM is tax deductible and could really make a difference in someone's life. All of our TEAM members are volunteers so your donation goes directly into services. To make a donation, please use the coupon on the back page of this newsletter.



What Caused my Breast Cancer?

“We all wonder what causes breast cancer. I, too, have questions about what caused my breast cancer. Diagnosed at 53, I was told that even though my mother died at age 48 from the disease, my breast cancer was unlikely to be due to an inherited genetic defect since inherited cancer usually shows up at an earlier age in offspring. No other high risk factors applied to me. Did my diagnosis have something to do with the where I lived? The sad truth is nobody knows; there is no conclusive evidence about what causes this disease.” These are the words of Gail Frankel as she testified at a Senate Environment and Public Works Hearing regarding the need for breast cancer and the environment research legislation.

Thank goodness the National Breast Cancer Coalition (NBCC) saw the need to correct the persistent underfunding of research in this important area, while also increasing opportunities for innovative research. Members of NBCC agreed that in order to truly understand what causes breast cancer, and how to prevent it, we must first focus on formulating the right questions. While a limited amount of research currently focuses on the relationship between breast cancer and environmental factors, the ware still many issues that must be resolved to make this research more effective.

The Causes of Breast Cancer are Largely Unknown – While less than 30% of breast cancers are explained by known risk factors, there is little consensus in the scientific community on how the environment impacts breast cancer. Studies have explored the effect of isolated environmental factors such as diet, pesticides and electromagnetic fields, but in most cases there is no conclusive evidence. Furthermore, there are many other factors that are suspected to play a role but have not been fully studied.

Challenges in Conducting Environmental Research - Identifying links between environmental factors and breast cancer is difficult. Laboratory experiments and studies of cancer clusters have limitations that make it challenging t establish, with certainty, whether an environmental exposure increased a woman’s risk of breast cancer. An added challenge is the measurement of exposures over a lifetime as exposures are intertwined and may be confounded by socioeconomic, occupational and reproductive factors.

Beyond Pink Team is proud that all Iowa Senators and Representatives are cosponsors of S.757/H.R.2231 the Breast Cancer and Environmental Research Act. However, the Act still has not passed both houses of Congress. If you are about breast cancer and the environment, join the Iowa Breast Cancer Advocacy Network. Email christine.carpenter@cfu.net stating your email address and “I want to join IBCAN.” IBCAN will send you approximately six or fewer email alerts per year with information on who to email/call and what to tell them about supporting this and other important breast cancer legislation.

RELAY FOR LIFE

The American Cancer Society held the Black Hawk County *Relay for Life* at Hawkeye Community College on June 9-10, 2006. Unfortunately, the poor weather conditions made it difficult to celebrate survivorship and enjoy the many fun activities available.



Marie Iverson carrying banner in 2005 Relay for Life

The Beyond Pink TEAM sponsored a team at the Relay again this year. Once again, Marie Iverson was our team captain. She is very dedicated to the Relay and does a great job of motivating walkers. The Beyond Pink team had 25 walkers, and \$1,800.00 was raised by them for cancer research.

If you would like to walk on our Beyond Pink team next year, please contact Marie Iverson at 233-1398.



FACT: Young women with breast cancer struggle with issues that their post-menopausal counter-parts don’t face, such as the possibility of early menopause, pregnancy after diagnosis, generally more advanced cancers at diagnosis, and high mortality rates.

A Survivor's Story By Carol French Johnson

My phone was ringing as I walked into the Cedar Falls Library office on Tuesday, April 19, after a lunch meeting. The surgeon had performed a biopsy on Friday and told me I would hear from him on Monday. Monday, always a busy day, came and went and the call didn't come. One small optimistic voice in my head said that I hadn't heard because the results were negative. But the Tuesday call was NOT good news. The small breast lesion was indeed a cancerous tumor. He would biopsy the second tumor on Thursday and if also malignant, then I would need a mastectomy.

The surgeon told me all of this and more as I sat in his office that dismal Tuesday afternoon. I felt totally lost. Charles, my husband, was teaching a class and couldn't be with me as I tried to put my mind around the fact that everything in my life had suddenly and inexorably changed. I was just plain numb and unbelieving. It turned out that the second tumor was also malignant. Surgery was scheduled and my breast was removed.

Somehow I went from a middle-age woman in the prime of her life to a cancer patient with whom physicians talked about "survival" statistics and whose body was irrevocably damaged. Instead of planning a new library service for the community, I was focused on decisions involving chemotherapy and radiation. Always a reader my entire life, I was suddenly incapable and unwilling to read anything about breast cancer. Because the librarian profession is 80% female, I immediately began hearing from

friends and colleagues across the nation, many of whom are breast cancer survivors. They sent me articles, websites and their own stories. Initially, I could barely look at any of the material and this was so unlike me. I am a library administrator, a take-charge person and yet I simply didn't want to take control at all. I wanted to cry and feel sorry for myself. I was completely despondent and I remember telling my sister that I would never be happy again.

Of course I was wrong. Humans are invariably adjustable. Sometime during those early hazy days after surgery I remember thinking that I had heard humans don't tolerate extreme emotional issues for more than two weeks before they begin to "adjust". And around two weeks out of surgery I was beginning to move away from the utter despair I had been feeling. I became impatient with my attitude and was simply tired of feeling sorry for myself.

Slowly I began welcoming family, friends and colleagues who expected and needed to share my pain. And I learned so much about the generosity and support of others. While I was focused on what had been lost, and what might happen in the future, family and friends were rejoicing in where I was right then – alive and basically healthy.

I understand that many people call me a cancer survivor but I see myself as a "life" survivor. All of us experience heartbreaks, fearful moments and times of despair. Life on this planet brings trials to even the most charmed lives. We are all, in one way or another, survivors of our life's experiences. Of the inspirational books I have been

given, my favorite is Caren Goldman's, Healing Words for the Mind, Body and Spirit. Under the word "grief" is a Latin proverb that should have significance for all of us: "There is no grief which time does not lessen." This is a great reminder that the human spirit is indomitable.

Care and Share By Jeanne Mullen

Care and Share is a cancer support group for individuals, families and friends who are dealing with any type of cancer. The group meets the first Tuesday of each month at 1:30 p.m. and 5:30 p.m. The evening group was begun in order to accommodate younger individuals who cannot come to the afternoon group.

The group is held at the Cancer Treatment Center, 200 East Ridgeway Avenue in Waterloo. It is facilitated by an oncology social worker and there is no charge to attend. For more information please call (319) 272-2800.



FACT: One in every 229 women between the ages of 30 and 39 will be diagnosed with breast cancer within the next 10 years.

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Iowa Breast Cancer Edu-Action

Who Are We?

Iowa Breast Cancer Edu-Action includes breast cancer survivors and their supporters. We are members of the Beyond Pink TEAM. **Our mission** is to: take Action, Educate, Advocate, Make a difference (TEAM).

What We've Done

For the last ten years we have:

- ❖ Visited with Iowa congressmen to secure their commitment to breast cancer research.
- ❖ Participated in email and phone call campaigns to Congress to secure guaranteed access to quality care for all.
- ❖ Created the Iowa Breast Cancer Resource Guide, secured funding, and distributed 9000+ free copies
- ❖ Translated the ACS Guide "For Women Facing Breast Cancer" into Serbo-Croatian for the Bosnians in Iowa

We Meet:

When: 7:00 p.m. on the 4th Thursday of each month, except November when we meet the 3rd Thursday, and December when we do not meet.

Where: Area Education Agency
267, 3706 Cedar Heights Drive,
Cedar Falls, Special Education
Building, Child Find Room

Need more Information?

Email or call:
Christine.carpenter@cfu.net
(319)266-0194

Support and Rehabilitation Programs

Care and Share	Support group for anyone dealing with cancer. Meets the 1 st Tuesday of every month at 1:30 p.m.
Touch of Courage	Breast cancer support group. Meets the 1 st Monday of every month at 1:30 p.m. and 5:30 p.m.
Reach to Recovery	Provides information and support for women who are faced with breast cancer. Visits available before and after surgery.
Look Good...Feel Better	Consultation with a trained cosmetologist to help a cancer patient feel more comfortable with the physical changes that occur during treatment.

For more information call the American Cancer Society at 319-272-2880 or 888-266-2064.

Resources Available:

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

Allen College of Nursing Library and Media Center 1825 Logan Avenue Waterloo, IA 50703 (319) 235-2005	American Cancer Society 2101 Kimball Avenue, Suite 130 Waterloo, IA 50702 319-272-2880 or 888-266-2064 1-800-ACS-2345 (available 24 hrs)
Breast Care Center at United Medical Park 1753 West Ridgeway Waterloo, IA 50701 319-833-6100	Covenant Cancer Treatment Center 200 E. Ridgeway Avenue Waterloo, IA 50702 319-272-2800 Include Cancer Information Library
National Cancer Institute 1-800-4CANCER	National Coalition for Cancer Survivorship 1-505-764-9956
National Lymphedema Network 1-415-923-3680	Y-Me 1-800-986-8228
Covenant Lymphedema Therapy 319-272-7894	Physical Therapy Partners Lymphedema Therapy 319-233-6995

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