



Touch of Courage

. Connection

Cedar Valley Breast Cancer Task Force

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Hormone Replacement Therapy and Breast Cancer Risk: Results of Womens Health Initiative Studies

by Dr. Sue Joslyn

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In the 1990s, Hormone Replacement Therapy (HRT) medications were among the most frequently prescribed medications in the United States. Almost 35% of postmenopausal women were taking HRT. Based on results of research available at the time, HRT was expected to lower a woman's risk of heart disease and osteoporosis, along with easing symptoms of menopause including hot flashes, night sweats, and vaginal dryness. Imagine the shock to millions of women when, in 2002, a large multi-center randomized clinical trial known as the Women's Health Initiative (WHI) revealed that HRT use was associated with increased risk of heart disease, breast cancer, stroke, and pulmonary embolism. The news headlines caused panic, and subsequent reports did little to calm the panic or explain the study results. However, research evidence is far from black and white, and hopefully this brief review will help explain results of the WHI clinical trials of HRT.

The WHI was the first large (16,608 women), well done experimental study on the effects of HRT on long term health benefits and risks, including risk of invasive breast cancer. In high quality clinical trial experiments funded by the federal government, researchers are required to set criteria for monitoring unexpected disease. The study is then observed by reviewers not associated with the study, and if cases of disease exceed the set number, reviewers can call for an end to the study for safety and ethical reasons. That is what happened in the WHI study, which was supposed to continue through 2005, but was stopped in 2002

based on health risks that exceeded health benefits.

Results of the study were presented in terms of "person years" which is one way to describe the risk of disease for a group based on available information. For every 1000 women taking HRT and followed for 10 years (10,000 person years), women experienced 7 more cases of coronary heart disease, 8 more strokes, 8 more pulmonary embolisms, and 8 more invasive breast cancers than the comparable group of women who were not taking HRT. The study also showed that the HRT group experienced 6 fewer colorectal cancers and 5 fewer hip fractures.

A second report from the WHI that looked specifically at breast cancer reported 199 cases of invasive breast cancer among women taking HRT compared to 150 cases among women not taking HRT. Tumors diagnosed in the HRT group were larger and were more likely to have spread compared to tumors diagnosed in women not taking HRT. These results suggested that HRT stimulates breast cancer growth and makes diagnosis more difficult.

A third WHI study looked at the effects of estrogen alone (ERT, not combined with progesterone) in postmenopausal women with hysterectomies. ERT is not given to women who still have their uterus, because it has been shown to increase risk of uterine cancer. The study found that the use of ERT increased the risk for stroke, decreased the risk of hip fracture, does not affect the risk of coronary heart disease, and possibly lowered the risk of breast cancer.

Based on these WHI studies, as well as many other studies, the prolonged use of HRT/ERT for chronic disease prevention is not recommended. Short term use of lower dose HRT may be appropriate for management of menopause symptoms, but each woman needs to discuss her individual risk profile with her physician.

And if you are a woman who took HRT for many years, don't panic. Researchers still do not know what causes breast cancer – most women who took HRT did not develop breast cancer, and women not taking HRT developed breast cancer. All that is known is that HRT increases risk of breast cancer in large populations of women. It may be that HRT works with some other factor in promoting the growth of breast cancer.

Because the specific cause of breast cancer is not known, the importance of early detection can not be stressed enough. The American Cancer Society, along with most other medical groups, recommends regular mammography (once each year beginning at age 40 years) for women at average risk, along with an annual clinical breast exam by a physician and monthly self breast exams. If a woman's doctor believes the woman is at high risk for developing breast cancer based on family history, reproductive history or lifestyle factors, she may begin regular mammography at an earlier age, and/or have additional screening with ultrasound or MRI.

Dealing with Menopausal Symptoms by Nancy Mchone, RN BSN OCN

The cause of hot flashes is not completely understood. It does have to do with declining levels of hormones. Anyone who has ever experienced or suffered from hot flashes will tell you they can be miserable. The usual treatment, if one chooses to treat them, is a hormone replacement. For most women diagnosed with breast cancer, hormone replacement is not an option.

So how does one survive the declining hormone levels without hormone replacement?

Some resort to "natural" or alternative therapies. There is some evidence that Black Cohosh can help relieve menopausal symptoms. It seems to have some estrogen like effects but how it works is not clearly understood. Soy products contain isoflavones or phytoestrogens. Phytoestrogens are plant estrogens that can act like a weak form of estrogens produced naturally in the body. Because of the "estrogen connection", the medical community is not in agreement as to their safe use in women diagnosed with breast cancer.

Non-hormonal guidelines that may be effective for menopausal symptom of hot flashes include vitamins. Starting with Vitamin E, 800 IU daily for 2-3 weeks. If the hot flashes persist add Vitamin B6, 200 or 250 mg daily for 2-3 weeks. Persistent menopausal symptoms may benefit from adding Vitamin C, 500 mg three times daily. If these vitamins are ineffective, oftentimes a prescription antidepressant will be tried.

The most effective prescription has show to be Venlafaxine (Effexor). Starting doses are 37.5 mg daily for seven days and then 75 mg daily. Other prescription agents that are effective against hot flashes include Catapres-TTS, Aldomet and Bellerгал-S.

Some practical suggestions for hot flashes include dressing in layers; avoiding caffeine and alcohol, exercising regularly and learning relaxation techniques.

Medicare Drug Program that Helps Breast Cancer Patients Now!

As a result of the incredible grassroots advocacy and hard work of the National Breast Cancer Coalition (NBCC), a new Medicare program covers five oral breast cancer medications.

The new Medicare program (Section 641 Demonstration Program) began

providing coverage for certain breast cancer drugs on September 1, 2004 and will continue through December 31, 2005. This Demonstration Program will provide transitional coverage until January 1, 2006, when the new Medicare Prescription Program is expected to cover all prescriptions. The program is currently accepting applications to cover certain oral breast cancer drugs, like tamoxifen, that have not previously been covered by Medicare.

Participation in the program was limited to 50,000 people nationwide but less than 10,000 people are currently in the program. If Medicare patients believe they are eligible they should submit an application as soon as possible because they have a good chance they will be covered.

More information and application materials for the Demonstration are available on the following Web sites:

- 1) National Breast Cancer Coalition: www.stopbreastcancer.org
- 2) Centers for Medicare and Medicaid Services: www.cms.hhs.gov

Five oral breast cancer drugs for women with breast cancer in stages 2-4 will be covered by the Demonstration Program: Anastrozole (Arimidex), Exemestane (Aromasin), Letrozole (Femara), Tamoxifen (Nolvadex), and Toremifene (Fareston).

If a patient has been diagnosed with a covered disease and is taking a covered drug, the following five eligibility requirements must also be met to participate in the Demonstration Program:

- The patient must have Medicare Part A and Part B
- Medicare must be the primary payer
- The patient must have a signed document from a doctor stating that she needs one of the drugs covered under this program for the specific covered condition

(continued on page 5)

Navigating the Cancer Journey

The words “you have cancer” may be a part of your past, or they may be a part of your future. When you or your loved one hears these words you may experience a number of feelings. But one thing you don’t have to feel is alone. Throughout the cancer journey, your American Cancer Society is here to help.

“The Navigator program was created as a free, confidential resource to link cancer survivors and their support networks to community programs and services. One goal of the American Cancer Society is to improve quality of life for cancer survivors. By providing a survivor access to the many wonderful resources available, Navigator is doing just that, making their cancer journey a little easier.

The Midwest Division of the American Cancer Society has twenty-seven Navigators conducting individual assessments and making appropriate plans for each cancer survivor to strategically meet their needs. Navigators are personal contacts that cancer survivors have with the American Cancer Society. They learn about each survivor’s needs, whether it is emotional support and counseling, need for financial resources, reliable cancer information or practical healthcare information.

Jane Federwitz, Navigator for the Black Hawk County area, can be reached by calling 1-888-381-6839 or 1-800-ACS-2345.

The American Cancer Society is the nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer through research, education, advocacy and service. For more information, call 1-800-ACS-2345 or visit www.cancer.org.

National Breast Cancer Coalition Fund Collecting Breast Cancer Stories

The National Breast Cancer Coalition Fund is collecting breast cancer stories through its Stop Breast Cancer: Personal Stories, Public Action campaign!

In some way, breast cancer touches all of us and our stories must be heard! We’ve lost our mothers, sisters, partners, daughters, and our friends. Perhaps you are currently being treated for breast cancer -- or are a survivor. Your story is so important to us because it will give us the insight we need to show the Administration and Members of Congress the crisis the U.S. health care system is facing. Your story will also help us identify strategies for improvement. Our number one priority is guaranteed access to quality care for all. As an organization, we are truly committed to making this happen, but we can’t do this alone. We NEED you to submit your story so that we can fight for your right to guaranteed access to quality care.

Whether your health care experience was good or bad, tell us YOUR story! Click on the following link and let your voice be heard.

<http://www.stopbreastcancer.org/bin/WApps/personalstoriesfrm/asp?strid=642&depid=5>

If you prefer to receive materials about this campaign by U.S. mail, call our toll free number at 1-800-622-2838 – ext. 579.

Breast Cancer and the Environment: Science News from Silent Spring Institute Julia G. Brody, Ph.D

Rachel Carson’s Legacy

This year marks the 40th anniversary of Rachel Carson’s death. A courageous and outspoken woman and an extraordinary scientist, Carson died of breast cancer just two years after the 1962 publication of her book, *Silent Spring*, touched off the modern environmental movement. Since her death, many have wondered about a connection between the environmental toxins that inspired her work and the disease that killed her.

Questions about breast cancer and the environment have become ever more compelling as women with breast cancer have stood together at rallies, walks, and swims and in the halls of Congress; and by becoming visible in our communities, they have transformed that gnawing question, “Why did I get breast cancer?” into “Why do we have rising breast cancer rates worldwide? What can we learn to bring risk back down and truly end the epidemic?” Many have been frustrated, though, that the breast cancer research establishment has invested so little in prevention.

So in 1993, leaders in the Massachusetts Breast Cancer Coalition decided that breast cancer activists across the country needed “a lab of our own.” Ten years ago, they founded Silent Spring Institute as a partnership of scientists and activists with a mission to study the links between the environment and women’s health, beginning with breast cancer.

In one stunning discovery last year, the New York Breast Cancer Study Group reported that among women with the high-risk mutations BRCA1 and BRCA2, the risk of being diagnosed with breast cancer by age 50 was 24% for those born before 1940 but rose to 67% for women born more recently.

Physical exercise and healthy weight in adolescence were associated with later onset of disease. But what about the possible role of the 70,000-plus synthetic chemicals that have come onto the market since the 1940s?

To celebrate our tenth anniversary, Silent Spring Institute is launching a column to update breast cancer activists about environmental science. This is our first edition. We hope it

will provide insight into research priorities, inspire new inquiry, and guide action.

Holiday Party Pampering

By Dawn Colbert

The Touch of Courage Breast Cancer Support Groups were treated to a day (night) at the spa for their holiday party. Teri Grahlman and Connie Trask from Beauty Control Products were present to pamper the ladies with lip treatment, eye treatment, foot soaks, hand massages, and foot massages. They took the ladies on a journey to a beautiful beach with warming rays of sun (ahhhhhh, how relaxing.....).



Also present were Covenant Massage Therapists, who gave the ladies chair massages. Both were thoroughly enjoyed by everyone present.

The evening group was also entertained by The Cedar Valley Singers, which was most delightful. We all had an enjoyable day of partying and are looking forward to meeting again in January.



Annual Celebration

By Dee Hughes

The Cedar Valley Breast Cancer Task Force held their Annual Celebration of Accomplishments on October 8, 2004. Nearly 100 members, supporters, and breast cancer survivors attended the luncheon meeting. This year's event was sponsored by Covenant Medical Center.

The program included breast cancer survivor, Mary Walker, sharing her experience with diagnosis and treatment. Her experience did not go perfectly, however, she worked through it at each stage. Everyone learned that we can do much to improve our healthcare system.

Dr. Sue Joslyn, Epidemiologist at UNI, spoke on "Breast Cancer Epidemiology and Racial Differences". While there is some disparage in screening and early detection, there may be other factors that lead to the difference in survival rates for different ethnic groups.

Three committee members were honored for their dedication to the Cedar Valley Breast Cancer Task Force and Iowa Breast Cancer Edu-action. Barb Daniels was honored for her many years as Treasurer, fundraising efforts, as well as many years of dedicated service to the committee. Gabbi DeWitt was recognized for her above and beyond efforts to help the women of the Cedar Valley get breast and cervical cancer screening and treatment through the Care For Yourself program. Cheryl Wheaton was honored for her tireless work and many talents in revising the Iowa Breast Cancer Resource Guide and other materials through Iowa Breast Cancer Edu-action. All three women are assets to our organization, and we are very appreciative of their time, talents and dedication.



Cheryl Wheaton, Gabbi DeWitt and Barb Daniels

To learn more about the Cedar Valley Breast Cancer Task Force, contact Dee Hughes at (319)235-3179.

- The patient cannot have comprehensive outpatient prescription drug coverage from any other insurance (other than a Medicare Advantage plan or Medigap policy), including Medicaid, TRICARE, or an employer or union group health plan or other source of comprehensive coverage for these drugs
- The patient must live in one of the 50 states or the District of Columbia

A Survivor's Story
By Carolyn Weichers

I was diagnosed with breast cancer in September of 1995. I had had several bouts with lumps and even a biopsy in previous years, but it was a shock to me and my family when I had a lump that was malignant. I can remember the hopeless feelings I had and the scary questions I wanted answered; but I wasn't sure I really wanted to know the answers. My husband and I felt the need to move quickly and to get every bit of information we could and to get it right now. It was not something we wanted to be patient about. We did get answers and we found everyone to be helpful but found that we had to work through things in our own way. I underwent chemotherapy and radiation treatments for the rest of that year. It was an experience that has ultimately changed my life.

There are many events that have brought me to the peace that I have now, living with the threat of breast cancer. I have, through many different channels, met other women that are brave and strong just as I feel I am. Together we have tried to do something to educate women in our world about breast cancer. I became one of the original members of Iowa Breast Edu-Action and we took on the huge project of writing an Iowa Breast Cancer Resource Guide. It was a tremendous amount of work but what a worthwhile project. Finally, I felt that my having experienced breast cancer would

actually make a difference to others! It was very important to me to get information out to women right at the beginning of their diagnosis. I felt strongly that that is the time they need the most support and this Resource Guide will do that!

The other avenue that introduced me to breast cancer women, was my volunteering for the Reach to Recovery Program of the American Cancer Society. I know there is a close community of breast cancer survivors. We are a strong and vital group of women. We are braver than we ever thought we could possibly be. This sisterhood and closeness begins when we first hear the diagnosis of breast cancer. From then on we need to be with others who have had similar experiences. We need to ask and answer questions and communicate hope and strength to each other. I have found this sisterhood to be a healing touch for me and I want to share it with others. Therefore I am a strong advocate of the Reach to Recovery Program and take part in the visits very often.

Breast Cancer survivors are awesome women. They are strong and have a huge voice when they work to help each other. Get involved in some aspect of this great sisterhood and you will be the one to be rewarded!

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), with the meetings being held at Covenant Cancer Treatment Center at 200 E. Ridgeway Avenue in Waterloo at 1:30 and 5:30 p.m.

For those of you who are long term survivors, please remember what a critical role you play in the journey of the newly diagnosed. 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.

American Cancer
Society Office Moves

The American Cancer Society office in Waterloo has moved to the Kimball Ridge Center of the Covenant Medical Center campus. The new address is 2101 Kimball Avenue, Ste. 130, Waterloo, IA 50702. An Open House was held for the community on December 3.

Study Announcement
Recruitment of
Volunteers

Women who have survived breast cancer are invited to participate in a study. The purpose of this study is to help better understand survivors' information use, participation in their health care decision making related to breast cancer, and potential changes in perceived family quality of life.

If you volunteer, you will participate in an informal interview either face-to-face or over the telephone with an interviewer. The interview usually last about one hour. Participants are eligible to receive a gift card to Target as compensation for their time.

If you would like to participate in this opportunity, please contact:

Dr. Elise Radina
Principal Investigator
Assist Professor of Family Services
229 Latham Hall - UNI
319-273-2401
Elise.Radina@uni.edu



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 Cedar Valley Cancer Committee. **Our mission** is to serve as a catalyst for the prevention and cure of breast cancer.

What We've Done

- ❖ Visited with our congressional representatives to secure their commitment to breast cancer research.
- ❖ Participated in fax and letter campaigns o Congress for a commitment to a national strategy for the fight against breast cancer.
- ❖ Created the Iowa Breast Cancer Resource Guide, secured funding and distributed 4000+ copies
- ❖ Iowa Breast Cancer Edu-Action is a subcommittee of the Cedar Valley Cancer Committee

We Meet:

When: 7:00 p.m. on the 4th Thursday of each month.

Where: Area Education Agency 7
Special Education
Building Conference
Room 5

Need more information?

Call Christine Carpenter
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