



Touch of Courage

Connection Beyond Pink TEAM



April 2007
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GENETIC TESTING FOR BREAST CANCER

By Joginder Singh, M.D.

Breast Cancer is a common cancer. One in 9 women will have breast cancer in their lifetime. Most women are scared of the hereditary nature of breast cancer. They would like to know the chances of breast cancer in their siblings and children. It should be noted that **most breast cancers are sporadic and no hereditary cause is found.** Only 7-10% of breast cancers are due to hereditary factors. Major causes of hereditary breast cancer are due to alterations of genes BRCA1 and BRCA2.

What are BRCA1 and BRCA2 mutation?

Every human cell (except red blood cells) has a nucleus, which has 23 pairs of chromosomes. Chromosomes contain DNA (Deoxyribonucleic acid). DNA exists as two long paired strands spiraled into a double helix. Each strand is made up of millions of chemical building blocks called bases. There are only four different chemical bases in DNA (Adenine, Thymine, Cytosine, Guanine) but they can be arranged and rearranged in countless ways. The order in which bases occur determine the message to be conveyed much as specific letters of the alphabet combine to form words and sentences. Cell function is determined by protein and structure of proteins and function depends on structure of DNA. If there is mutation or change in normal base

pair sequence in DNA proteins formed may not function or function differently. It should be noted, that some mutations are silent. Like the words GRAY and GREY are different but mean the same. However, if you change GRAY and GREY to GRZY, it does not mean anything and the protein may not function. BRCA is located on chromosome 17 and BRCA2 is located on chromosome 13. 500 different mutations have been found in BRCA1 and 300 in BRCA2, however, many mutations are silent and some are of unknown significance.

Who should be tested?

Because these tests have implications not only on the individual being tested but also on the whole family, the individual being tested should be given detailed information about the risks and benefits of testing.

Features that increase likelihood of having BRCA mutation are:

1. Multiple cases of early onset breast cancer.
2. History of ovarian cancer in same family.
3. Breast and ovarian cancer in same woman.
5. History of bilateral breast cancer.
6. Ashkanazi Jewish heritage since there is a higher incidence

- of a particular mutation in those families.
- 7. Male breast cancer.

Pattern of Inheritance

These mutations are transmitted by **autosomal dominant** inheritance, which means that they are transmitted equally by males and females. 50% of offspring's of affected persons will carry the mutation; it does not depend on sex.

It is a very common misunderstanding among patients that inheritance only comes from mother, whereas fathers transmit genes equally.

What can be done if BRCA mutation is found?

- 1. Monthly breast examinations starting at the age of 18.
- 2. Clinical exam every 6 months beginning at age 25.
- 3. Mammograms and MRI of breast beginning at age 25 or individualized depending on the age of the youngest relative with cancer. MRI is more sensitive than mammograms in mutation carriers.
- 4. Prophylactic mastectomy decreases risk of breast cancer by more than 90%.

- 5. Prophylactic oophorectomy (removal of ovaries) after childbearing age decreases risk of both breast and ovary cancer.
- 6. Tamoxifen or Raloxifene considered chemoprevention could be considered.

Benefits of gene testing:

- 1. Gives relief when tests are negative.
- 2. Intervention can be done to prevent cancer if results are positive.
- 3. Informed decisions and fewer check ups.

Limitations of testing:

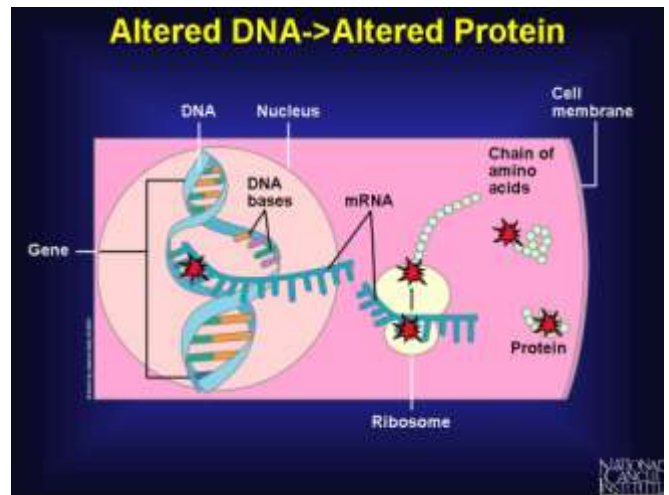
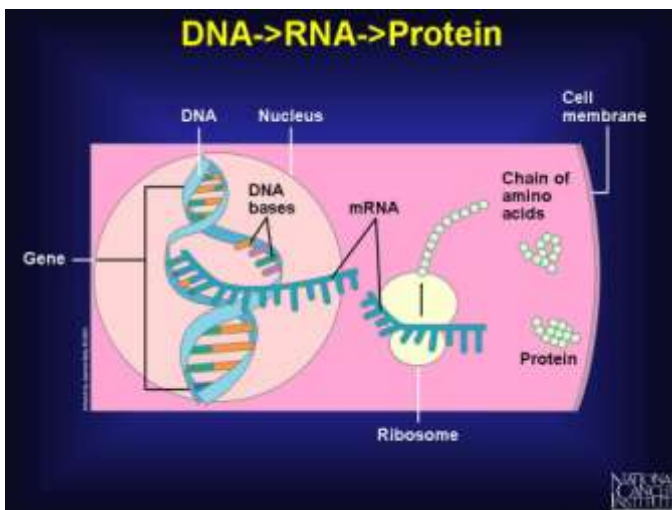
- 1. Psychological distress if positive.
- 2. Some mutations may never lead to cancer, but give distress because we may never know the meaning of such variation such as GRAY and GREY words.
- 3. Insurance issues even though there are laws against insurance discrimination.

The decision to undergo testing should be personal and voluntary. These tests should not be done to please relatives, friends, children, siblings, or health care providers.

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.

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.



Plant it Pink – Hope Blooms for Breast Cancer

By Dee Hughes

In the spring of 2008, we hope to have more than 10,000 pink tulips blooming throughout the Cedar Valley in honor of the more than 10,000 women and men that will be diagnosed with breast cancer in the United States each year. The Beyond Pink TEAM is taking orders for premium quality Pink Impression tulips that you can pick up this fall and plant in your garden so they will bloom next spring.

Last fall, members of the Beyond Pink TEAM planted 400 Pink Impression tulip bulbs in a flower bed at the Covenant Cancer Treatment Center. The flower bed is at the north end of the building and will be visible when you drive down East Ridgeway Avenue. We expect them to bloom at the end of April and beginning of May.

Much of the money raised from the sale of the tulip bulbs will go to our Beyond Pink Fund. This is a fund we established at the Waterloo/Cedar Falls and Northeast Iowa Community Foundation. With successful fundraising we hope to help many women living with breast cancer that are in need of limited financial assistance.

Order your tulip bulbs now, and be part of the Plant it Pink: Hope Blooms for Breast Cancer show next spring.



Mail this part of the form and your check by August 1, 2007 to:

**Dee Hughes
203 Bourland Avenue
Waterloo, IA 50702**

<p style="text-align: center;">Save this Portion!</p> <p><i>Pick bulbs up on: Saturday, Oct 13, 2007 8:00a.m.–1:00p.m. at the parking lot of Covenant Cancer Treatment Center 200 E. Ridgeway Ave. Waterloo, IA</i></p>	<p>Name _____</p> <p>Address _____</p> <p>City/Zip Code _____</p> <p>Phone Home _____ Work _____</p> <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left; border-bottom: 1px solid black;">Number of bags</th> <th style="border-bottom: 1px solid black;"></th> <th style="text-align: right; border-bottom: 1px solid black;">Cost</th> </tr> </thead> <tbody> <tr> <td style="border-bottom: 1px solid black;">_____</td> <td style="border-bottom: 1px solid black;">Bag(s) of 12 tulip bulbs at \$10.00 per bag</td> <td style="border-bottom: 1px solid black;">_____</td> </tr> <tr> <td style="border-bottom: 1px solid black;">_____</td> <td style="border-bottom: 1px solid black;">Bag(s) of 50 tulip bulbs at \$40.00 per bag</td> <td style="border-bottom: 1px solid black;">_____</td> </tr> <tr> <td style="border-bottom: 1px solid black;">_____</td> <td style="border-bottom: 1px solid black;">Bag(s) of 100 tulip bulbs at \$75.00 per bag</td> <td style="border-bottom: 1px solid black;">_____</td> </tr> <tr> <td colspan="2" style="text-align: right;">Total:</td> <td>_____</td> </tr> </tbody> </table>	Number of bags		Cost	_____	Bag(s) of 12 tulip bulbs at \$10.00 per bag	_____	_____	Bag(s) of 50 tulip bulbs at \$40.00 per bag	_____	_____	Bag(s) of 100 tulip bulbs at \$75.00 per bag	_____	Total:		_____
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Relay for Life

The American Cancer Society's Relay for Life in Black Hawk County will be held at Hawkeye Community College June 15 and 16, 2007. Opening ceremonies begin at 5:00 p.m. on Friday, June 15. The event will continue through the night, ending Saturday, June 16, at 8:00 a.m.

Many activities are planned, including the survivor lap which will be held immediately following the opening ceremonies that begin at 5:00 p.m.. The Survivor Reception will follow the survivor lap. All Cancer survivors and their care givers are invited to the reception. Light refreshments and entertainment will be offered. Other activities will include the luminaries, food, fireworks, camping, movies for the overnights.

For more information, contact the American Cancer Society at 319-272-2880.

Urgent Message from the Sister Study for 2007

The Sister Study is the only long-term study of women aged 35 to 74 whose sister had breast cancer. It is a national study to learn how environment and genes affect the chances of getting breast cancer. In the next three years, 50,000 women whose sister had breast cancer, and who do not have breast cancer themselves will be asked to join the study. Currently, there are approximately 33,000 women who have volunteered for the study.

You can join the study if

- Your sister, related to you by blood, had breast cancer
- You are between the ages of 35 and 74
- You have never had breast cancer yourself
- You are a woman living in the United States or Puerto Rico

For more information about the study and how to join, please go to the sisterstudy.org website or call toll free **1-877-474-7837**. A study representative will ask you questions to find out if you are eligible and answer questions you may have.

If you are deaf or hard of hearing, you can call toll free **1-866-889-4747**.

Help Advocate for the Breast Cancer and Environmental Research Act

It's time for our breast cancer advocacy work in the 110th Congress to begin! We are delighted to tell you the **Breast Cancer and Environmental Research Act (BCERA) was reintroduced in the Senate (S. 579) and the House (H.R.1157)**. The National Breast Cancer Coalition and the Iowa Breast Cancer Advocacy Network has worked for many years to pass this legislation. It is supported by an overwhelming majority of lawmakers in both parties. It also has deep grassroots momentum across the country.

We lack any conclusive scientific evidence about the connection between the environment and the development of breast cancer. The BCERA legislation would help address that knowledge gap by funding the best long-term research strategies. It is only through comprehensive and collaborative research models that we can discover the causes of breast cancer, and gain the knowledge needed to prevent it, treat it more effectively, and, hopefully, eradicate this disease.

The Breast Cancer and Environmental Research Act would establish a national strategy to study the links between the environment and breast cancer. It would authorize the National Institutes of Health (NIH) to make peer-reviewed grants to establish multi-institutional and multi-disciplinary Centers to study environmental factors that may be related to the development of breast cancer. Specifically, \$40 million per year in Fiscal Years 2008-12 would be authorized for this purpose. In addition, a panel of consumers and researchers would advise the Secretary.

It is now time to get to work calling our Senators and Representatives. (Senator Harkin - 202/224-3254; Senator Grassley - 319/232-6657; Representative Braley - 319/287-5104; Representative Loeb sack 202/225-6576; Representative Boswell 888/428-5642; Representative Latham 866/428-5642; and Representative King 202/225-4426) to urge them to show their support by signing on as a co-sponsor immediately. Passage of this legislation will be one of the Iowa Breast Cancer Advocacy Network's highest priorities. As always, thanks so much for all you do!

If you have any questions, contact Christine Carpenter at 319/266-0194 or christine.carpenter@cfu.net.

A Survivor's Story

By Anonymous

I just celebrated my 53rd birthday, my sister her 59th, and my mother just celebrated her 85th. We're all bilateral breast cancer survivors. My mother was diagnosed at age 36 on one side, and at age 46 on the other. I was diagnosed at age 32 on the right side and then again two years later, on the left.

When I was just 32, I felt a lump in an area just a little above my breast, so it didn't register at first that it might be breast cancer. I was expecting to have to deal with breast cancer at some point in my life because of family history, but this lump wasn't really in my breast, I thought. A few months passed and then it began to bother me so I had it checked out. After several exams and a biopsy I learned that it was breast cancer. I had a modified radical mastectomy with good results. No lymph nodes were involved and the doctor decided surgery would be sufficient, and no chemo or radiation would be needed. Two years later I repeated the scenario – this time the cancer was discovered on my mammogram. The story of my diagnosis and treatment was pretty textbook for the time – 20 years ago.

Reflections

There are many more women out there who have been through this than you realize. At first, I felt very alone. At 32, there were few others my age that had breast cancer. I was active in the YMCA but was uncomfortable in the locker room. This was merely my self-consciousness; the other women got comfortable with my appearance quickly and were completely supportive. Now,

I'm amazed at how often I find women (and men with wives, sisters, mothers) who have also been touched by this disease. And many are survivors.

There's nothing like a positive attitude! I think breast cancer gave me a new appreciation for what a gift every day is. Through the recovery process I found out how many friends I had and was overwhelmed with their caring and generosity. Everyday I am grateful for my wonderful husband; always loving and understanding and never once expressed disappointment in my changed body.

Never underestimate the value of denial! After my surgeries I did everything to get back to "normal". Diet, exercise, work, play. I want to give and get the most out of every day so that no matter what happens, I can feel I had a life well-lived. There is no point in worrying about what the future may bring. And worrying is what I deny myself.

Every woman has to decide for herself whether a support group will help her. I tried attending a support group, but stopped because I just didn't want to talk about cancer so much. Some women with advanced cancers didn't survive and it was too hard for me to deal with. I didn't feel a support group was helping me deal with my situation and I didn't feel strong enough to participate just to try and help others. This may sound cold, but I had a "denial" strategy that didn't fit in with support groups.

I always regarded breast cancer as a survivable disease. This is probably the most important attitude I have. Sure, I know lots

of women haven't survived but I know lots more who have. I received the gift of this attitude from my mother who was already a survivor at the time of my diagnosis. I think every woman, when faced with a breast cancer diagnosis, has to confront the fear that she may die. But once I confronted that, it helped for me to just regard it as a "bump in the road".

Find a primary physician who understands breast cancer. I have a doctor right now who understands the risks of cancer recurrence in other parts of my body and screens for these. It provides me with peace of mind that we are doing all we can do.

Hope for the Future

My mother has breast cancer again – discovered 40 years after her last occurrence. I have hope because there are so many new drug therapies now. I get strength from her courage and she keeps a good perspective. She may get the remission we are all hoping for or she may not. Regardless, she is happy for the many good years she has had and she focuses on her love for Dad and us.

This may happen to me too, as it may happen to any of us. I will try to deal with whatever happens with the quiet grace and acceptance that my mother is teaching me now.

Printing donated by:
Clinical Radiologists, PC
Vandanda Jain, M.D.
Cassandra Foens, M.D.

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