

# **Touch of Courage**

# . . . . Connection

# **Beyond Pink TEAM**

# OncoType DX By Mukund Nadipuram, MD

# **APRIL 2008**

Volume 12 Number 2

# Inside this Issue

2 Election 2008: Watch, Read, Stay Informed

2 Dates to Remember

Touch of Courage Support Group

Young Survivor's Open House - Meet, Mingle and Learn

Young Survivor's Conference

RAGBRAI Grant

4 Go Green!

Watch for the Tulips

A Survivor's Story

Relay for Life

Cedar Valley Cancer Committee 1607 Heath Street Waterloo, IA 50703 319-232-3219

Website:

www.cedarvalleybreastcancer.org

Today the treatment plan for women with breast cancer is tailored to each patient depending on certain test results. Tumors are examined by a pathologist to determine the type of breast cancer it is, as well as newer tests that could be helpful in tailoring treatment options.

One of the tests for identifying the specific type of breast cancer a woman has is whether the tumor is Estrogen Receptor(ER) positive or not. If a tumor is ER-positive, that means the tumor growth is fed or accelerated by estrogen. In many cases, a drug is used to suppress the estrogen production, (estrogen blockade) thereby preventing growth of the cancer cells. Other deciding factors for treatment include tumor size and axillary lymph node involvement.

Approximately 25,000 women were diagnosed with ER-positive breast cancer with negative axillary lymph nodes (no sign of spreading) in 2005. This type of breast cancer accounts for half of all breast cancers. Treatment guidelines recommend chemotherapy for all women whose tumors are 1 cm or larger, and for smaller tumors if some of the tissue tests indicate a less favorable long-term outcome. Approximately 80% are treatable with "hormonal therapy", such as the drugs Tamoxifen or Arimidex. Adding chemotherapy reduces the risk of recurrence; however the absolute benefit for the individual

patient is small and ranges from 2 to 5%. Therefore, the vast majority of patients taking chemotherapy for ER-positive breast cancer with negative lymph nodes may be over treated, and may have benefited from hormone therapy alone.

Treatment recommendations have generally been based on several predictive features. There are tools that are currently available such as "adjuvant online", providing decision making help for clinicians and patients. Although such tools helps somewhat to make informed decisions, when faced with the choice, many patients and clinicians error on the side of over-treatment because of imprecise nature of predicting treatment benefit.

## What is OncoType DX?

A number of molecular diagnostic tests and prognostic molecular signatures have been evaluated which are also commercially available now.

#### **OncoType DX is:**

- 1. A currently standardized multigene, (21 genes/16 tumor genes, and 5 reference gene), study by molecular technique.
- 2. It is done utilizing the tumor tissue that is removed from the breast.
- 3. It more reliably predicts prognosis than standard clinical criteria in patients with ER-positive, node-negative breast cancer.
- 4. Its performance has been validated in a large population

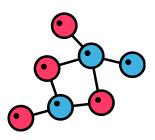
based study.

## How is OncoType DX resulted?

The assay (or analysis) includes 16 tumor genes and 5 reference genes with the result expressed as a computed recurrence score. Less than 11 is a low risk. Between 11 and 25 is intermediate risk. Greater than 25 is high risk.

A National Surgical Adjuvant Breast and Bowel Project (NSABP) clinical trial indicated that only patients with an elevated recurrence score derived benefit from the chemotherapy. It is clear that patients with very low recurrence score do very well with hormonal therapy alone, and patients with very high recurrence score benefit from chemotherapy, but, there is still uncertainty as to whether chemotherapy is necessary for patients who have mid-range, (11 to 25 recurrence score), and who meet established clinical criteria for "adjuvant chemotherapy". Hence there is currently an ongoing clinical trial (TAILORx) to address this exact question.

OncoType DX represents a major step forward into the era of personalized medicine for breast cancer. By integrating a molecular diagnostic test into clinical decision making, patients and clinicians will be able to make more informed choices regarding the most appropriate treatment options.



# Election 2008: Watch the Videos, Read the Responses, Stay Informed

# by Christine Carpenter

The road to the 2008 election has begun and soon we will have new leadership in office. Now is the time to tell the candidates that breast cancer issues don't just matter to us but that we vote on these issues.

The National Breast Cancer Coalition (NBCC) recently launched the 2008 presidential campaign effort, the Breast Cancer Caucus. As a first step in NBCC's 2008 Breast Cancer Caucus, the Coalition asked the candidates to describe their positions on NBCC's public policy priorities and provide a short video to describe what he or she would do to eradicate breast cancer. All of those responses have been posted on the website <a href="https://www.breastcancercaucus.org">www.breastcancercaucus.org</a>

Now it is time for you to review the videos, post your comments and vote on the candidate you believe will do the most to meet the Coalition's mission of ending breast cancer.

This year alone more than 240,000 women will be diagnosed with breast cancer and nearly 40,000 women will die from this disease.

Women have a one in eight lifetime risk of being diagnosed with breast cancer. We still do not know what causes breast cancer, how to prevent it, or how to treat it effectively. We intend to change this and we will – with your help.

Go to <u>www.breastcancercaucus.org</u> and help eradicate breast cancer.

## **Dates to Remember**

## April 15

Meet, Mingle and Learn – Young Survivor's Open House (see article for details)

#### **April 26-29**

National Breast Cancer Coalition Annual Advocacy Conference in Washington, DC

#### June 20-21

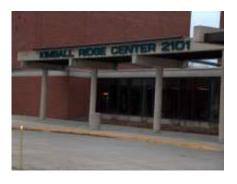
Relay for Life (see article for details)

#### October 4

Pink Ribbon Run Cedar Falls Community Main Street

# 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 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.



# Meet, Mingle and Learn by Dee Hughes

Come meet, mingle and learn with other young women cancer survivors. This is a free social and educational event to bring young women together who are surviving cancer. Learn from each other and from our speakers: Michelle Busch, Dietitian from Wheaton Franciscan Healthcare; Amy Kimball, Physical Therapist from Physical Therapy Partners; and Gloria Strickert, Chaplain with Allen Hospital.

Meet, Mingle and Learn is sponsored by the Beyond Pink TEAM. Activities and speakers are scheduled from 4:30-7:00 p.m. and you won't want to miss any of it. However, please come and go as your schedule allows. We will have refreshments and door prizes.

Come and enjoy the fun, meet new friends and learn about body image after cancer from our speakers. All adult, young women with a cancer diagnosis are welcome.

The Meet, Mingle and Learn event will be held on:

Tuesday, April 15 at
Area Education Agency 267
Conference Center
Seminar Room B
3712 Cedar Heights Drive
Cedar Falls, IA

# Young Survivor's Conference by Paula Pecenka

I think every young cancer survivor should attend at least one Annual Conference for Young Women Affected by Breast Cancer. When I went to the conference in Denver, CO in February of 2006, there were about 400 of us there. This year, the conference was in Jacksonville, FL from February 22-24 and more than 800 of us attended.



Cressie Golden, Paula Pecenka ShanQuiesha Robinson at the Annual Conference for Young Women Affected by Breast Cancer

The conference is a great place to learn about new treatment options and also a great way to connect with people that are almost identical to you - - having cancer, treatment and so on. We chose workshops to attend, and I probably learned the most from *Learning about New Research and Advocacy*. There was a lot of information on new treatment options for survivors who are years out from their initial diagnosis.

There are so many educational opportunities, as well as social events at the conference. I would encourage everyone to go to the Young Survival Coalition website at <a href="www.youngsurvival.org">www.youngsurvival.org</a> and view past sessions of the conference to get a better feel for it.

It was great to see the friends I made in 2006, and to make new friends this year. Cressie, ShanQuiesha and I are eager to share what we have learned with other young women with breast cancer. It helps when you know you are not the only one going through this. We will be at the *Meet, Mingle and Learn* Young Survivor's Open House on April 15<sup>th</sup>.

We look forward to seeing you there!

# RAGBRAI Grant For Young Survivors by Dee Hughes

On January 10, 2008, the Beyond Pink TEAM was awarded a \$2,110 grant from the Cedar Falls RAGBRAI committee. This grant money is a portion of the proceeds raised at the

concert in the dome during the RAGBRAI stop in Cedar Falls last summer to benefit local cancer charities. The Beyond Pink TEAM was one of two organizations receiving grants.

The grant was awarded to the Beyond Pink TEAM to send two young women living with breast cancer to the Annual Conference for Young Women Affected by Breast Cancer. The conference was held February 22-24, 2008 in Jacksonville, Florida.



Dee Hughes, Paula Pecenka, Kim Burger and Cressie Golden accept the RAGBRAI grant check

Two of our Beyond Pink TEAM members, Cressie Golden and Paula Pecenka, were chosen to go to the conference. Cressie was diagnosed at age 41 and Paula at age 25. Both are very interested in helping other young women diagnosed with breast cancer. By attending the conference, they would learn more about living with their own disease, as well as helping the Beyond Pink TEAM learn what we can do locally to meet the needs of the young woman living with breast cancer.

We are very grateful to the RAGBRAI committee for this grant. Young people with cancer have issues unique to them, such as dealing with young children, pregnancy, and personal relationships. The grant will help us in our efforts to make living with cancer easier for young women.

# Go Green! by Cindy Harris

It's time to start thinking about putting corngluten down on your yard that will stop weed growth. Remember, it is a pre-emergent so it needs to go down early - about the time you begin to see tulips close to the house coming up. However, if your yard is like mine, there may still be many inches of snow covering it! But as soon as that snow gets close to being gone, get a layer down.

Many of us recycle aluminum cans but how about cardboard, glass and plastic? What do you do with your computer monitor, oil, paint - whatever? We can make such a difference in what goes into our ground water and atmosphere by being careful of what we throw into our dumps. When grocery shopping, try and pick items with packaging that is easily recyclable.

There is a great web site that tells you where to take things that can't be placed into parking lot recycling bins. On the site, enter the item you want to recycle and the zip code. It then brings up the nearest location you can take the item. If your garage and basement get cluttered like mine sometimes, this site is essential in helping you get cleaned up. Go to <a href="https://www.earth911.org">www.earth911.org</a>

# Watch for the Tulips by Dee Hughes

In 2006, the Beyond Pink TEAM planted 400 pink tulip bulbs at Covenant Cancer Treatment Center (200 E. Ridgeway in Waterloo) as a kick off to our *Plant it Pink: Hope Blooms for Breast Cancer* campaign. Last spring we were looking forward to the big show of blooms, but the weather didn't cooperate. Hopefully, this will be a more cooperative spring.

More than 5,000 pink tulip bulbs have been planted in beds throughout the Cedar Valley and orders for bulbs



will again be taken this summer. We want pink tulips blooming every spring in honor of all women living with

breast cancer, and to remind us there is hope.

# A Survivor's Story: Scars, Marks and Tattoos by Debra (DJ) Corson

Seven was never my lucky number. I should have known it would be bad news when I was scheduled to learn the results of my biopsy for breast cancer on 7-17-07.

To share my story, I have selected excerpts from my journal and "updates" sent to friends and family.

#### Surgery

Our son asked me how I was doing as I was leaving for surgery. I said, "I feel like this is the first day of feeling bad for months." He said, "Mom, I believe this is the first day of you getting better."

#### Chemo

Saturday—not great, but OK. Sunday—definitely not good. I better take something for this nausea thing...hum, I have three different meds for nausea, which one? This one can make you dizzy, this one is likely to cause a huge headache, this one makes you drowsy. Monday—THIS is BAD! Must not have taken the right thing for nausea ... Food repulses me. I can't watch TV because it is full of food commercials. I just want to get into a dark room, crawl into a ball, and sleep.

It's important for me to focus on the chemo as helping me get to better (not making me sick).

#### Losing my hair

It is always so windy at Hawkeye (Community College). When I walk across campus, I take \$20. If my wig blows off, the accumulative effects of the

chemo have me so worn down, I know I can't run after it. With the 20 bucks, I'm hoping some passing student will run after it for the reward money.

From where we draw strength I've been playing the song Stand, by Rascal Flatts repeatedly. It helps me stay strong.

The outpouring of support from friends is both overwhelming and humbling. All I can do is appreciate with my whole heart what has been done for me. Then, *pay if forward* because I can never pay it all back.

# Finishing treatment

A celebration—my hair is growing back! I feel like a CHIA pet--just put some fertilized mud on my head, water it, and watch it grow! I'll be glad when I have enough eyelashes to use mascara again. Wouldn't you know, the wild hair on my chin is already back!

I am in charge of my attitude, what I contribute to life, and how I treat my body. I am NOT in control of the outcome of this illness. I can hope for a miracle, but I cannot make one happen. And I am not a failure if one doesn't happen.

My husband, who is in law enforcement, often talks about SMTs--Scars, Marks, and Tattoos. In his work, they are important for identification purposes. Breast cancer surgery, chemotherapy, and radiation gives survivors some SMTs of their own, but they aren't just physical.

Our physical, emotional, and spiritual scars, marks, and tattoos serve as an important part of our identification: who are we today, and who we are becoming.

# Relay for Life by Jill Roberts

Relay for life. What is it? It is a fun-filled overnight event designed to celebrate survivorship and raise money for research and programs for your American Cancer Society. During the event, teams of people gather at Hawkeye Community College for the Black Hawk County Relay and take turns walking laps, each team tries to keep at least one team member on the track at all times.

How to participate? You can buy a luminary or donate money to a team member or be a volunteer. There are plenty of opportunities available. If you don't have a team and wish to participate please contact the American Cancer Society or <a href="https://www.cancer.org">www.cancer.org</a> or call Jill Roberts at 233-8911.

When is it? This year's Relay for Life will be held June 20-21<sup>st</sup> at Hawkeye Community College. The event begins on Friday night at 6:00 p.m. and goes to Saturday morning.

Encourage someone you know to help join in the fight against Cancer. I hope to see you there!

# Printing Donated by:

NuCara New Image Boutique

April 2008

## **Edu-Action**

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:** 6:30 p.m. on the 4<sup>th</sup> Thursday of each month, except November when we meet the 3<sup>rd</sup> 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:

<u>Christine.carpenter@cfu.net</u> (319) 266-0194

## **Support and Rehabilitation Programs**

Care and Share Support group for anyone dealing with cancer.

Meets the 1<sup>st</sup> Tuesday of every month at 1:30 p.m. Breast cancer support group. Meets the 1<sup>st</sup> 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:**

Touch of Courage

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

Allen College of Nursing American Cancer Society

Library and Media Center 2101 Kimball Avenue, Suite 130

1825 Logan Avenue Waterloo, IA 50702

Waterloo, IA 50703 319-272-2880 or 888-266-2064 (319) 235-2005 1-800-ACS-2345 (available 24 hrs)

Breast Care Center Covenant Cancer Treatment Center

at United Medical Park 200 E. Ridgeway Avenue 1753 West Ridgeway Waterloo, IA 50702 Waterloo, IA 50701 319-272-2800

319-833-6100 Include Cancer Information Library

National Cancer Institute National Coalition for Cancer 1-800-4CANCER Survivorship 1-505-764-9956

National Lymphedema Network Y-Me

1-415-923-3680 1-800-986-8228

Covenant Lymphedema Therapy Physical 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: Sate: Zip:
\$ amount of donation
OGeneral Donation ONewsletter Donation ONBCC Scholarship Fund
Make checks payable to the Cedar Valley Cancer Committee and send to 1607 Heath Street, Waterloo, IA 50703