



# Touch of Courage . . . Connection

## October 2013

TAKING ACTION – EDUCATING – ADVOCATING – MAKING A DIFFERENCE

IN THIS ISSUE

## “Not So Common Breast Diseases”

By Douglas M. Duven, M.D., F.A.C.S of the Breast Care Center

**“FACT: Men can carry and pass on the BRCA gene mutation.”**

Breast cancer occurs in men & women. Approximately one male is diagnosed for every 100 women. Male breast cancer often presents with a lump or mass. Mammograms are possible for men if indicated. Ultrasound assists in evaluating the male breast tissue. Biopsies are the same as for women – usually an ultrasound guided core biopsy. If a cancer is found, a mastectomy is usually recommended. Male breast cancer is also tested for estrogen and progesterone receptors, Tamoxifen is often prescribed for the ER+/PR + tumors. Men with a lump that is not centrally located (beneath the nipple) should be evaluated for a possible cancer

**Fact:** Men can carry and pass on the BRCA gene mutation. The maternal side of the family used to be the focus, now both maternal and paternal sides need to be evaluated for breast, ovarian and pancreatic cancer.

Many men develop a breast lump or enlargement that is not cancer. Gynecomastia is the growth of male breast tissue, commonly located beneath the nipple. Male breast tissue can be affected by hormonal fluctuations and medical conditions. Gynecomastia can be a side effect of many medications, including testosterone supplements. Dietary

supplements such as those used by body builders are also a possible source. Some medical conditions such as kidney disease/failure, prostate cancer also raise the incidence of gynecomastia.

Paget’s Disease of the breast is a malignancy, often presenting with a persistent rash, irritation or lesion of the areola or nipple. A punch biopsy of the lesion often is the most frequent biopsy type used to rule out Paget’s Disease. Paget’s can be non-invasive or invasive. Women should be encouraged to report any persistent rash or lesion of their breast to their primary care physician. Frequently, a steroid containing cream is prescribed initially. If there is no improvement using the cream, referral for biopsy is recommended. Paget’s is treated with surgery. These tumors are tested for the estrogen and progesterone receptors, with anti-estrogen therapy often recommended. Chemotherapy may be indicated for an invasive Paget’s tumor.

Malignant Phyllodes tumors account for less than 1% of breast cancers and typically present as a rapidly enlarging, palpable mass in middle-aged to older women, and may develop over several months. The mammographic appearance is often telling—a very large, relatively circumscribed, round or oval mass. The mass may become extremely large. At close inspection, the margins are often ill defined rather than sharply circumscribed. When detected at a

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screening examination, the appearance may mimic a fibroadenoma. The ultrasound appearance is similar to that of fibroadenoma, though a phyllodes tumor more frequently contains cystic spaces than does a benign fibroadenoma. On ultrasound, the margins of a phyllodes tumor are typically ill defined. Surgical treatment is similar to other breast cancers, lumpectomy when appropriate or mastectomy.

Inflammatory Breast Cancer is a rare, but aggressive form of breast cancer. Frequently, it presents with redness, swelling, tenderness and a warm sensation of the breast. Often this is initially mistaken for an infectious process. The swelling of the breast tissue and skin is due to the blockage of the lymph channels. The breast skin may have the appearance of orange peel. Often there is no specific mass palpated within the breast. Other symptoms are a rapid increase in breast size, heaviness and marked asymmetry. Ultrasound often shows significant skin edema. Diagnosis is made by biopsy of the abnormal skin or by core biopsy of a lesion within the breast. Many inflammatory breast cancers are advanced before diagnosed, often with lymph node involvement, sometimes with distant metastasis. Inflammatory breast cancer is most frequently treated with aggressive chemotherapy prior to any definitive surgery. Hormonal therapy is used if the tumor is estrogen/progesterone receptor positive.

Mastitis is an infection of the breast. Frequently, women who are nursing have mastitis, but the condition is not limited to those women. Mastitis can occur at nearly any age. These infections can arise from a breast duct, the nipple can be the entrance site for common skin bacteria, the fluid in the ducts serves as a host for the bacteria. Redness, swelling, fever, and pain are the presenting symptoms. Sometimes, the infection can break through the skin or drain through the nipple. An ultrasound can help to detect an infected pocket of fluid, often this pocket can be drained. The fluid removed may be evaluated by the lab for the type of bacteria and which antibiotics will work best. Oral antibiotics are usually used and often need to be taken for an extended course to fully treat the infection. Surgical removal of the chronically infected area may be required if the mastitis recurs. Women who smoke have a higher incidence of mastitis.

Women and men should report any change(s) of their breast(s) to their physician.

## Mammogram Procrastination

Women have a tendency to put others needs first, but when it comes to an annual mammogram starting at age 40, women need make it an absolute priority. We have seen far too many women who have skipped their mammograms, some for a couple of years to those who haven't had one for several years and occasionally a woman who has put off a mammogram for 20 years or more. Some women luck it out and everything is fine, but too often, a breast cancer has been allowed to go unchecked and is much more advanced than if the woman would have had regular mammograms. Advanced cancers often require a more extensive surgical procedure and require more adjuvant treatment with chemotherapy, and radiation therapy. The risk of lymph node involvement increases as the tumor size increases.

**FACT:** Mammograms are not perfect, but mammograms do pick up the earliest cancers.

**FACT:** Early is a whole lot better than later.

What contributes to the procrastination?

- 1) "I have no family history of breast cancer, so I am not concerned." Many women diagnosed with breast cancer have no family history. The lack of history does not translate into lack of risk.
- 2) "I don't have insurance coverage." There are several programs available to allow women to get screening mammograms either at a reduced or no cost. Contact "Care For Yourself" at 319.292.2225 to see if you qualify.
- 3) "Mammograms hurt" – Mammography techniques today allow for little discomfort and it is just for a few seconds. Women who are menstruating should wait until the week after their period to avoid premenstrual tenderness.
- 4) "I'll take my chances." This is very high risk reasoning.

Fear, for whatever reason, can be a powerful deterrent. We encourage you to take the 5-10 minutes to get a mammogram. Please encourage the other women in your life to get their screening mammogram every year. You can say, "I love and care about you and want you to be well, please get your mammogram".



Join in the fight to end breast cancer!

The following organizations, businesses and individuals have endorsed The Breast Cancer Deadline 2020:

Beyond Pink TEAM  
Iowa Breast Cancer Edu-action  
Splash of Color Breast Cancer Support Group  
Allen Hospital  
Covenant Cancer Treatment Center  
Wheaton Franciscan Healthcare  
Cedar Valley Breast Care Center  
Eastern Iowa Chapter of Oncology Nursing Society  
NuCara – New Image Boutique  
Mercy Center for Breast Health – Mason City  
St. Lukes Bone and Breast Health – Cedar Rapids  
Partners in Obstetrics and Gynecology – Waterloo  
Breast Care Center United Medical Park  
City of Waterloo and Mayor Buck Clark  
Iowa State Senator Bill Dotzler  
Iowa State Senator Jeff Danielson  
UNI's Recycle, Reuse Technology Transfer Center – Dr. Catherine Zeman  
Community Memorial Hospital - Sumner  
City of Cedar Falls and Mayor Jon Crews  
Iowa State Representative Bob Kressig  
UNI's Center for Energy and Environmental Education – Dr. Kamyar Enshayan  
City of Dike and Mayor Michael Soppe  
Integrative Medicine for Women and Dr. Marilyn Hines  
Visions Hair Studio and Mo Hardy  
Clark and Associates Prosthetics  
Edward Jones Investments – Jana Eilderts  
Waverly Health Center - Waverly  
Iowa State Representative Walt Rogers  
Former U.S. Representative Leonard Boswell  
U.S. Representative Steve King  
U.S. Representative Tom Latham  
U.S. Representative Dave Loebsack  
HyVee Stores - Waverly, College Square Shopping Center, University Avenue, Crossroads Shopping Center, Ansborough Avenue and Logan Avenue  
Afro-American Community Broadcasting, INC – KBBG FM Radio – Lou Porter

To learn more visit. ....  
[www.breastcancerdeadline2020.org/get-involved](http://www.breastcancerdeadline2020.org/get-involved).

## Beyond Pink TEAM Summer Highlights



Pink Heal Tour 2013

Once again the "Heal Pink Tour" visited the Cedar Valley. Three "pink" fire trucks along with a huge silver ribbon spent the day celebrating all women cancer survivors. Over 100 cancer survivors were treated to pink carnations donated by Flowerama and coupons for a FREE Scratch Cupcakery cupcake. Thirty cancer survivors were surprised by a visit from firemen and their pink truck. "I don't know who sent these people, but it really made my day!" one survivor shared on her facebook page.

A huge thank you to the following businesses and groups who helped make this day possible: CVSi Motorsports – Black Hawk Rental – The Other Place-University Avenue – Hy-Vee-College Square – Scratch Cupcakery – Nagle Signs – Flowerama – Mix 93.5 – KWWL – Crystal Distribution – Panera Bread-Café – Dr. Douglas Duven – PDCM – Superior Fire Protection – Agendia – Genomic – Myriad – American Cancer Society – Breast Care Center – Covenant Cancer Treatment Center – Cedar Valley Cancer Center – Cedar Falls and Waterloo Fire Departments.



**Cookin' for a Cause** – sponsored by the State Bank & Trust Company in Dike. Event was held as part of the town's Watermelon Days and benefited the Beyond Pink TEAM.

**Pretty In Pink Horse Show** – hosted by the Northeast Iowa Saddle Club (NEISC) in July was an inspiration of Emily Parks, a breast cancer survivor. This is their 2<sup>nd</sup> Annual Event to benefit the Beyond Pink TEAM. Read Emily's story, page 5 of this issue.



# Beyond Pink TEAM Celebrates 25 Years!

Join the Beyond Pink TEAM on October 17 for a celebration reception at the Gallagher Bluedorn Performing Arts Center, UNI Campus, Cedar Falls from 5:00 – 7:00 pm.

**Breast Cancer Survivors will be honored and remembered.**

**Survivor and caregiver stories will be shared.**

**Beyond Pink TEAM accomplishments and awards will be announced.**

The public is invited to attend. For reservation information, visit:

[www.beyondpinkTEAM.org](http://www.beyondpinkTEAM.org)

or call Pat Buls at 319-232-8691.



## Support Group Meeting Dates

October 1, 1:30 p.m.**Care & Share Cancer Support Group**

Covenant Cancer Treatment Center  
200 E Ridgeway, Waterloo  
Jeanne 319.272.2816

July 7, 1:30 p.m.**Touch of Courage Support Group**

Breast Cancer Support Group  
2101 Kimball Ave, Waterloo  
Pat Buls 319.232.8691

October 14, 1:30-3:30 p.m.**Look Good...Feel Better**

Hair – Make-up – Nails - Skin  
American Cancer Society Office  
2709 University Ave, Waterloo  
RSVP – 319.234.0990

November 4, 1:30 p.m.**Touch of Courage Support Group**

Breast Cancer Support Group  
2101 Kimball Avenue, Waterloo  
Pat Buls 319.232.8691

November 4, 4:45-6:45 p.m.**Grundy Area Breast Cancer Support Group**

Grundy County Hospital - Grundy Center  
Kristi Barnett 319.824.4129

November 14, 5:00-7:00 p.m.**Splash of Color – Women of Color Breast Cancer Support Group**

Waterloo Public Library – Waterloo  
Cathy 319.493.8857

August 8, 5:00-7:00 p.m.**Splash of Color - Women of Color Breast Cancer Support Group**

Waterloo Public Library  
Cathy 319.493.8857

December 2, 1:30 p.m.**Touch of Courage**

Breast Cancer Support Group  
2101 Kimball Ave, Waterloo  
Pat Buls 319.232.8691

December 3, 1:30 p.m.**Care & Share Cancer Support Group**

Covenant Cancer Treatment Center  
200 E Ridgeway, Waterloo  
Jeanne 319.272.2816

December 9, 1:30-2:30**Look Good...Feel Better**

Hair – Make-up – Nails - Skin  
American Cancer Society Office  
2709 University Ave, Waterloo  
RSVP – 319.234.0990

January 6, 1:30 p.m.**Touch of Courage**

Breast Cancer Support Group  
Location TBD – check BPT website  
Pat Buls 319.232.8691

January 7, 1:30 p.m.**Care & Share Cancer Support Group**

Covenant Cancer Treatment Center  
200 E Ridgeway, Waterloo  
Jeanne 319.272.2816

## 2013 Cancer *Survivorship* Conference

Tuesday, October 29, 2013

5:00 – 8:30 p.m.

Waterloo Center for the Arts  
225 Commercial Street, Waterloo

If you are a cancer survivor or a caregiver to a loved one with cancer, this is for you. Hear from Wendy Harpham, MD,FACP & Cancer Survivor – *"Happiness in a Storm: Embracing Life as a Health Survivor"* and Heidi Krame, RDDN & Cancer Survivor – *"Tastefully Inspired: A Fresh Approach to Wellness"*.

Register TODAY by calling 319.272.2273. The first 100 people to register by Monday September 30 will receive 2 FREE books at conference written by keynote speakers.

## Splash of Color 3<sup>rd</sup> Annual 3K Fundraiser Walk

Saturday, October 12, 2013

Sullivan Park, Waterloo

Registration fee (includes t-shirt:

\$18 / Adult and \$10 / student

For more information contact:

Cathy Ketton – 319.493.8857 or

Doris Saddler – 319.290.1294 or

visit: [www.beyondpinkTEAM.org](http://www.beyondpinkTEAM.org)



## October Breast Cancer Events Benefiting Beyond Pink TEAM

**Saturday, October 5** – 8:00 am – **Pink Ribbon Run** – Cedar Falls Community Center

**Sunday, October 6** – 7-9 pm – **"Delivering Fashion"** Style Show at Scheels – Cedar Falls - tickets available from Cedar Falls Cheer Team or at Scheels

**Monday, Wednesday, Friday, October 7, 9 and 11** – 9-11 am & 2-4 pm all days – **Tulip Bulb Pick-up** – Covenant Cancer Treatment Center

**Friday, October 11** – 7-10 pm – Zumba's **"Dancing Through Time"** – Electric Park Ballroom, Cattle Congress grounds, Waterloo

**Saturday, October 12** – 7:30 am – **Splash of Color Walk** – Sullivan Park, Waterloo – see promo above

**Thursday, October 17** – 5:00 pm – **Jesup Volleyball "Pink Out"** – Jesup High School

**Thursday, October 17 & 18** – 7:00 pm – **Black Hawk Hockey & Great Clips Pink Out** – Young Arena, Waterloo

**Wednesday, October 23** – 7:00 pm – **UNI Soccer Pink Out** – Cedar Valley Youth Soccer Complex, Ridgeway & DeWitt Road, Waterloo

## FIGHT LIKE A "COWGIRL" -

*Emily Parks, a cancer survivor giving back*

Everyone's first question is 'How'd you find out you had cancer?' I guess that's how this story should start. I was taking my usual morning shower and thought to myself, 'That's a lump, that's never been there before! How could this be? What do I do?' I decided to wait, not to panic, let this sink in for a few days. Letting myself panic and lose my mind was not going to help me so I might as well get used to the idea for a few days and gather my thoughts and strength. I was sure I'd need it.

After the initial shock, I showed my husband and told my mom, then headed to the doctor. At the office they felt the lump and sent me to the Breast Care Center the next day. There, at age 31, I had my first and last mammogram in my life. The results turned into a biopsy and a week of waiting and wondering which, by now, you know the results.

The call came Thursday, had a consult on Friday, and was scheduled for surgery the following Wednesday. One thing I didn't know was that with cancer things happen fast and some of the worst parts are "not knowing" what to expect. All of this was foreign to me so I chose the least invasive option; lumpectomy and to do the genetic test for cancer that day.

Normally I spend 4-5 days a week at the barn where we board our horses, this wasn't a normal week. I remember riding my horse that weekend for the last time before anything was done. We were scheduled to go to a competitive trail ride, but that was cancelled since surgery and a lot of bouncing doesn't mix well.

So, I had surgery and was more nervous about the IV needle than the surgery - heck, I'd be asleep for the surgery. No need to be nervous about that especially when you have a great team of doctors! As I recovered, we found out I am BRCA1 positive (I have the gene for breast cancer). My tumor was exactly 2 cm which is between stage 1 and 2 and it was triple negative breast cancer, which is not fueled by hormones, it is a faster growing more aggressive type. The only up side to this was during surgery they tested the sentinel nodes, or the first few lymph nodes, to see if the cancer had spread at all and that came back clear!! Great News!

My treatment was 8 weeks of chemo every other week. Of course, with all the drugs proposed for treatment you get the full disclaimer of side effects, none of which are pretty and most are plain scary. Obviously, most everyone gets a new hair (un)do during treatment.

We did go to Mayo hoping for some miracle treatment that would be easier, faster, better - none of which was the case. We found out more about my cancer, got a lot of questions answered, found that their prescribed treatment was the same as the doctor in Waterloo talked about and

they ran a few more tests. The results were very reassuring since they all came back negative.

Upon returning, surgery was scheduled to install a port for administering treatments and I started chemo shortly after the port site healed. A few weeks later, as I sat in my hometown watching a friend in a horse show my hair started falling out and blowing away like loose hay in the wind. Later we went home and used a pair of new horse clippers to shave it off (now my hair hasn't been over 2" long). After the first month of treatment I looked at the calendar, and felt mortified. This was August and I wouldn't be done until the last week of OCTOBER! Yikes, it felt like an eternity!!

During all of this I wasn't able to ride much at all. A few of our friends helped us keep the horses exercised when we couldn't. When I could be there it was very relaxing, I appreciated just feeling good enough to go see them when possible.

After Chemo was finally over and knowing that I am BRCA1 positive, there was a big decision to make: Mastectomy or Not. So we went back to Mayo to consult with surgeons, radiology (my next step if I didn't have a mastectomy) and talk about the risk of recurrence.

My decision was mostly made, if recurrence happened I did not want to go through treatments again taking 6-7 months of my life. Reconstruction did not sound like anything I needed and was another 4-6 months of no riding. Side effects of radiation weren't any better than the chemo. So double mastectomy it was and I've never regretted it. I remember getting on my horse and saying to my husband "If I had reconstruction I wouldn't be able to ride yet." I made the decision to do what I could to reduce risk moving forward, and I will NOT LIVE IN FEAR.

Instead of fearing my future, I thought what can I do? Why did this happen to me? And what am I going to do with it? As I went to horse shows with friends and saw silent auctions raising money for clubs and groups an idea formed: "Why doesn't the horse community do something for this cause? Just like everyone else, people who have horses have been diagnosed with cancer." A year later that idea became the Pretty In Pink Horse Show! This July was the 2nd annual Pretty In Pink Show! During the show we held a silent and live auction for the large items, handed out tons of prizes, sold t-shirts, and even our lunch stand donated a portion of their proceeds from their sales. All of our items are donated by the generous people in the Cedar Valley and major companies who sell horse related items. So we get quite a range of items to auction off. This year we raised over \$2,700 for the Beyond Pink TEAM and all of the money stays local! Check us out on Facebook at N.E.I.S.C.A. Pretty In Pink Horse Show and stay tuned for details on next year's show.

## "Going Green"



*By Cindy Harris, breast cancer survivor*

With Fall and Winter comes the colds, flu and all those nasty germs. This makes some turn to more antibacterial soap and sanitizers. Plain soap and water kills just as many germs as these products. And it's much safer and it is less expensive too. Contrary to advertising, the chemicals don't work better. They are dangerous and more expensive. But, if you want to use those products, check for TRICLOSON. This antimicrobial chemical disrupts thyroid function and hormone levels in humans. This is dangerous. They have proven that when it hits the waste waters it can cause sex changes in aquatic life. We need to keep this away from humans and out of the water we drink.

Another problem is the over usage of this and other antibacterial chemicals. It is like helping to cause the so called "super germs" that are resistant to our antibiotics. You can always carry a small, refillable spray bottle of peroxide/water mixture to spray cart handles, hand, - whatever. Remember, the few chemicals in our lives, the safer we are.



## Did you know? . . .

You can read the current issue and past issue of the "Touch of Courage Newsletter" at your convenience on the Beyond Pink TEAM website at [www.beyondpinkTEAM.org](http://www.beyondpinkTEAM.org).

All you need to do is go to the website, enter your email address, click on submit and you will be notified when the latest issue of the "Touch of Courage Newsletter" is available. Help us save!

**MISSION – Beyond Pink TEAM is a nonprofit organization whose mission is to provide breast cancer prevention, education, support and advocacy for comprehensive, quality care in the Cedar Valley and surrounding communities.**

### 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.beyondpinkTEAM.org](http://www.beyondpinkTEAM.org)

**Living Beyond Breast Cancer** includes a helpline, newsletter and information. Survivors Helpline: 888-753-5222 [www.LBBC.org](http://www.LBBC.org)

**Young Survival Coalition** connects with other young women diagnosed with breast cancer. [www.youngsurvival.org](http://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](http://www.cancercare.org)

**Iowa Cancer Consortium** offers cancer information and links to resources in Iowa. [www.canceriowa.org](http://www.canceriowa.org)

**American Cancer Society** offers cancer information and services. [www.cancer.org](http://www.cancer.org). Local office: 319-234-0990 – 2709 University Ave, Waterloo

**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](http://www.stopbreastcancer.org)

**M.D. Anderson Cancer Center**, University of Texas offers patient and cancer information. [www.mdanderson.org](http://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](http://www.komen.org)

**Iowa Breast Resource Guide** is available on the Iowa Breast Cancer Edu-action website. [www.iowabreastcancer.org](http://www.iowabreastcancer.org)

# Touch of Courage • • • Connection

Cedar Valley Cancer  
Committee  
4756 Charolais Dr  
Waterloo, IA 50701  
[www.beyondpinkTEAM.org](http://www.beyondpinkTEAM.org)

Connect with us...Your support financially or through volunteering is both needed and appreciated. Please feel free to complete the following and forward to Cedar Valley Cancer Committee at address listed.

Name \_\_\_\_\_

Address \_\_\_\_\_

City State Zip

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

I would like to participate with the Beyond Pink TEAM by:

- Willing to write a survivor story for the newsletter
- Volunteer: *(Check all that apply)*
  - Assist with Support Groups
  - Development (Publicity)
  - Events (Fundraisers, Annual Luncheon, Projects and more)
  - Education at Health Fairs/Presentations
  - Advocacy
- Willing to write letters or make phone calls to legislators for breast cancer issues, through the Iowa Breast Cancer Advocacy Network.
- Interested in making a donation. Make checks payable to: Beyond Pink TEAM *(all donations are tax deductible)*
  - BPT Fund
  - NBBC Scholarship Fund
  - Area of Need