



Touch of Courage . . . Connection

April 2016

TAKING ACTION – EDUCATING – ADVOCATING – MAKING A DIFFERENCE

IN THIS ISSUE

Lymphaticovenular Anastomoses (LVA) - A Treatment of Lymphedema

By: Mindy Bowen BSN, RN, CAPA, RN-BC
Nurse Clinician, University of Iowa Hospitals and Clinics
Department of Plastic and Reconstructive Surgery

Lymphedema is a complicated medical condition that is poorly understood. Patients are often misdiagnosed, undergo unnecessary tests, and are managed incorrectly. Lymphedema is a common problem and a chronic condition that does not improve and slowly worsens. Lymphedema research is in its infancy, but we know enough to know we can help. Treatment for breast cancer can cause lymphedema. The disease can occur early, within the first few years, or later. It is the direct injury to the lymphatic system that creates the risk. Radiation can also increase the risk. 56% of breast cancer survivors will develop lymphedema within two years.

Once lymphedema develops, early treatment and diagnosis is important. We have highly sophisticated diagnostics, for example: Indocyanine Green lymphography (ICG), which is very sensitive and very accurate. We also use a BioImpedence measurement as well as limb measurements.

After a diagnosis has been confirmed, non-surgical options and surgical interventions are discussed. Nonsurgical options would include, exercise, compression garment, massage, pneumatic compression. One of the surgical interventions that the University of Iowa offers is the Lymphaticovenular anastomoses (LVA). LVA is a treatment for lymphoedema

that can improve lymph circulation by the connection of lymph vessels and veins. While the LVA is most effective in patients with early disease, it can still be offered selectively in those with more advanced disease.

LVA is an advanced, minimally-invasive procedure. It uses an ultra-high power microscope and a super-microsurgical technique. The lymphatic vessels are in the range of 0.2-0.5 mm and are connected to nearby veins. The size of these vessels is similar in size to a human hair. This surgery by-passes the lymphatic obstruction and reconnects the lymphatics with nearby veins. This allows lymphatic fluid to bypass the obstruction and flow directly into the bloodstream reducing symptoms of lymphedema. This procedure takes approximately eight hours and involves a one night stay in the hospital. The incisions are about one inch long and only go superficially under the skin surface. This is where the lymphatics and veins will be found. There are usually 4-6 incision sites that we will use to perform the anastomosis. We use an "Octopus" technique where we will use quite a few lymphatic vessels and anastomose them into a vein. So instead of just one lymphatic vessel to one vein we use numerous lymphatics into one vein.

Continued on page 4

Didn't Let Cancer Get Me Down - Found Support with BPT

A Survivor's Story

Page 2

Go Green!

Page 3

Fundraisers Thank You

Page 3

Upcoming Fundraisers

Page 3

Cedar Valley Relay For Life Dates

Page 4

Support Group Meeting Dates

April – May – June - July

Page 4

More Lymphatic Treatment Info

Page 5

Young Cancer Survivors

Page 5

Resources

Organizations for support and education

Page 6

Support and Volunteer Opportunities form

Page 6

Didn't Let Cancer Get Me Down – Found Support with BPT

By Cari Tyler, Survivor

Growing up, I was a very healthy child, only getting sick or the flu a handful of times. Even in my 20's and into my early 30's, I rarely had to call into work sick. So when I went in for my yearly OB/GYN appointment on April 29th, 2015 (which also just so happened to be my 35th birthday!) all I could think was, "Ugh! I hope they don't poke around for very long."

All women look forward to this EXTREMELY fun appointment every year, right? Yeah, not so much! This year was a little different for me though, because my maternal grandmother, who just turned 80 the previous summer, had been diagnosed with cancer that fall and I had questions. When the midwife came in and before the actual exam started, I told her about my grandma's cancers. She had been diagnosed with breast and uterine cancer. The midwife listened to my concerns and reassured me that the odds were extremely low that I would have anything. We continued on with the physical exam (UGH!). When she did the breast exam, she said there was a lump that I should get checked out just to ease my mind and hopefully confirm what she already told me. What we both didn't know is how this appointment would be the beginning of what felt like a horrible nightmare.

My next appointment was with the breast care doctor, who did an ultrasound and a biopsy telling me my results would be back the following week. I enjoyed the weekend and didn't think much about it because I had a small lump tested a few years and it came back normal. I also was thinking about what the midwife had told me; my chances of getting any kind of cancer, especially at my age, were about 1:500,000.

When I waltzed into the room that following week with my son (I really thought everything would come back normal and I'd be in and out of there quickly) and the doctor broke the awful news that it was in fact cancer, time literally stopped. I looked at my son's puzzled face and knew I had to keep it together for him. It all felt like an out-of-body experience. I did ok until I got into the car and called my mom to break the news. We both just sobbed together. I was referred to an oncologist, who ordered lots of scans and tests. During my bone scan, I told the nurse who was watching the scan that my hip had been hurting for months, but my insurance wouldn't pay for an x-ray until I had gone through physical therapy first. She then

looked closer at the scan of my hip and after leaving to discuss this with the doctor, she told me they were going to take two x-rays just to check it out and the results would be sent to my oncologist.

May 28th 2015...the day all my scans were back and my results were shared with my mom and myself...THE DAY my world was turned upside down The cancer had spread to lymph nodes in my armpit and my hip had a tumor on it which had eaten away almost half of the neck of the femur and ball joint. The oncologist said (and later my hip doctor would say the same thing) she didn't know how I hadn't fractured it yet. Immediately, I was put on crutches because I refused a wheelchair or a walker (COME ON! I'm a 35 year old single mom and extremely independent...absolutely not!). I also had to start Zoladex shots to shut down my ovaries since my cancer was hormone-fed. This meant no more children....the hardest thing to accept next to having cancer at such a young age. Don't get me wrong; I know how blessed I am to even have a child to begin with (especially such an amazing son!). I just always hoped to have more children someday, but I guess it wasn't meant to be. But I only got about 30 minutes to let this devastating news soak in. A whole 30 minutes from the time I was told my ovaries needed to be shut down to the gut wrenching shot I had to get to start the shutdown. (Did I mention I really HATE needles?). Breast cancer, Stage 4, grade 2, ER+(100%), PR+(70%), HER-.....these are all the terms used to describe my cancer.

June 1st-mediport surgery.

June 8th-total hip replacement surgery.

At first, I had the typical feelings and emotions that everyone has when given awful news...I was angry, bitter, cried A LOT, anxiety, trouble sleeping, couldn't turn my mind off, and depression. My mind went through all the "what if's" and "why me's". I felt like I was given a death sentence, like there wasn't any hope for me and this was the end of the road. This lasted for a few weeks and then almost a week after my hip surgery, I decided this wasn't getting me anywhere. I had an 8 year old son who needed me and family/friends who loved me. Sitting around having a pity party wasn't helping anyone. That's when I got up and started to push myself to get back on my feet and start living again. I wasn't going to let this beat me or define me. I'm a fighter! I always have been. I was going to fight this no matter what. I was going to fight not only for myself, but for my son and all the family/friends who had my back through all

of this. Life had dealt me crappy cards, but what's the use in getting down about it? I can't change it, so the only option I have is to make the best of it and live life to the fullest, even more so now. Two and a half weeks after my hip surgery, I walked without crutches and three weeks after surgery, I went home from my parents' house.

Middle of July-The margins from the tumor on my hip tested positive for cancer cells. Two different oncologists and I discussed this and decided to go ahead with two weeks of radiation on my hip to make sure we kill any remaining cancer cells that got missed or broke loose during surgery.

July 29th-oophorectomy surgery (removal of ovaries).

August 31st-I went back to work after being off since May 28th.

September 10th-first cycle of medications finished. Not much at all for side effects besides a low white blood count. Lump in breast went from 2.5cm to approximately 1cm.

I'd never really dealt with major medical bills other than when I had my son. Since my son and I were really healthy, I signed up for a health savings account insurance plan at work in 2014. Not much was used that year, so when 2015 rolled around and my medical "mess" started with the bills flooding in, I was extremely anxious and nervous. I'm really good with budgeting my finances. I've never had anything this huge and life-changing have such an impact on my budget. I didn't know how I was going to make it work, but I knew I would somehow do it. When I got the opportunity to talk to someone about financial help, I was given Gabbi's name and number with Beyond Pink TEAM. When I called and talked to her, she explained the program and how it worked. She then signed me up and we talked it over about where I wanted the monetary help.

Because of this program, I was able to have some financial relief for a few months so I could be off work for my surgeries. I could now take that extra money and put it towards my medical bills. As a single mom that was off work for 3 months and lots of new things to worry about, this was a huge weight off my shoulders. It really gave me one less thing to worry about. I can't thank everyone enough for this program and what it did for me. It's nice to know there are programs and organizations out there like BPT that will help someone out when times get tough. Thank you, Gabbi, and an extra special thank you to the Beyond Pink TEAM for the support!

Go GREEN !

By Cindy Harris, a Survivor

Shoo Flies, Ants and Spiders!



I know we have had a pretty mild winter but I am still tired of it and very ready for Spring!! I want my windows open and the smell of fresh air in the house. And I am ready for the heat of summer, bring it on. Of course with the nice weather will come the pests and bugs.

White vinegar is such a great cleaner but it will also help keep ants away. They hate the smell. So if you wipe your counters and floors down once a week with a mixture of white vinegar and water it will deter the ants. Wiping them down with **alcohol** will help with ants and flies. They are both sensitive to alcohol. In fact, alcohol works like the toxic bug sprays when used on the bugs but without all the chemicals. If you use **corn meal** in areas you see ants coming in, they will take it back to the nest, they will all eat it, swell up and die. **Coffee grounds** around the foundation will deter them too. (Coffee grounds will also help keep cats out of your garden).

How about spiders, use a 16 oz glass spray bottle of water (glass is best to use with essential oils) with 15 – 20 drops of **peppermint essential oil**, shake well (shake before each use) and spray around windows, doors, in the basement, around the foundation and you will keep spiders out. They will not let peppermint on their feet if at all possible. The mild peppermint smell in the house is pretty nice too.



Thank You to these Fundraisers Benefiting BPT

GoldWing Road Riders Association IA-Chapter "I"



BPT representative, Marty Mullnix accepted a \$400 check from Sue Tasker and Lisa Fleming from the proceeds from their quilt raffle sales. The quilt winner gave the quilt to a friend who recently was diagnosed with cancer. What a thoughtful "giving forward".

Janesville Fire-Rescue



With Marty Mullnix, BPT representative, Janesville Fireman, Chris Renner holds the "recycled fire hose" koozies which raised \$300 for the BPT.

Upcoming Fundraisers Benefiting BPT

Cedar Basin Jazz Pink Token Day Sunday, June 26 from noon-6 pm at the Sturgis Park during the jazz festival. Purchased a pink beverage token and benefit the BPT. Meet some of our volunteers and help us support breast cancer survivors in the Cedar Valley.

NEISCA Pretty in Pink Horse Show Saturday, July 16 from 9 am-2 pm at the D & R Arena, 2577 Joplin Ave, Denver, IA. Rain date is July 30th. Treat yourself to a great show and auction and support the BPT.

Waterloo Buck's "Breast Cancer Awareness – Pink Out Night" – Saturday, July 23, first pitch 7:05 pm. Join in the fun with "PINK" jersey auction, 50/50 raffle, games and more to support the breast cancer survivors in the Cedar Valley.



10th Annual Pink Ribbon Run
Mark Your Calendars for
Saturday, October 1 downtown Cedar Falls.



In the Cedar Valley

UNI RFL

Saturday, April 9, 2016 – 3 pm-12 am

UNI McLeod Center
2501 Hudson Rd, Cedar Falls

Black Hawk County RFL

Friday, June 17, 2016 – 2 pm-10 pm

Hawkeye Community College
1501 E Orange Rd, Waterloo

Bremer County RFL

Friday, June 10, 2016 – 5 pm-10 pm

Wartburg College Football Field
100 Wartburg Blvd, Waverly

Buchanan County RFL

Friday, June 24, 2016 – 5 pm-10 pm

Independence Junior Senior High School
700 20th Avenue SW, Independence

Butler County RFL

Friday, July 8, 2016 – 6 pm-11 pm

Butler County Fairgrounds
101 Main Street, Allison

Grundy County RFL

Friday, June 10, 2016 – 5 pm-11 pm

Grundy Center High School
1006 m Avenue, Grundy Center

For information about the Beyond Pink TEAM Fund, go to: www.beyondpinkteam.org
Click on Beyond Pink Fund under CARE or call Gabbi at 319.292.2225.

Support Group Meeting Dates

April 4, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
2101 Kimball Ave, Waterloo
Pat – 319-232-8691

April 5, 1:30 p.m.

Care & Share Cancer Support Group
Covenant Cancer Treatment Center
200 E Ridgeway, Waterloo
Jeanne – 319-272-2816

April 11, 1:30-3:30 p.m.

Look Good ...Feel Better
Hair – Make-up – Nails – Skin
Covenant Cancer Treatment Center
200 E Ridgeway Avenue, Waterloo
RSVP at 319-493-8857

April 19, 4:30-7:00 p.m.

Young Cancer Survivors
Meet, Mingle and Learn
Unitarian Universalist Church
3912 Cedar Heights Dr., Cedar Falls
Gabbi – 319-292-2225

May 2, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
2101 Kimball Ave, Waterloo
Pat – 319-232-8691

May 3, 1:30 p.m.

Care & Share Cancer Support Group
Covenant Cancer Treatment Center
200 E Ridgeway, Waterloo
Jeanne – 319-272-2816

May 12, 5:00-7:00 p.m.

Splash of Color – Women of Color Breast Cancer Support Group
Waterloo Public Library, Waterloo
Cathy – 319-493-8857

June 6, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
2101 Kimball Ave, Waterloo
Pat – 319-232-8691

June 7, 1:30 p.m.

Care & Share Cancer Support Group
Covenant Cancer Treatment Center
200 E Ridgeway, Waterloo
Jeanne – 319-272-2816

June 13, 1:30-3:30 p.m.

Look Good ...Feel Better
Hair – Make-up – Nails – Skin
Covenant Cancer Treatment Center
200 E Ridgeway Avenue, Waterloo
RSVP at 319-493-8857

June 21, 4:30-7:00 p.m.

Young Cancer Survivors
Meet, Mingle and Learn
Unitarian Universalist Church
3912 Cedar Heights Dr., Cedar Falls
Gabbi – 319-292-2225

July 5, 1:30 p.m.

Care & Share Cancer Support Group
Covenant Cancer Treatment Center
200 E Ridgeway, Waterloo
Jeanne – 319-272-2816

July 11, 1:30 p.m.

Touch of Courage
Breast Cancer Support Group
2101 Kimball Ave, Waterloo
Pat – 319-232-8691

Cover Lumphedema article Continued

When the surgery is successful it works really fast. We know this by the results we see in the patients and by the testing that we perform preoperatively and postoperatively. We use different measurements and staging systems. One staging system is the Campisi staging which measures where you are clinically with swelling. We also use the Indocyanine Green (ICG) Dermal backflow staging system for the lymphographic staging. Before and after measurements are recorded as well as a Bio-impedence reading.

The below photo is from a patient that had LVA surgery using the Octopus technique, notice the reduction in the staging and the difference in the measurements and size reduction in her right arm. She not only had a good reduction in the size of her arm, but both her Campisi and Lymphographic scores dropped and she had complete relief of her right arm pain.



For more information or if you would like to set up a consultation with Dr. Wei Chen please give our office a call at 319-384-8129.



More Information on Lymphatic Treatment

Patients are seen for outpatient lymphedema therapy when they are unable to manage their lymphedema independently at home, have had a change in medical status, or after any surgical procedure. Lymphatic treatment is considered complete decongestive therapy (CDT). CDT includes five parts: short-stretch compression bandaging, manual lymphatic drainage, skin and nail care, therapeutic exercise, and transition to compression garments.

Typically, after undergoing LVA surgery, patients are seen in the clinic three weeks after surgery to initiate therapy if indicated. This requires clearance from the surgeon and a physician order to initiate treatment. At those visits, we assess the patients swelling and initiate a program to help assist in movement of that fluid. Typically the first things initiated are multi-layered short stretch compression bandaging and manual lymphatic drainage to help assist with lymphatic movement. The therapist will also educate the patient on proper skin and nail care techniques, instruct in a home exercise program, and teach the patient and or caregivers how to perform short-stretch wrapping and self-manual lymphatic drainage as appropriate. After LVA surgery, we use the new pathways the surgery made to manually drain the lymphatics into their "new connections". Patients typically report a decreased feeling in heaviness, tightness or discomfort as the lymphatics drain appropriately. We also expect that there will be a circumferential reduction to the affected limb.

Complete Decongestive Therapy should only be performed and instructed by a Certified Lymphedema Therapist (CLT). Patients are typically seen 2-3 times a week ranging in length of treatment from a few weeks to a few months based upon their progress and how severe their lymphedema is. Once appropriate reduction of the affected limb has been achieved, we assist in determining the correct type of compression garment in conjunction with a certified fitter.

Information provided by:

Kathryn Eberle OTR/L, CLT
Covenant Lymphedema Clinic
Wheaton Franciscan Healthcare
319-272-2352

Third-Party Events

We often receive information from individuals planning to hold special events to raise funds for our organization and we are always excited to partner with the community in this way. A third-party event is any fundraising activity hosted by a non-affiliated group or organization or individual which benefits Beyond Pink TEAM. Some examples of these kinds of fundraising opportunities include golf events, jeans days at businesses, bake sales, horse show, benefits or workplace contests. We have drafted guidelines to facilitate these opportunities which can be found on our website at www.beyondpinkteam.org to make the process easier. Please contact **Marty Mullnix** at 319-269-7176 or mapanix@cfu.net to notify us of a third-party event or for more information.

Looking for a Speaker . . .

Do you want to learn more about the mission of the Beyond Pink TEAM and who we are, you can have a Beyond Pink TEAM representative speak at your Church, organization or group. Just contact **Lori Seawel** at lori.seawel@seawel.com.

Volunteer for BPT . . .

If you are interested in volunteering for the Beyond Pink TEAM or at any of our events, please visit our website at www.beyondpinkteam.org or contact **Marty Mullnix** at mapanix@cfu.net.

YOUNG CANCER SURVIVORS

Meet, Mingle and Learn with other young women

Living After Cancer – Angie Gray, Holistic Wellness Coach

Tuesday, April 19, 2016 at Cedar Valley Unitarian Universalists – 3912 Cedar Heights Dr, Cedar Falls (just south of AEA267)

This is a **FREE EVENT** and open to all young women living with cancer. Light meal provided

Agenda

4:30-5:00 p.m.	Refreshments and table discussions
Begin 5:00-6:00 p.m.	Table Discussions
6:00-6:45 p.m.	Angie Gray, Holistic Wellness Coach
6:45-7:00 p.m.	Wrap up and final questions

Event sponsored by Beyond Pink TEAM and Panera Bread of Iowa

Contact Gabbi DeWitt with questions at 319-292-2225.

Connect with other young cancer survivors



BPT Young Cancer Survivors



beyondpinkteam@gmail.com



MISSION – Beyond Pink TEAM is a nonprofit organization whose mission is to provide breast cancer prevention, education, support and advocacy for comprehensive, quality health care for ALL 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

Living Beyond Breast Cancer includes a helpline, newsletter and information. Survivors Helpline: 888-753-5222 www.LBBC.org

Young Survival Coalition connects with other young women diagnosed with breast cancer. 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.cancer.org

Iowa Cancer Consortium offers cancer information and links to resources in Iowa. www.canceriowa.org

American Cancer Society offers cancer information and services. www.cancer.org.

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.breastcancerdeadline2020.org

National Comprehensive Cancer Network® (NCCN) provides state-of-the-art treatment information in easy-to-understand language to people with cancer and their caregivers. NCCN.org/patients

Dr. Susan Love Research Foundation offers clear, comprehensive information on breast cancer prevention, detection, treatment and long-term survivorship as well as reliable, up-to-date health information. www.dslrf.org/breastcancer/

National Cancer Institute's website offers information about cancer, breast cancer, clinical trials, cancer statistics, research and funding, and the latest news. They will also answer your questions by calling 1-800-4CANCER. www.cancer.gov

Touch of Courage ... Connection

Cedar Valley Cancer
Committee
4756 Charolais Dr
Waterloo, IA 50701
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:

- Writing a survivor story for the newsletter
- Volunteering: *(Check all that apply)*
 - Assisting with Support Groups
 - Education (Health Fairs/Presentations)
 - Development (Publicity)
 - Advocacy – Deadline 2020
 - Events (Fundraisers, Annual Luncheon, Projects and more)
- Making phone calls and sending emails to policy makers for breast cancer issues.
- Become part of the Breast Cancer Advocacy Network.
- Making a donation. Make checks payable to: Beyond Pink TEAM
(all donations are tax deductible)
 - BPT Fund
 - Advocacy Fund
 - Area of Need