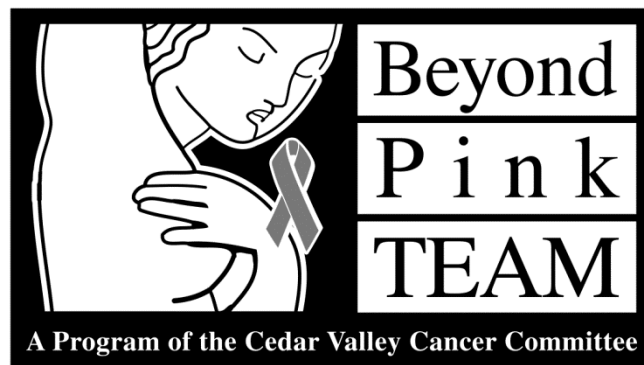


# Touch of Courage

. . . Connection

April 2018



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## POST MASTECTOMY PAIN SYNDROME

By Jill Kuyava, MSPT

Millennium, Hudson, IA

Post mastectomy pain syndrome or PMPS is a chronic pain condition thought to be as a result of direct nerve trauma, usually of the intercostobrachial nerve or axillary nerve pathways, and neuromas. It can occur in 20-63% of people who undergo surgery and following chemo or radiation, depending on which resource you read. With more modern surgical techniques being done, occurrence is decreasing. Symptoms can include dull, burning, aching, stinging, stabbing, itching persistent sensation in the anterior chest, medial- upper arm and armpit, increased by shoulder girdle movement. It is diagnosed after three months post mastectomy, lumpectomy, and after all other causes have been ruled out. The risk of developing PMPS increases with axillary node dissection, especially with a larger number of nodes removed. Pain increases also with stress, infection, anxiety and depression.

PMPS can cause difficulty sleeping, pain with movement which can cause a frozen shoulder, difficulty performing tasks at home and make

it very hard to work. Other effects can be soft tissue fibrosis and scarring, decreased strength, limited range of motion, lymphatic efficiency and swelling, reduced bone density, nerve hypersensitivity which can make even light touch of clothing hard to tolerate. It can affect mood, social life, and difficulty or inability returning to work.

Treatment can include; biofeedback, hypnosis, desensitization, pain medicine (which is not usually that effective), Neurontin, and injections. Specific treatments by therapists will guide you through gentle massage, range of motion (ROM), low intensity strength and cardio exercises prescribed for the specific individual, as well keeping a watchful eye on potential issues such as lymphedema, axillary web syndrome, causalgia or CRPS, and frozen shoulder. These programs can significantly decrease pain, brain fog, and chemotherapy related fatigue while increasing your strength, endurance, ROM, self-esteem and memory. Walking is often a huge part of these programs. If you obtain the recommended 150-180 minutes of

*Continued on page 2, column 1, Pain*

*Pain, continued from page 1*

moderate to high intensity exercise per week, recurrence also is significantly reduced.

Research on exercise and rehabilitation during cancer treatments continues to show positive effects for cancer patients, particularly breast cancer. As a result, there has been an increase in the number of therapists specializing in this population. Oncology patients' referral to a rehabilitation program should be that as a cardiac patient referred to cardiac rehabilitation, immediate. If you, as a patient, experience any of the above-mentioned symptoms of PMPS, it is encouraged to be proactive and speak with your oncologist or nurses about rehabilitation options and starting an exercise program.

## SURVIVOR & BEYOND

By Cathy Wilson-Sands, survivor

I had my first scare of potentially having breast cancer in my late 20's. A biopsy revealed I had dense and fibrocystic breasts. I continued to have concerning calcifications requiring biopsies every year or two. Just as my surgeon and I were ready to consider bilateral mastectomy to reduce my cancer risk, I had my sixth biopsy and was actually diagnosed with cancer. I was of course upset and concerned, but I had anticipated hearing the news five times before so I wasn't shocked.

Probably the most difficult thing was to explain my diagnosis to my sons. They had misperceptions about what a cancer diagnosis meant. And being elementary aged, it was a bit embarrassing for them to talk about

breast cancer with their friends and teachers. My nurse navigator gave me a book for children from the American Cancer Society. It was helpful for them and they wanted to take the book to school to share with their class. It helped break the ice for them and helped them to deal with their concerns.

I am blessed to have a supportive family who along with my friends, church family, and work associates were there to help me along the way. I was amazed by how many women reached out to me with cards and calls of support and to share their story of survivorship with me. I quickly realized I had many, many sister survivors that I could call upon for advice and support. Neighbors and friends stopped with food to lighten my load. After my surgery, when my husband had to return to work, my sister came to spend a week with me to care for me and my children. I kept telling her I didn't need her to come, but I was so glad she did. It helped me to heal on the inside and outside.

I really ended up with the best possible scenario for a breast cancer diagnosis. Since I had such a history with lumps and biopsies, I had regular follow-up and was good about monitoring with self-breast exams. I felt a new lump one day and promptly followed up. I was diagnosed with stage 1 breast cancer and based on the size of the lump, no lymph node involvement, and my hormone receptor status I was a candidate for hormonal based therapy. Most women I knew with breast cancer had to undergo chemotherapy infusions, so at first I was concerned that a pill everyday would be effective. I was lucky to have a healthcare team that used the latest evidence-based practice and engaged me in decision-making by sharing statistics on

survivorship and risk of reoccurrence. We worked together to determine my treatment plan. Since I had a bilateral mastectomy, I didn't have to undergo radiation. A year after my diagnosis, I did have a hysterectomy and my ovaries removed based on my family history with breast and ovarian cancer. I celebrate my "D" day (diagnosis day) every year and I am blessed to call myself a survivor for 11 years now.

My experience with cancer has shaped me as a person and in my career as a nurse. From my friends and family I have learned that it is OK to accept offers of help. I have learned from other survivors the power of a positive attitude and a sense of hope in a cancer journey. My journey has influenced my decision to pursue an opportunity to practice in oncology as I wanted to be able to impact physiologic, emotional, and spiritual healing of those dealing with a cancer diagnosis.

I wish I had known about the Beyond Pink TEAM at the time of my diagnosis. In my current role as the Director of Cancer Services at UnityPoint Health Community Cancer Center, I have seen the results of the support offered by the Beyond Pink TEAM. It is truly making a positive difference in the lives of so many.

*American Cancer Society has a variety of books for youth about cancer related situations. Go to [acs.bookstore.ipgbook.com](http://acs.bookstore.ipgbook.com) to check out their bookstore of resources.*

## Mark Your Calendars

Saturday, July 21 –  
**Pretty In Pink Horse Show**

Ellsworth  
 Equestrian Center,  
 709 Ellsworth  
 Avenue – Iowa



12th ANNUAL  
**PINK RIBBON RUN**  
 2018

Presenting sponsors, University of Iowa Community Credit Union and Oakridge Realtors want you to mark your calendars for the 12<sup>th</sup> Annual Pink Ribbon Run for Saturday, October 6<sup>th</sup>.

Check the Beyond Pink TEAM website, [www.beyondpinkteam.org](http://www.beyondpinkteam.org) for registration materials beginning in July.



**Oakridge**  
 REALTORS



Thank you to Carpetland USA for their donation to the Beyond Pink TEAM from an earlier promotion. This is their second contribution to BPT. Your continued support to our organization and breast cancer survivors of this community is greatly appreciated.

Saturday, July 21 – **5<sup>th</sup> Annual Buck's Pink Out**

Riverfront Stadium, 850 Park Road – Waterloo

**Game Time: 6:35 p.m.**

Join in the festivities celebrating 5 years of supporting the Beyond Pink TEAM with:

- Jersey Auction
- 5<sup>th</sup> Annual Pink Out t-shirts for sale beginning in June. Wear your t-shirt and get \$1 discount on your ticket purchased game day.
- 50/50 Raffle
- Other raffle items
- Fun, games and more!

Want volunteer? Contact Jessica Rucker at [jmiller1321@gmail.com](mailto:jmiller1321@gmail.com) if you are interested.



## Camp for Children

The Beyond Pink TEAM recently learned about a local camp that is reaching out to support kids who are coping with a parent's cancer diagnosis.

Camp Kesem at University of Iowa, founded in 2016, is a FREE week-long summer camper for children ages 6-18 who have been affected by a parent's or guardian's cancer. Camp dates for 2018 are June 3<sup>rd</sup>-June 9<sup>th</sup> at Camp Little Cloud located in Epworth, Iowa, which is a small town located about 25 minutes west of Dubuque. There is not a cut-off date, but it may take at least a week to process all the necessary forms once the application has been approved

To apply go to <http://kesem.force.com/login?locale=us> to Kesem Central, where you will click sign up and create an account. Make sure you select 'camper family' for registration type. Then you will be prompted to pick a camp.

To learn more about the camp, go to <http://campkesem.org/about-kesem>

The Beyond Pink TEAM hopes this information is helpful to families living with a cancer diagnosis.

## Support Group Meeting Dates

**April 2, 1:30 p.m.**

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

**April 3, 1:30 p.m.**

**Care & Share Cancer Support Group**  
 Covenant Cancer Treatment Center  
 200 E Ridgeway Ave., Waterloo  
 Jessica – 319-272-2816

**April 9, 1:30-3:30 p.m.**

**Look Good ...Feel Better**  
**Hair – Make-up – Nails – Skin**  
 Covenant Cancer Treatment Center  
 200 E Ridgeway Ave., Waterloo  
 To reserve a seat call 1-800-227-2345

**April 17, 4:30-7:00 p.m.**

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

**May 1, 1:30 p.m.**

**Care & Share Cancer Support Group**  
 Covenant Cancer Treatment Center  
 200 E Ridgeway Ave., Waterloo  
 Jessica – 319-272-2816

**May 7, 1:30 p.m.**

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

**May 10, 5:00-7:00 p.m.**

**Splash of Color – Women of Color**  
**Breast Cancer Support Group**  
 Cathy – 319-504-2703 for details

**June 4, 1:30 p.m.**

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

**June 5, 1:30 p.m.**

**Care & Share Cancer Support Group**  
 Covenant Cancer Treatment Center  
 200 E Ridgeway Ave., Waterloo  
 Jessica – 319-272-2816

**June 11, 1:30-3:30 p.m.**

**Look Good ...Feel Better**  
**Hair – Make-up – Nails – Skin**  
 Covenant Cancer Treatment Center  
 200 E Ridgeway Ave., Waterloo  
 To reserve a seat call 1-800-227-2345

**June 19, 4:30-7:00 p.m.**

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

**July 3, 1:30 p.m.**

**Care & Share Cancer Support Group**  
 Covenant Cancer Treatment Center  
 200 E Ridgeway Ave., Waterloo  
 Jessica – 319-272-2816

**July 9, 1:30 p.m.**

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



Remember when smoking in public was the norm? Lighting up in restaurants, offices, buses and airplanes was standard—no big deal. Fortunately, individuals and policy makers started paying attention to what public health officials were telling them for years: second-hand smoke can be deadly. Over time, the culture shifted. Now, it's almost shocking to see someone smoking indoors!

It may surprise some to know that we're facing a similar situation today. There is a strong body of public health evidence demonstrating that lawn weed killers pose unnecessary and unacceptable health risks (including, but not limited to, multiple types of cancers, neurobehavioral and developmental issues, and autism), especially to child health. However, treating lawns

with these chemicals is seen as normal, even expected! We need to rethink that.

Children are especially vulnerable to pesticides due to their unique hand-to-mouth behaviors, and because their small bodies and brains are still growing. Protecting them from chemical exposure is important for healthy development through adolescence and adulthood. In addition to children, pesticides can harm wildlife and pollute local streams. Public health officials, pediatricians, conservationists, and pollinator experts agree—pesticide exposure should be limited as much as possible.

Good Neighbor Iowa, a program initiative of University of Northern Iowa's Center for Energy & Environmental Education, wants to do to unnecessary urban pesticide application what's already been done to smoking! Good Neighbor Iowa is a statewide campaign urging school districts, park managers, and childcare centers to manage their grounds naturally, to protect child health, wildlife, and water quality. Managing turf without weed killers is easy, practical, and reduces exposure to harmful chemicals. There's no need to put ourselves in harm's way for a "perfect" lawn.

**To learn more call (319) 273-7150, or on website, [GoodNeighborIowa.org](http://GoodNeighborIowa.org), or on Facebook at [www.facebook.com/goodneighborIowa/](http://www.facebook.com/goodneighborIowa/).**

*Dear Beyond Pink TEAM,*

*I can't thank you enough for your financial help. It helps in so many ways. This has been a challenging year for me. Your assistance has really lightened the load. So thank you, thank you, thank you.*

*C, S & T*





Beyond Pink TEAM is a member organization of the National Breast Cancer Coalition and represents all of you on the Board of Directors. Each year the grassroots National Breast Cancer Coalition (NBCC) Board of Directors, with input from our members, sets public policy and legislative priorities for the coming year. They serve as the foundation of our legislative advocacy work throughout the year, and along with grassroots mobilization efforts, provide the context for the action alerts sent to our network. As we develop specific strategies to forward our priorities, your prompt attention and action on alerts will be critical to our success.

## Legislative Priorities

### PRIORITY #1:

**\$150 Million for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for FY2019:** As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 to "eradicate breast cancer by funding innovative, high-impact research through a partnership of scientists and consumers." The DOD BCRP is widely viewed as an innovative, unique, and efficient medical research model which has proven to be accountable to the public and has produced extraordinary results. NBCC seeks continued funding for this successful program.

### PRIORITY #2:

**A bill to add Metastatic Breast Cancer as a Qualifying Condition for Medicare Coverage.** This legislation would waive all waiting periods for Medicare eligibility on the basis of disability for all individuals with metastatic breast cancer and provide Medicare health care coverage including drugs and biologicals and all interventions used for the treatment and alleviation of symptoms relating to metastatic breast cancer.

### PRIORITY #3:

**Preservation of the Medicaid Breast and Cervical Cancer Treatment Program:** Congress enacted the Breast and Cervical Cancer Treatment Act in 2000 after years of NBCC grassroots lobbying and influence. NBCC remains committed to ensuring all women and men screened and diagnosed with breast cancer through federal screening programs have access to the treatment they need.

## Public Policy

### PRIORITY #1:

**Guaranteed Access to Quality Care for All:** Ensuring access to quality, evidence-based health care has been a top priority of NBCC for many years and is an essential component of **Breast Cancer Deadline 2020®**. Prior to the passage of the Affordable Care Act (ACA), the NBCC grassroots Board of Directors approved a *Framework for a Health Care System Guaranteeing Access to Quality Health Care for All* which built on NBCC's Principles for Quality Care. In 2010, NBCC endorsed and advocated for the passage and implementation of ACA which marked important steps forward in access to quality health care for individuals with, and at risk of, breast cancer. The Coalition opposes and will work to defeat any

and all efforts to repeal the ACA or replace it with something less expansive.

### PRIORITY #2:

**Ensuring the Participation of Educated Patient Advocates in all Levels of Health Care Decision Making:** NBCC continues to work to ensure that educated patient advocates who represent a constituency, have a meaningful "seat at the table" in all levels of health care decision making which affects their lives.



*"Iowa is the best. At NBCC we ask women and men across the country to take on the very hard work of advocacy focused to ending breast cancer. Advocate leaders working in their state and local communities to forward Breast Cancer Deadline 2020 - are essential to our success. And there is not a group of advocates more committed to doing what it takes to end breast cancer than the Cedar Valley Cancer Committee: Beyond Pink TEAM!*

*Thank you for being outstanding examples of the kind of leaders and activists we need in every community across the nation.*

*We couldn't do this without you!"*

*Fran Visco, President*



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

**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](http://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](http://NCCN.org/patients)

**National LGBT Cancer Network** works to improve the lives of LGBT cancer survivors and those at risk. [www.cancer-network.org](http://www.cancer-network.org)

**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](http://www.cancer.gov)

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 the address listed below.

Name \_\_\_\_\_ Phone \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_

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

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

**Touch of Courage . . . Connection**

Cedar Valley Cancer Committee  
1753 W Ridgeway Ave, Suite 104  
Waterloo, IA 50701  
[www.beyondpinkteam.org](http://www.beyondpinkteam.org)