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TOUCH OF COURAGE

CONNECTION NEWSLETTER

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CHOOSING FLAT

BY STACY GLASCOCK – A SURVIVOR AND "CHOOSING FLAT" ADVOCATE

In 2015 at age 46 when I first heard the words, "You have breast cancer," my brain just screamed, "GET THEM OFF!" I quickly dismissed lumpectomy as an option because I couldn't be left with the nagging thought, "Did they get it all?" But being a

woman brought up in our hyper-sexualized world where Barbie's figure has been the ideal, I initially thought I wanted a bilateral mastectomy with reconstructive surgery. The scheduling for reconstruction would require coordination between both a general surgeon and plastic surgeon making the appointment several weeks out, whereas mastectomy alone could be done within days. I opted for sooner, thinking I could undergo reconstruction at a later date.

After my surgery, chemo, and radiation had been completed, I met with two plastic surgeons who described the brutal process I would endure should I choose reconstruction. I learned that some implants were known to actually cause women to develop certain types of lymphoma and that even today there appear to be additional links with other cancers, although more research is needed in this area. Women with implants can also experience Breast Implant Illness (BII). The body's reaction to and rejection of implanted foreign objects can result in ongoing pain, auto-immune disorders, fatigue, rashes, and joint pain along with many other mystery ailments. Women are sometimes told these symptoms are "in their head" and they struggle to find a medical provider to believe them. In the end, I did not feel reconstruction was worth the risk and I ultimately decided to stay flat. This would also alleviate the need for future mammograms as well as more surgeries which are inevitable due to the limited lifespan of implants.

I count myself lucky to have had a surgeon who respected my wish to simply remove my breasts. Major barriers, however, still exist for women considering mastectomy. Many women are not offered or educated on the option of Aesthetic Flat Closure (AFC) by their surgeons or healthcare providers. Patriarchy and lack of up-to-date information still plague the medical field. Even female surgeons struggle with their own internalized prejudices and traditional views of what they think women should want. 'Flat denial' is the term used to describe a surgeon's unilateral action, due to either negligence or intentional disregard, to deny their patient the agreed-upon flat closure. In a recent study, Dr. Deanna Attai, a breast surgeon at the University of California Los Angeles, found that over 20% of women who request flat closure experience flat denial. Some examples of things said to my flat friends by their surgeons have been, "You don't really want to do that," "You won't be happy with your result," and "You're too pretty to throw in the towel." Due to flat denial, many women have experienced horrible disfigurement and faced multiple surgeries to repair the damage.

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A SURVIVOR'S WILL - A STORY OF NIKKI COONS

BY JEFF COONS (HUSBAND) WITH THE HELP AND APPROVAL OF HER DAUGHTER BELLA AND SISTER ALICIA

After finding a lump in her left breast, Nichole Coons was diagnosed with triple negative breast cancer, stage 3a, Oct 2021, at the age of 42. At that point, she was very opposed to the standard of care (chemo,

etc.), and being involved in natural wellness, was more interested in trying a different route. Ultimately, after thinking and weighing options, and continually being told she'd "die in six months" otherwise, she did end up reluctantly starting the traditional treatments.

Off to a hard start, she initially had an allergic reaction. Going forward, she did not tolerate the chemo well, and formed a blood clot (thankfully a minor incident), in her arm. The treatment continued, and eventually the immunotherapy caused her to develop severe ulcerative colitis. It was debilitating. She suffered from bleeding, it kept her up at night, was unable to work, and could rarely leave the house. 2022 was a long difficult year for her. In the summer of 2022, I, her caretaker husband was diagnosed with Multiple Sclerosis. However, despite being sidelined from any further standard of care, Nikki diligently pursued and applied as many natural healing modalities and treatments as her body would tolerate. She remained fierce and hopeful.

In April 2023, the ulcerative colitis had progressed to the point (blood loss, blood clotting, extreme fatigue, malnutrition, etc.) where a colectomy was necessary. The surgery went well, and Nikki was filled with fresh hope. She was able to eat better, be more active, and could sleep through the night. Her plan was to have a mastectomy and vigorously continue the natural cancer treatment protocols she had well researched. Much to all our shock (including her surgical team), the pathology report of her removed colon showed evidence the breast cancer had metastasized there. This was apparently an extremely rare move for triple negative breast cancer. At this point, being diagnosed with Stage 4, the possibility for the mastectomy was taken from her. Then, almost as if the term "Stage 4" held some sort of curse, scans and tests began showing the cancer had also moved to her bones. Desperate and afraid (her family and myself, more so than Nikki, because she was so brave, strong, and hopeful), we tried to raise funds to pursue some of the unconventional Stage 4 treatments Nikki was interested in. Simultaneously, being consumed by medical bills and expenses, Nikki sought to be able to apply for Social Security (which sadly, she was just now able to do so, being Stage 4). The application, in and of itself, is ridiculously long, complex, and daunting, let alone the approval waiting time. Nikki began trying

to fill out the application, but the support she needed to complete that task (social workers), unfortunately didn't really live up to their promises.

The pain from the cancer in her bones kept her up at night, made walking and everyday living difficult, and forced her to take a myriad of painkillers. This was hard for her, considering she preferred natural healing, for much of her life. On Saturday, June 10, the morning of our son's graduation party, which was to be at our home, the cancer in her spine had weakened those bones to a point where something fractured or crumbled. Despite the excruciating pain, and inability to stand, she refused the EMTs to take her to the hospital, as she didn't want to miss our son's party. Hours later, as she lay in bed still, in great pain, the party was scheduled to begin. Miraculously, after our family surrounded her and prayed, she stood up, on her own, and came out to the party! No one there knew how badly she was hurting, and those of us who were there that morning were amazed at her strength and will to be there for her son. Sadly, after the party, she was again unable to stand, and was taken to the hospice house (by no means with the plan or understanding that she was "going there to die," but rather because they could be more liberal with her pain medication). The next couple of days at the hospice were dark. Nikki required lots of medicine, just to prevent her from writhing in pain, and was unable to eat or drink. It wasn't long before the doctors said she would die soon. After more fervent prayer, we were given another miracle, and by that Thursday, Nikki was sitting up, and eating! On Friday, June 16, she was released to go home!

After a brief glimpse of hope (she was able to celebrate Father's Day, with family, at home), the reality of her condition sank back in. Over the course of the next week she continued to deteriorate and was cared for in our home by us and the wonderful hospice nurses. During the night on June 25, she passed in her sleep, with her hand in mine. This was just two short months after being diagnosed with Stage 4. She was a loving mother to two wonderful children, a favorite "Aunt Kiki," almost a grandmother (or "Mimi") to her first grandchild, and a cherished wife to a very grateful husband. She beat odds, proved doctors wrong, and even though we saw the severity of her condition, we were still stunned by her death (she seemed unstoppable). Her bravery, hope, constant positivity, and strength were breathtakingly inspiring. Even near the end, when she knew her time was short, she remained full of peace and hope. One of her frequent sayings was, "Everything is in divine right order."

METASTATIC BREAST CANCER ACCESS TO CARE ACT

PASSAGE OF LEGISLATION TO WAIVE THE 24-MONTH WAITING PERIOD FOR MEDICARE AND THE 5-MONTH WAITING PERIOD FOR SOCIAL SECURITY DISABILITY INSURANCE BENEFITS FOR ELIGIBLE INDIVIDUALS WITH METASTATIC BREAST CANCER.

BACKGROUND - Individuals diagnosed with metastatic breast cancer automatically qualify for disability benefits from the Social Security Administration (SSA) as long as they apply and meet the SSA's technical qualification rules. An individual must have been employed within the last ten years and currently be unable to work due to their disability in order to earn Social Security disability insurance benefits (SSDI). Once an individual is approved for SSDI, there is a five-month waiting period to begin receiving benefits. Following approval of SSDI, individuals with metastatic breast cancer are eligible for Medicare coverage based on their disability. There is also a waiting period for Medicare coverage, once someone is deemed eligible.

Eligibility for Medicare includes individuals over the age of 65, those with disabilities, and those with two specific diseases, End-Stage Renal Disease or Amyotrophic Lateral Sclerosis (ALS). Individuals under age 65 with disabilities other than ESRD or ALS must have received Social Security Disability Insurance (SSDI) benefits for 24 months before gaining Medicare eligibility. These eligibility rules include individuals diagnosed with metastatic breast cancer.

Metastatic breast cancer is cancer that has spread from the breast to the bones, lungs, or other distant parts of the body. 90% of breast cancer deaths are a result of metastatic disease. There are treatments, some of which have extended survival for men and women with metastatic breast cancer. There is no cure.

Federal Precedent for Extended Coverage

The National Breast Cancer Coalition, NBCC, urges Congress to enact legislation to amend the Social Security Act to eliminate waiting periods for disability insurance benefits and Medicare coverage for eligible individuals with metastatic breast cancer.

In 2001, Congress passed a bill to add Amyotrophic Lateral Sclerosis (ALS) as a qualifying condition for automatic Medicare coverage and, in 2020, waived the five-month waiting period for SSDI for individuals with ALS, thus creating a federal precedent. Based on the limited life expectancy of individuals with metastatic disease, an average of 3 years, NBCC believes that both automatic SSDI and Medicare coverage should also apply to metastatic breast cancer patients who qualify.



SENATOR GRASSLEY, WHERE IS YOUR NAME? WE ARE DYING TO KNOW.

Did you know that if you are under 65 years old and have metastatic breast cancer, you automatically qualify for Social Security Disability Insurance (SSDI)? But, even if you are eligible, you won't receive your monthly disability insurance payments for five months and then must wait another 24 months before receiving Medicare insurance coverage for your health care. So even though your employer has deducted SSDI from your paycheck and you are now disabled, you may not live long enough to receive the benefit.

Beyond Pink TEAM advocates are working with the National Breast Cancer Coalition to pass the Metastatic Breast Cancer Access to Care Act (HR 549/S 663). We are urging Congress to enact legislation to amend the Social Security Act to eliminate waiting periods for disability insurance benefits and Medicare coverage for eligible individuals with metastatic breast cancer.

Beyond Pink TEAM advocates have met with all of lowa's Congressional Representatives and Senators. Because we asked, Senator Ernst is the lead Republican sponsor in the Senate and all four lowa Representatives (Mariannette Miller-Meeks, Ashley Hinson, Zach Nunn, and Randy Feenstra) are cosponsors of this important legislation. We are so grateful for their support of women and men with metastatic breast cancer.

We have asked Senator Grassley to cosponsor S. 663 many times, and yet he has not. Please call Senator Grassley's office 202-224-3744 or email Nic_Pottebaum@grassley. senate.gov and say, "I urge Senator Grassley to cosponsor S. 663, the Metastatic Breast Cancer Access to Care Act. All other lowa Congress men and women have. Where is your name Senator Grassley? We are dying to know."

FUNDRAISERS

Cedar Valley has been generous with donations from various fundraisers. Here are those held from September 1 through November 30, 2023.

Amvets Ladies Auxiliary #49 Bambino's Black Hawk County Sheriff's Office **Buchanan County Health Center Bunger Family Foundation** Cedar Falls Public Safety Cedar Valley Cyclists Community Motors Farrell's eXtreme Body Shaping Fishin' for a Cure Gallagher Family Foundation Grundy Girls Night Out Pat Homeister's birthday Kwik Trip Inc Orange Theory Fitness Peet Jr High Salon Professional Academy Scheels Smitty's Pampered Chef fundraiser by Kristen Teig-Torres Visions Hair Salon













CANCER AND SKIN CARE

BY MO HARDY

Cancer and skin care are a big question, not only in the summertime, but in the winter as well. Cancer treatments cause harm to our skin, no matter what the treatment is. It can cause dryness, redness, and increase sensitivity to skin conditions we may already have. Because of the damage the cancer treatments cause to our skin, it is best to use a non-scented lotion to help with the itchiness and cracking of the skin that may occur.

An aloe vera plant will be your best natural moisturizing lotion to use on your skin. Not everyone has an aloe vera plant at home, so a clear and fragrance-free body soap and laundry detergent will also aid in the prevention of skin irritations, along with anything hypoallergenic. Using a humidifier if you feel your skin becomes too dry will also help. And as always, drink plenty of water.

Watch that you don't scrub your skin during treatment such as when washing your hands or you bathe. Lukewarm water is better than hot water and pat your skin dry. Don't rub it!

The sun's UV rays can also stimulate the effects of the cancer treatments on your skin, so try and find a physical or mineral sunscreen. These types of sunscreens work best as they sit on your skin's surface and reflect any unwanted UV and even UVB rays. Their active ingredient is zinc oxide which prevents the lotion from seeping into the skin. These are gentler on your skin. The active ingredient zinc oxide in these types of sunscreens allows it to sit on top of the skin rather than being absorbed. This creates a physical barrier between your skin and the sun's UV rays and you're that much more protected.



The 17th Annual Pink Ribbon Run is in the books! And thank you to the Cedar Valley Community, the sponsors (see list), the many volunteers, all registered participants, and most importantly, the Survivors!!!

Highlights from 2023

Registered Participants = 1,243 Total Amount Raised = \$71,871.83 With RunSignUp donations of \$12,562.78 ranging from \$1.00 -\$1,000.00 Survivors = 190

Survivor Years =1,641, ranging from less than 1 year to 36 years

The funds raised provide financial support to breast cancer individuals currently going through treatment or those with on-going expenses related to treatment. As of November 30, 2023, the Beyond Pink TEAM has assisted 101 individuals with over \$125,000! The Pink Ribbon Run, along with year-round donations do make a difference! And these dollars all stay in the Cedar Valley area.

The planning for the 18th Annual Pink Ribbon Run is beginning to take shape. If anyone knows of a business, individual, or organization that would like to be involved as a sponsor or volunteer, please contact **Nikki Ladage**, **319.230.2317** or **nmladage@gmail.com** with your interest.

Pink Ribbon Run Sponsors

GreenState Credit Union Oakridge Real Estate KWWL Bambinos Community Auto Group **Xpressions** 93.5, The Mix Nagle Signs, Inc. Transcend Defy Limits Scheels Urban Pie PDCM Insurance First Bank MercyOne Forbin/VGM UnityPoint Health John Deery Motors NuCara New Image Boutique Lincoln Savings Bank Cedar Valley Breast Center Kimball Beecher Family Dentistry Advanced Heat Treat Corp. Carolan Seeds Avalon Plastic Surgery Center Tea Cellar **SMACK** Pump Haus Pub & Grill Culligan Get Roasted Coffee Company Martin Bros. Second Street Brewing Co. Cindy Lou's BBQ 4 Queens Scratch Cupcakery Runner's Flat KI & Kompany Here's What's Poppin'



DONATIONS

The following individuals and businesses donated to the Beyond Pink TEAM during September 1-November 30,2023. Thank you for your generosity and support of Cedar Valley breast cancer survivors.

Linda Anders Cindy Angel Anne Barloon Regina Blumhardt Lisa Broderson Karen Broell CanAm Automotive, Craig Lindsay Jeff Coons Tammy Cooper DI Corson Ianice Crowe Cinda Dodd Carol Duffy Kristina Eiklenborg Ryon Eiklenborg Tammy Farrell Lyman Frank Robbie Fye Leach

Robert Goodrich Brandon Goodrich Travis Gruenbera Marianne Hartz Monique Heddens Carol Hellman Pamela Hickman Deanna Hughes Karen K Jessen Mary Jo Juel Amy Knoll Laura Larson, DC Lisa Levh Joyce Lubben Suad Mahmutovic Kim Marmison Kevin McConnell Carol Miller Katie Mitchel

Stan Nielsen Rhoda Olson leanne Olson Iulie Pitzen Kathy Porter Marilyn Schons Jane Shea Sue Shirley Kenneth Smith Ian Smith Virginia Sundquist Rodney Thorson Teri Trask Linda Trimbell Sarah Trost Denise Ward Roger White

In Memory of:

Debbie Brecher

By Paul Fitzgerald

Del Carpenter

By Marty Mullnix

Jodie Fitzgerald

By Paul Fitzgerald

McMains Family member

Memorial and Honorarium

Donations

McMains Family membe By Trish Pedersen Sherry Shumacher By Team Sherry (George DeBord)

In Honor of: **Sara DuBois**, survivor By Patricia Kinnaird

RADON

You can't see it, smell it, or taste it, but radon gas can seep into our homes from underground and cause lung cancer. Radon is the #1 cause of lung cancer in non-smokers, and the #2 cause of lung cancer in smokers.

It's so prevalent in lowa that the entire state is considered high-risk for high levels.

Testing is simple and inexpensive. The lowa Department of Health and Human Services offers a hotline where you can ask questions and order low-cost radon test kits. Call toll-free 1-800-383-5992 from 8:30 a.m. to 4:30 p.m.



JOIN BEYOND PINK TEAM MEMBERS FOR THE 2024 ADVOCATE LEADERSHIP SUMMIT IN WASHINGTON, DC, MAY 4-7, AT THE PARK HYATT HOTEL!

The Summit is the National Breast Cancer Coalition's premier annual breast cancer advocacy event. The Summit offers discussion sessions with top researchers and advocates, as well as skill-building, message training, and strategic planning activities to energize us for the important work in the year ahead. Learn more at stopbreastcancer.org.

Scholarships and shared hotel rooms are available for Beyond Pink TEAM members. Apply for a Beyond Pink TEAM scholarship. The application deadline is Wednesday, January 31. Contact Christine.B.Carpenter@gmail.com or 319-830-1192 for a scholarship application. "It's the most empowering weekend of my life." Won't you join us at the Summit?



CONTINUED FROM PAGE 1

Although steadfast in my decision to remain flat, I had much work to do for my self-acceptance and self-worth. We are all programmed from birth to fit into our specific gender roles and as women we are taught that much of our identity and self-worth are based on traditional beauty and sexuality. We are inundated with advertisements and media regarding fashion, beauty products, and cosmetic procedures that show and tell us what we should aspire to look like. We are taught to feel that we are never enough just as we are. With time I found flat support groups on social media and a podcast that helped me overcome the negative thoughts I initially had about my physical appearance. Social media has been a huge help in connecting survivors and their stories, educating women on the dangers of implants, and getting out the message that flat closure is a legitimate option after a breast cancer diagnosis.

Weighing all your options at diagnosis can be challenging and ultimately every woman needs to make the best decision for herself. Make sure you are comfortable with your surgeon and feel that they can and will genuinely deliver the best outcome according to your wishes. Advocate for yourself and ideally have someone with you who also advocates for you.

Since finding my way through not only cancer, but also societal programming, and realizing my self-worth beyond what my body looks like, I have never felt more confident about my physical appearance. Letting go of what we think others think of us and being free from trying to meet the expectations of others is truly liberating. As horrible as cancer is, I have a newfound freedom from so many of the burdens I once carried. We are so much more than our breasts.

Stacy has a Facebook page that you can join and follow. It is "Flat AF in Iowa".



DATES TO REMEMBER JANUARY - APRIL 2024

January 2, 1:30 pm

Care & Share Cancer Support Group MercyOne Cancer Treatment Center 200 E Ridgeway Ave, Waterloo Courtney 319-272-2816 for meeting info

January 8, 1:30 pm

Touch of Courage Breast Cancer Support Group

Masks are optional Community Foundation of NE Iowa 3117 Greenhill Circle, Cedar Falls Pat 319-610-4424 for meeting info

January 16, 2024, 5:00-7:00

BPT All Cancer Survivor Group Masks are optional Cedar Valley Unitarian Universalists Church 3912 Cedar Heights Drive, Cedar Falls Angela 319-231-3143 for meeting info

February 5, 1:30 pm

Touch of Courage Breast Cancer Support Group

Masks are optional Community Foundation of NE Iowa 3117 Greenhill Circle, Cedar Falls Pat 319-610-4424 for meeting info

February 6, 1:30 pm

Care & Share Cancer Support Group MercyOne Cancer Treatment Center 200 E Ridgeway Ave, Waterloo Courtney 319-272-2816 for meeting info

March 4, 1:30 pm

Touch of Courage Breast Cancer Support Group

Masks are optional Community Foundation of NE Iowa 3117 Greenhill Circle, Cedar Falls Pat 319-610-4424 for meeting info

March 5, 1:30 pm

Care & Share Cancer Support Group MercyOne Cancer Treatment Center 200 E Ridgeway Ave, Waterloo Courtney 319-272-2816 for meeting info

April 1, 1:30 pm

Touch of Courage Breast Cancer Support Group

Masks are optional Community Foundation of NE Iowa 3117 Greenhill Circle, Cedar Falls Pat 319-610-4424 for meeting info

April 2, 1:30 pm

Care & Share Cancer Support Group MercyOne Cancer Treatment Center

200 E Ridgeway Ave, Waterloo Courtney 319-272-2816 for meeting info

April 16, 5:00-7:00

BPT All Cancer Survivor Group

Masks are optional Cedar Valley Unitarian Universalists Church

3912 Cedar Heights Drive, Cedar Falls Angela 319-231-3143 for meeting info



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. beyondpinkTEAM.org

f You can also find us on Facebook.

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

Cancer Care is a national nonprofit organization offering counseling, support, financial assistance, and education to individuals with cancer and their families.

cancercare.ora

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

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

National Comprehensive Cancer Network® (NCCN)

provides state-of-the-art treatment information in easyto-understand language to people with cancer and their caregivers. NCCN.org/patients

National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk. cancer-network.org

National Cancer Institute 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. cancer.aov

National Cancer Institute for NCI dictionaries of cancer terms, genetics terms, and cancer drugs. cancer.gov/publications/dictionaries

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

CancerChoices is an independent, science-informed resource, helping you make sense of your choice in integrative cancer care.

cancerchoices.org

The Cancer Journey Short 3–5-minute videos featuring survivors, doctors, social workers, and advocates who share their experiences of diagnosis, treatment, aftertreatment, living with metastatic cancer, and advocating to end this disease.

beyondpinkteam.org/the-cancer-journey.html

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.

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		
☐ Writing a survivor story for the newsletter	$\hfill\square$ Making phone calls and sending emails to policy makers for breast cancer issues	
\square Become part of the Breast Cancer Advocacy Network	□ Become a member of the Beyond Pink TEAM - Complete this form, send with a check for \$5 to Jeanne Olson, BPT Treasurer, to address at bottom of this page. Meetings are 3rd Thursdays each month (except December) at 7:00 a.m.	
□ Volunteering: (check all that apply)		
☐ Assist with Support Groups	☐ Advocacy – Contact Congress/Ignite the Cancer Conversation	
☐ Development (Publicity)	☐ Education (Health Fairs/Presentations, Newsletters)	
□ Events (Fundraisers, Projects and More)		
☐ Donate. Make checks payable to Beyond Pink TEAM. (All donations are tax deductible)	Mail To: Cedar Valley Cancer Committee Dba Beyond Pink TEAM 1407 Asbury Lane Waterloo, IA 50701	Scan here for more information on the
☐ BPT Fund		Beyond Pink TEAM.
☐ Advocacy Fund		BeyondPinkTEAM.org

☐ Area of Need