



Cedar Valley Cancer Committee

IN THIS ISSUE

PAGE 2

Cancer Journey Video Is Up And Running!

PAGE 3

Having Cancer is Enough Without Worrying About Costs

PAGE 4

Where they are now - Be A Thriver Not Just a Survivor In Life

PAGE 5

Donations

PAGE 6

NBCC and BPT Advocates Focus for the 118th Congress

Beyond Pink TEAM Support Groups

PAGE 7

Dates To Remember April - May - June - July

PAGE 8

Resources, Support and Volunteer Information

TOUCH OF COURAGE

CONNECTION NEWSLETTER

FINDING THE RIGHT CANCER-RELATED INFORMATION

COLLEEN MORETTI, ASSOCIATE EDITOR, CURE

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The internet is flooded with information for cancer survivors, and it is vital they recognize reliable sources from those that are not.

Most videos on YouTube about cancer rehabilitation were of low quality and did not provide sufficient information for cancer survivors, according to a recent study. The research highlights the need for survivors to better understand how to find reliable, personalized sources.

The study, which was published in the *Journal of Cancer Survivorship*, investigated the quality, reliability, and accuracy of cancer rehabilitation videos on YouTube. Researchers used the keywords “cancer rehabilitation” and “oncology rehabilitation,” and 53 of the first 200 videos met criteria of high quality and reliability — most others were of low quality.

Of note, high-quality videos ran longer, had more views and scored higher on reliability. Heal® spoke with Nicole Reilley Dosey, network manager of outpatient therapy services, including oncology rehab, lymphedema and pelvic health services, at Allegheny Health Network in Jefferson Hills, Pennsylvania, about the challenges cancer survivors face when searching for beneficial, reliable resources on the internet.

“There is a variety of information out there covering a lot of different perspectives, from the patient’s experiences to professional advice,” she said. “When doing my own research, the biggest concern was reliable sources with good content.”

It can be challenging for cancer survivors to search YouTube and Google to find a video or article that is reliable, informative, and tailored to their needs. Reilley Dosey noted that not every video on the internet is for every cancer survivor, and rehabilitation or exercise therapy is often tailored to specific side effects, treatments, or diagnoses.

Prior to researching online, cancer survivors should better understand what they are looking for. If they want exercises to help with lymphedema (swelling, usually of the arms and legs), then that should be the search term — not just “cancer rehabilitation,” which can lead anywhere and may not be beneficial.

CONTINUED ON PAGE 3

THE CANCER JOURNEY VIDEO IS UP AND RUNNING ON THE BPT WEBSITE

You or your love-one has received a cancer diagnosis. What questions should you ask? How can you help your loved one? How do you navigate treatment? How do you endure the journey? The Beyond Pink TEAM website has help for you with The Cancer Journey.

The Ignite team developed this collection of videos to help you answer some of those questions. You can find them on our website: beyondpinkteam.org/the-cancer-journey. These videos feature survivors, doctors, and social workers who share their experiences of diagnosis, treatment, after-treatment, and living with metastatic cancer.

Following is an outline showing the topics and subtopics included within “**The Cancer Journey**”:

START HERE

- Video Introduction
- Navigation Instructions
- Who is “The Cancer Journey” Site for?
- Reach Out to “The Cancer Journey” Developers
- Finding the Right Cancer-Related Information

DIAGNOSE

- Overview of Breast Cancer
- Questions to Ask Your Doctor
- Her-2 Positive
- Second Opinion
- Understanding Your Pathology Report
- Advice from Breast Cancer Survivors
- Telling Others About Your Cancer
- Self-Advocate
- Breast Cancer Disparities

TREAT

- Overview of Breast Cancer Treatments
- Chemotherapy
- Radiation
- Surgery
- Targeted Therapy
- Hormone Therapy
- Immunotherapy and Cancer
- Clinical Trials

CARE

- Balancing Personal Life
- Managing Side-Effects
 - Sexual Health & Side-Effects
 - Chemo Brain
 - Avoiding Infection
 - Cancer Treatment & Heart Health
 - Fatigue



- Exercise
- Managing Anxiety
- Mindfulness
- Eating for Wellness & Managing Weight
 - Cancer-Fighting Foods
 - Cancer-Fighting Diet
 - Starving Cancer Cells
 - Maintaining a Healthy Weight
 - Healthy Weight During Cancer Treatment
 - Body Weight & Cancer Risk
- Advice for Caregivers
- Advice for Long-Distance Caregivers

THRIVE

- Living with Metastatic Cancer
- Cancer Survivorship
 - Rehab After Cancer
 - Rediscovering Your Purpose
 - Unspoken Topics
- Resources Available to Patients
- Emotional Support
- Reduce Risks Through Lifestyle
- Quality of Life: Doctors Give Advice

ADVOCATE

- National Breast Cancer Coalition (NBCC)
 - NBCC’s Project LEAD
 - Research to End Breast Cancer
 - NBCC’s Artemis Project
 - Breast Cancer Vaccines
 - DOD Breast Cancer Research Program
 - Research for Other Medical Conditions
 - An Advocate’s Role with Research
- Influencing Policy
- Access to Care
- Stay Informed & Get Involved
- Why I Am an Advocate
- Join Our Advocacy Efforts



“The Cancer Journey” can be accessed via the Beyond Pink TEAM website (beyondpinkteam.org) by going to the “Education” tab and selecting “The Cancer Journey” from the popup menu. The direct link is: beyondpinkteam.org/the-cancer-journey. It can be viewed on mobile devices as well as a computer monitor and is meant to be very interactive, allowing the user to pick and choose the path they wish to follow.

HAVING CANCER IS ENOUGH WITHOUT WORRYING ABOUT COSTS

TRACI MCNALLY- A SURVIVOR

I reported for my regular mammogram in August 2021 and later received a call from the breast center asking me to return for additional imaging. I returned 6 days later for another mammogram and was asked to wait while it was reviewed. They came and said I needed an ultrasound to investigate further. I asked if it would take long since I had another appointment elsewhere in the building. It didn't occur to me that this could be serious; I was only concerned about getting to my next appointment on time. After the ultrasound they asked me to come back the next day for a biopsy. I had a sense of God-given peace as I reported for the procedure, and it went smoothly. Mary, the breast navigator, called me Monday with the results. I had Invasive Ductal Carcinoma and Ductal Carcinoma in Situ.

The tumor was very small – just 5 mm. I had shared all of this with my husband but not the rest of my family. My only concern was comforting them and assuring them that there was nothing to be concerned about. Everything was going to be alright. I'll have a lumpectomy and depending on what they find from the lymph node biopsy, possibly some radiation. I began to think about the financial repercussions of a cancer diagnosis. But, again, I thought I'll have the lumpectomy and any additional treatment before the end of the year without any cost to us. After all we had already met our deductible.

My husband and I met with the surgeon, and he told us the lymph node was negative for malignancy and he had removed the tumor with an acceptable clear margin around it. Great! Report to oncology and be done with it!

It wasn't until we met with the oncologist that I fully understood the extent of my cancer. Yes, my tumor was tiny, but it merited the highest (worst) grade in all three categories of assessment. I would be required to have extensive chemotherapy treatment along with radiation. My mind immediately went to the cost again. We had a \$3000 deductible. We usually meet this during the year. One of these treatments would cost more than that! How would we pay for it?

When we went for the first treatment the social worker, Jessica, asked us about what we did for a living and our financial situation. She told us about Beyond Pink TEAM and said she would apply for a grant for us. A few weeks later we got notice that

we would receive a \$1500 grant that we could use for medical bills. What a relief! I am sharing my story to say THANK YOU to all of you who donated money, time, and resources with Beyond Pink. Your generosity is overwhelming! I am nearly done with treatment. I finished chemotherapy last May and radiation in June. I am still undergoing IV treatment until February 2023 due to the HER2+ status of my tumor but I am feeling well and doing well! Again, THANK YOU!



NOTE: Grants are available from the Beyond Pink Fund. Talk with your social worker, navigator, or check out BPT website, Beyondpinkteam.org/financial for more information.

CONTINUED FROM PAGE 1

"We like to make (cancer rehabilitation) individualized," she explained. "Such as what was the person's level (of exercise) before, where are they in the spectrum of survivorship, what are their goals. So, it does become challenging for the patient to determine what direction to go and what resources to look for."

Although not everything online is untrustworthy or dangerous, cancer survivors should be cautious and understand what is dependable versus what is not. Reilley Dosey highlighted that some of the most reliable information comes from reputable institutions — cancer centers, hospitals, survivorship clinics and advocacy groups.

It is also important for survivors to talk with their care team about what rehabilitation they should be doing, so they can better know what to look for in their search — the care team should be able to offer resources as well.

"One of the best resources is your local cancer center, to find out if they offer oncology rehabilitation or oncology exercise programs," she concluded. "When getting started with an exercise program, having a health care professional trained in oncology exercise will help you obtain better outcomes. Support groups are another great resource. There are so many platforms today from in-person to virtual that offer valuable information and programs.

Do your research, but don't wait; go out there and start moving."

WHERE THEY ARE NOW- BE A THRIVER NOT JUST A SURVIVOR IN LIFE

DONNA O'BRIEN- A SURVIVOR

I was diagnosed with Stage 3 breast cancer on November 17, 2008 (my husband's birthday). I had my surgery a few days before Thanksgiving. I was given the 4-6 weeks to heal from my surgery and started chemo on January 2, 2009. The first experience was the "Red Devil". I did not tolerate that well and was very sick through most of it. I then went into 12 weeks of Taxol and tolerated that better, but it still did a number on my stomach. After I completed the chemotherapy part of my treatment, I went into 35 radiation treatments. I did far better with the radiation, however, at the end, when radiation is almost complete, your skin is burnt and blistered like you have a very bad sunburn. I completed radiation in July of 2009 and then my surgeon wanted to wait until I was fully healed before we moved forward with more needed surgeries. So, I didn't begin further surgery until the end of August in 2009.

I cannot put into words effectively what I learned from going through this. It made me really stop and appreciate life more as a whole! I had just turned 45 years old when I was diagnosed, and it was a shocking diagnosis. I had no family history, I exercised regularly and for the most part, ate healthy.

My oldest son was in college and my youngest son was a senior in high school. I wanted his senior year to be special and fun filled, as he was also being recruited to play college football. Instead, he was focused on me and my health. He would come home every Thursday after school when I was receiving chemo to give me a shot that would increase my blood count and knew it had to be at a certain time. I tried to make it as normal for him as possible, but the reality was, his normal was going to be different. He largely based his decision to play football at UNI so that he would remain close. At that time, my prognosis was pretty scary. I had 21 out of 26 lymph nodes test positive. I knew I was in the fight of my life but always tried to find the positive in my experience and constantly tell myself I would get through this.

My husband was so supportive and went to every chemo treatment with me. When I was there, I would see others who did not have a family member or friend with them. They were having treatments to save their life with apparently no one to support them. It broke my heart. I noticed women receiving pillows during chemo. I asked the nurse who did this,

and she said it was a volunteer group called The Beyond Pink TEAM.

She told me how wonderful they were and that they helped breast cancer patients and their families in need. From there, I started to do my research to find out more about this organization.

What I learned was that they were simply AMAZING! They didn't just help get women to chemo, they helped make sure they had food on the table, beds in their homes, support when and where they needed it, and on and on. And everything they did was 100% funded by donations or grants. They were truly the definition of a volunteer organization! I was SO impressed! So, I started thinking.... how can I pay it forward after getting through this?



I had always loved to bake and so I decided I would come up with a unique product that we could provide for the Beyond Pink TEAM (BPT) to help them raise money. It would also help me focus on

something besides going through cancer treatment. Our niece was staying with us at the time, so she was my taste tester! One day as we were testing our recipes, she said..."That's It!" I stopped in my tracks, looked at my notes hoping I had documented things correctly and said, OK, let's do this!! From there, the Bambino was made.

We started donating product to help the BPT raise money for various events and soon thereafter, we were being asked to make Bambinos for special events, weddings, showers, etc. Our big break came when a customer who I had given Bambinos to as a baby gift approached me asking me where I had gotten the cookies as he really loved them! I told him that we made them, and he asked if we would make them for his customers' Christmas gifts. I, of course said yes immediately. Little did I know, we would be shipping over 400 dozen Bambinos all over the United States! We continue to provide customer gifts for this company to this day!

My goal was to always give a generous portion back to the BPT no matter how many we sold so this made

CONTINUED ON PAGE 7

DONATIONS

The generosity of so many has allowed the Beyond Pink TEAM provide financial support to breast cancer survivors in the Cedar Valley. These are the following donations from December 1, 2022 through February 28, 2023.

Anne Barloon
Anonymous
Olivia Blosch
Pat Buls
Cedar Falls Police Protective Association
City of Cedar Falls Public Safety Services
Mark Dahling - LeRoy's
Troy Davis
Krista Dougherty
Pam Flanders
Angela Fuller
Grundy Center Chamber- Main Street, Inc
Mary Lou Gutting
Grace Hernandez
Jennifer Hughes
Isle Casino Hotel
Kirsten Koester

Brooke Kolder
Amber Krebsbach
Jess McDowell - JoyWheel
Jodie Muller
Marty Mullinx
Panera Bread
Beth Petersen
Maria St. John
Scheel's
Jodie Schmidt
Crystal Schmitz
Sue Shirley
True Time Racing Services
UNI
Macy Vance
Waterloo Fire Fighters - IAFF Local #66
Doris Webber
Karmen Woelber



THANK YOU
for remembering these individuals in this manner.

In honor of Pat Homeister
Gary Fober

In memory of Bob Olson
Dee Hughes



FUNDRAISER DONATIONS

Cedar Falls Police Protective Association
City of Cedar Falls POS
Farrell's Extreme Bodyshaping
Grinnell Women's Soccer
Grundy Center Girls Night Out
Isle Casino
Joy Wheel
LeRoy's
Panera Bread
Beth Petersen Family Game Night
UNI Volleyball
Waterloo Fire Fighters



Thank you



NBCC AND BPT ADVOCATES FOCUS FOR THE 118TH CONGRESS



Metastatic Breast Cancer Access to Care Act

The Metastatic Breast Cancer Access to Care Act has been introduced in the 118th Congress in both the House and Senate. This bill had overwhelming support in the 117th Congress, but leadership never took it to the floor for a vote. The bill asks for level funding (the same amount as last year). We are happy to report, as of March 15, the following HAVE signed on to show their support:

- Senator Ernst
- Representative Feenstra
- Representative Miller-Meeks
- Representative Zachary Nunn

Representative Hinson has NOT signed on. She was Iowa's only Member of the House of Representatives that did not sign on to support this in the 117th Congress as well. Senator Grassley has also NOT signed on. **We need many Iowans to reach out to Senator Grassley and Representative Hinson, asking them to sign on.**

DOD Breast Cancer Research Program

The DOD Breast Cancer Research Program, which produces highly effective and innovative research, requires appropriations every year. We are asking for level funding (the same amount as last year) for FY 2024. A Dear Colleague Letter of support circulated in both House and Senate. As of March 21, Representatives Miller-Meeks, Zach Nunn, and Randy Feenstra have signed the Dear Colleague Letter of support. Representative Ashley Hinson has not responded to multiple emails requesting her support and the deadline has passed.



Please visit our Iowa Stop Breast Cancer Facebook group page to find details for contacting Iowa's Congressional offices:
<https://www.facebook.com/groups/217433641780809>.
 Join the group to receive alerts at key times.

BEYOND PINK TEAM SUPPORT GROUPS

The Beyond Pink TEAM currently has two support groups to assist breast cancer survivors within the community. They are Touch of Courage Breast Cancer Support Group and BPT All Cancer Survivor Group.

The **Touch of Courage Breast Cancer Support Group** was started in 1988 as a monthly support group. It has continued to this day. This group of women meet in the afternoon to share their stories and find fellowship. They have decided to have a purpose of giving back by making heart-shaped pillows for new survivors providing support and comfort with car seat belts. Currently this group meets on the first Monday of each month, unless a holiday, at the Community Foundation of NE Iowa, 3117 Greenhill Circle, Cedar Falls. Masks are optional.



The second group is **BPT All Cancer Survivor Group**. This group is open to any woman with any cancer diagnosis. Many women are balancing work and family along with their cancer diagnosis, so this group meets early evening. Meetings are held 4 times a year, January, April, June, and September late afternoons/early evening. Topics previously covered have been: Mindful Meditation, Nutrition Doesn't Have to Be Complicated, Relaxation with Yoga and just having a social time catching up. For the April 18th meeting, held at Cedar Valley Unitarian Universalists Church, 3912 Cedar Heights Drive, Cedar Falls. Stacy Glascock will be speaking on, Decision Regarding Breast Implants or Staying Flat. Masks are optional if no one is in active treatment.

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me incredibly happy that we were able to sell more and more! As the years went on, Bambinos began to be increasingly popular.

We opened a storefront in Waterloo on March 1, 2022, and have never looked back! We have continued to grow and so on International Women's Day, March 8, 2023, we opened our second Bambinos location. We



are so excited to be able to offer multiple locations in the area for our customers and look forward to continued growth with the company. Last year, we were able to give the BPT over \$21,000 in donations along with contributing products to their events, and we hope that number can continue to increase significantly over the years!

Bambinos has been a passion for me for many years and an absolute true labor of love. I am more excited

today than I was when we started this little cookie company as I think that along with the support of our customers, we are truly making a difference in the lives of those living with breast cancer. I hope that a cure is found and found quickly as I've seen it take the lives of too many, including young people everywhere.

Surviving cancer taught me many things but I feel that if through this you can find what really sets your soul on fire, you will be a "thriver", not just a survivor in life. My heart is full each and every day when I see the passion of the team at Bambinos, our employees and volunteers, knowing exactly what our WHY is, and helping to move this little cookie company in the right direction to make a difference. Isn't that really what life is about after all? I mean, what do you have to lose? Go for it always – when passion is your guide and motivation in whatever you do, there is no such thing as failure! God speed to all who can live their dream – you will never regret it!

DATES TO REMEMBER APRIL – JULY 2023

April 3, 2023, 1:30 pm

Touch of Courage
Breast Cancer Support Group

Masks are optional
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-232-8691 for info & location

April 4, 2023, 1:30 pm

Care & Share Cancer Support Group

Masks are required/encouraged
MercyOne Cancer Treatment Center
200 E Ridgeway Ave, Waterloo
Courtney 319-272-2816 for meeting info

April 18, 2023, 4:30-7:00 pm

BPT All Cancer Survivor Group

Masks are optional if no one is in active treatment
Cedar Valley Unitarian Universalists Church
3912 Cedar Heights Drive, Cedar Falls
Angela 319-231-3143 for info & location

May 1, 2023, 1:30 pm

Touch of Courage
Breast Cancer Support Group

Masks are optional
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-232-8691 for info & location

May 2, 2023, 1:30 pm

Care & Share Cancer Support Group

Masks are required/encouraged
MercyOne Cancer Treatment Center
200 E Ridgeway Ave, Waterloo
Courtney 319-272-2816 for meeting info

June 5, 2023, 1:30 pm

Touch of Courage
Breast Cancer Support Group

Masks are optional
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-232-8691 for info & location

June 6, 2023, 1:30 pm

Care & Share Cancer Support Group

Masks are required/encouraged
MercyOne Cancer Treatment Center
200 E Ridgeway Ave, Waterloo
Courtney 319-272-2816 for meeting info

June 20, 2023, 4:30-7:00 pm

BPT All Cancer Survivor Group

Masks are optional if no one is in active treatment
Cedar Valley Unitarian Universalists Church
3912 Cedar Heights Drive, Cedar Falls
Angela 319-231-3143 for info & location

July 10, 2023, 1:30 pm

Touch of Courage
Breast Cancer Support Group

Masks are optional
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-232-8691 for info & location

July 11, 2023, 1:30 pm

Care & Share Cancer Support Group

Masks are required/encouraged
MercyOne Cancer Treatment Center
200 E Ridgeway Ave, Waterloo
Courtney 319-272-2816 for meeting info



RESOURCES

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

 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.org

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

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

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

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.gov

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

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.

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:

<input type="checkbox"/> Writing a survivor story for the newsletter	<input type="checkbox"/> Making phone calls and sending emails to policy makers for breast cancer issues
<input type="checkbox"/> Become part of the Breast Cancer Advocacy Network	<input type="checkbox"/> 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.
<input type="checkbox"/> Volunteering: (check all that apply)	<input type="checkbox"/> Advocacy – Contact Congress/Ignite the Cancer Conversation
<input type="checkbox"/> Assist with Support Groups	<input type="checkbox"/> Education (Health Fairs/Presentations, Newsletters)
<input type="checkbox"/> Development (Publicity)	
<input type="checkbox"/> Events (Fundraisers, Projects and More)	
<input type="checkbox"/> Donate. Make checks payable to Beyond Pink TEAM. (All donations are tax deductible)	
<input type="checkbox"/> BPT Fund	
<input type="checkbox"/> Advocacy Fund	
<input type="checkbox"/> Area of Need	

Mail To:
Cedar Valley Cancer Committee
Dba Beyond Pink TEAM
1407 Asbury Lane
Waterloo, IA 50701

Scan here for more information on the Beyond Pink TEAM.



BeyondPinkTEAM.org