



Cedar Valley Cancer Committee

TOUCH OF COURAGE

CONNECTION NEWSLETTER

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IOWA – THE BEAUTIFUL?

Iowa is often associated with its iconic cornfields and farms, but the state offers much more than that. From rolling hills to towering bluffs and rushing rivers, Iowa is home to breathtakingly beautiful landscapes.

Despite its natural beauty, Iowa faces significant environmental and health challenges. Issues like water contamination, pesticide use, and alarming cancer rates have become pressing concerns for the state.

Is our water safe?

- Iowa ranks among the top 4 states for the highest level of nitrates in its water.

Is our soil safe?

- Iowa is also a leader in the use of weed killers.

What is something else that contributes to Iowa's standing?

- Iowa has the 4th highest incidence of alcohol-related cancers in the U.S., and the highest rate in the Midwest.

What is our national standing?

- Iowa has the 2nd highest and fastest-rising cancer rate in the United States. There are currently 1 in 20 Iowans living with cancer.

Is our environment contributing to Iowa's cancer crisis? While factors like lifestyle choices and genetics play a role, many are beginning to question the impact of environmental exposures on our health.

The 2024 Cancer in Iowa Report provides information on the status of cancer in our state, including the following:

- It is estimated that 21,000 new, invasive cancers (meaning cancers that were diagnosed as stages 1-4 as well as in situ or stage 0) will be diagnosed in 2025.
- An estimated 6,100 Iowans will die from cancer.
- The number of cancer survivors is growing, with an estimated 168,610 survivors in Iowa.

Each one of these Iowans represented by the statistics heard the dreaded words, "You have cancer". Receiving that diagnosis can throw your life into chaos and confusion. Your mind starts spinning when you hear all the new medical terms and facts. You may not understand all your options for treatments, yet you must make massive decisions that will impact you and your family not only physically, but emotionally and financially for years to come.

In her January Condition of the State address, Governor Kim Reynolds proposed a plan to create a partnership between the Iowa Department of Health

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SURVIVOR STORY - BRENDA ELSAMILLER



When as a 62-year-old wife, mom, and nana, my only health concern was my diabetes. I loved life, enjoying my grandchildren, traveling with my husband, and enjoying our farm. I had just started my new journey becoming an Independent Paparazzi Consultant. On October 5th, 2018, while I was driving home pulling my trailer full of jewelry, reminiscing over the wonderful day I had, I rubbed my armpit and there was a lump! I got scared. I didn't tell my husband for a couple of days.

I was then off to doctor's appointments, tests, until the day arrived when my fears were confirmed – it was breast cancer! My world came crashing down. I wasn't sure how to process it all.

How was I going to tell my family, my friends, and worst of all how do I tell my grandbabies? I had things I still wanted to do in life, like more time and travel with my husband and watch my grandkids grow. I wasn't finished with

life yet. I wasn't quite sure how to proceed or what I was facing or what was next.

My next step was cancer appointments and meeting my oncologist. He was amazing, welcoming, caring, and compassionate. Next came the treatments, losing my hair, several trips to ER, and several hospitals stays. This journey was pure hell for the next year.

My husband was always there to help me make decisions, and care for me when I was too sick to care for myself. Then at surgery time we opted for a double mastectomy. I wanted to take all precautions to prevent cancer from coming back. I was very nervous about the changes to my body, and how people were going to stare like they did when I was bald. And would my husband look at me differently? Who would want me? I must look like Frankenstein.

After healing from surgery, it was off to radiation – thirty-three sessions. The burns were painful, but I stayed strong. Whew! Then I was thinking now is the time to live life.

I am enjoying life again. My grandchildren have grown into adults of which I am so proud and they have blessed me with beautiful great-grand babies. My theory is always stay positive even when life is at its worst. I LOVE MY LIFE. I live each day to the fullest because you never know.

CONTINUED FROM PAGE 1

and Human Services and the University of Iowa. This partnership would establish a team of epidemiologists to research the behavioral, genetic, and environmental factors contributing to Iowa's health issues.

In an interview at WQAD News8 in Moline, IL Senate President Amy Sinclair, said, "I have spoken with folks at the University of Iowa and understand the need for that. I think we do need to know the 'why.' ...to see if that can be included in that Health and Human Services budget. I think it's valuable to Iowans and I think it's valuable to the University of Iowa to start moving in the right direction."

House Minority Leader Jennifer Konfrost says \$1 million is a nice start to study the issue but that doesn't help anyone currently getting a diagnosis today or tomorrow.

NOTE: This proposal still needs to be approved by the state legislature to move forward and begin the research process.

At **Beyond Pink TEAM**, **TEAM** stands for **T**ake action, **E**ducate, **A**dvocate, and **M**ake a difference—and that's exactly what we strive to do every day.

Taking Action: We offer support groups to help manage the emotional and physical toll of cancer treatments.

Educating: We have compiled resources and videos, 'The Cancer Journey,' available on our website, guiding patients through every step of their cancer experience.

Advocating: We attend the National Breast Cancer Coalition Summit annually to stay informed on the latest research and push for critical legislative support. We show up and ask good questions when cancer care and healthcare are being discussed.

Making a Difference: Thanks to our generous community, we provide financial assistance for medical and living expenses to those diagnosed with breast cancer for those in Black Hawk County and Northeast Iowa.

Together, We Can Make a Difference

Our dedicated volunteers can't do it alone—we need **YOU** to keep breast cancer prevention and treatment a top priority in Iowa. Your voice matters. By advocating for better policies, supporting life-saving research, and standing with us, you can help create a healthier future for everyone in our state.

Stay connected and make a difference. Follow **Beyond Pink TEAM** and **Iowa Stop Breast Cancer** on Facebook and join the movement to make Iowa a truly "beautiful land" for all.

HOPE AFTER A METASTATIC DIAGNOSIS (PART 2)

SARA DIESBURG, SURVIVOR



This article is an update to the April 2022 article “Hope After a Metastatic Diagnosis.” This is a feel good story for me.

I was diagnosed with Stage 2 triple negative breast cancer (TNBC) in the summer of 2015, just two years after moving back to Iowa to start my faculty job at UNI. I was 33

years old at the time and had never had a mammogram. I also had no family history of breast cancer. I successfully completed treatment, which consisted of chemotherapy, a lumpectomy, and radiation. I had obtained a pathological complete response (PCR) at the time, which meant they saw no more cancer on any scans or the margins around the removed tissue.

Unfortunately, my cancer recurred into stage 4 metastatic disease in March of 2020, when I was 37 years old and pregnant with my daughter. We discovered it came back when I had a seizure. The cancer had spread to a spot in my brain, a spot in my lung, and a lymph node. After giving birth to a healthy baby girl in April, I started stage 4

treatment consisting of a combination of immunotherapy, chemotherapy, and some pinpoint radiation. The life expectancy for someone in that situation was 2-3 years at the time.

The last article talked about changes I made to my diet, exercise, and stress to help the treatments do their work. I had too much to live for with my young family, and I didn't want to give up. At the time of me writing my last article, I was happy to report that I had “No Evidence of Disease” (NED) status and was living a normal life with monthly immunotherapy infusions.

A few updates have happened since that time. My scans continued to be clear of cancer, and through working with my Mayo oncologists, we stopped all cancer treatments in November of 2023. My scans continue to be clear. In lieu of some scans, I am now taking a blood test every 3 months, called Signatera, that can test levels of cancer DNA fragments circulating in my blood. These tests have wonderfully come back negative, finding no cancer DNA. These tests are new and are much easier than scans.

I want people to know that there are people who continue to survive a metastatic diagnosis. Statistics do not always determine fate.

INSURANCE COVERAGE FOR LYMPHEDEMA COMPRESSION GARMENTS AND SUPPLIES

Information provided by the Lymphedema Advocacy Group

In December 2022 the Lymphedema Treatment Act was passed by Congress to enable Medicare coverage for lymphedema compression garments and supplies. The new coverage went into effect on January 1, 2024, for traditional Medicare, however, most other insurance plans followed Medicare precedent.

Requirement for Coverage

- Needs a lymphedema diagnosis with the following applicable codes:
 - Q82.0 Hereditary lymphedema
 - I89.0 Lymphedema, not elsewhere classified
 - I97.2 Postmastectomy lymphedema syndrome
 - I97.89 Other postprocedural complications and disorders of the circulatory system, not classified elsewhere.
- A prescription for the item or items.
- Clinical notes must include the stage of lymphedema, and if a custom garment is ordered, notes must indicate why a standard-fit garment is not indicated for the patient.

Compression Supplies Covered

- Custom and standard-fit daytime and nighttime garments.
- Custom and standard-fit gradient compression wraps with adjustable straps.
- Bandaging supplies for the initial and ongoing phases of treatment.
- Accessories including but not limited to lining, padding, zippers, donning and doffing aids.

Quantities Covered

- Daytime Garments – 3 sets (one garment for each affected body part) every six months.
- Nighttime Garments – 2 sets (one garment for each affected body part) every two years.
- Bandaging Supplies – no set limit.
- Accessories – No set limit, determined on a case-by-case basis depending on needs of the patient.

VOLUNTEERS SHARE WHY THEY VOLUNTEER FOR BEYOND PINK TEAM

Jeremia Matz, Marketing Director of SCHEELS states his team is so proud to support the Beyond Pink TEAM in many ways. We have financially supported the organization for years and volunteer on a regular basis, especially for the Pink Ribbon Run. Our team volunteers to show their support, to help build awareness, and to honor those who are and who have fought this disease. We are grateful to be involved with an organization that does so much for so many in our community!



Jill Stone from New Image Boutique, NuCara Home Medical comments, "I volunteer with the Beyond Pink TEAM because I see the need for help daily with my breast cancer patients. The Beyond Pink fund has been an unbelievable asset for my patients. I handed out the quarterly newsletter, discussing BPT and their support groups. I feel like I am one of the first people to share information on Beyond Pink TEAM and what they do. I've helped at many events over the years and love spreading the word of what the Beyond Pink TEAM does in the Cedar Valley."

Survivor, Pat Sears shared, "My journey started 5 yrs ago when I had a lumpectomy. At that time, I was given a pillow with a note attached that Pat Buls was the facilitator for Touch of Courage, and it listed her contact information. I happened to know Pat and reached out to her. She

invited me to attend their monthly meetings. First, I would go occasionally. Then with my youngest daughter being diagnosed with breast cancer as well as my husband with prostate cancer I was unable to attend several meetings. However, in the last year or so, I have tried to make it a priority to attend the meetings. I enjoy the sharing among those who attend. Pat is great at informing us of any updated medical news of which she is aware.

Last October was the first 5 K (Pink Ribbon Run) that both my daughter and I took part in with a large group of family/friends. Nicole, my daughter, and I were able to help some of the evenings with packaging shirts and packets for the Pink Ribbon Run. To me, it is an honor, to help with such a great cause. Being involved shows we care!"

Marty Mullnix – As a volunteer board member of the BPT, I give of my time and talents in several ways. I gather articles and ideas for our quarterly newsletter, attend check presentations, staff table displays at community health fairs, make presentations to organizations and groups about BPT and what we do, attend fundraisers supporting BPT, and make donations to the BPT Advocacy. Why? It's a small way I can share who we are, what we do, and hopefully make a difference to the many individuals in our community affected by breast cancer. Donations received stay local!

SUPPORT BEYOND PINK TEAM GARDEN FLAG

Honor a breast cancer individual this spring with this garden flag. At the same time, you will be supporting the work of the Beyond Pink TEAM. To purchase a flag, contact Cheryl at jthayer58@gmail.com. The cost is \$15.00!



GEAR UP for the 19th Annual Pink Ribbon Run Saturday, October 4th!

NEW TO CANCER? HAVE ALL SORTS OF QUESTIONS?

The Beyond Pink TEAM has created a series of videos all in one place to help you through your cancer journey. Check it out on our website, www.beyondpinkteam.org or use this QR code. We're here to support you.



NBCC PRIORITIES



SHARED BY CHRISTINE CARPENTER, BPT ADVOCATE AND MEMBER OF NBCC

Advancing Breast Cancer Research & Care: Our Legislative Priorities

Beyond Pink TEAM is proud to serve as a voice for our members on the National Breast Cancer Coalition (NBCC) Board of Directors. Every year, the NBCC Board, with input from our grassroots community, sets clear legislative and public policy priorities to guide our advocacy work. Your quick action on our alerts is key to making these priorities a reality.

Legislative Priorities:

- **Funding for Research:**

We are pushing for \$150 million (level funding) for the Department of Defense's Breast Cancer Research Program. Since its start in 1992, this program has funded innovative, high-impact research that brings us closer to eradicating breast cancer.

- **Medicare Coverage for Metastatic Breast Cancer:**

A bill is on the agenda to recognize metastatic breast cancer as a qualifying condition for Medicare. This change would remove waiting periods and ensure patients receive full coverage for crucial treatments.



- **Protecting Treatment Programs:**

The Breast and Cervical Cancer Treatment Program, created in 2000 through NBCC's dedicated efforts, guarantees that those diagnosed with breast cancer receive the treatment they need. We remain committed to safeguarding this vital program.

Public Policy Priorities

Priority #1: Guaranteed Access to Quality Care for All

NBCC supports expanding Medicare while offering private options, automatic enrollment for those without coverage, and guaranteed benefits (including primary, preventive, hospital, and prescription care) through shared financial responsibility.

Priority #2: Access to Affordable and Effective Therapies

We advocate for reforms to ensure that only drugs proven to extend or save lives and that offer real value receive approval.

Priority #3: Food & Drug Administration Reform

NBCC calls for FDA reforms that prioritize drugs with meaningful clinical benefits, improve the accelerated approval pathway, and limit reliance on unvalidated surrogate endpoints.

Priority #4: Participation of Educated Patient Advocates

We insist that trained patient advocates—those personally affected by breast cancer and representing a patient-led organization—have a real voice in healthcare and research decision making.

Your engagement is essential to advancing our mission. Thank you for standing with us in the fight against breast cancer.



Beyond Pink TEAM members, Christine Carpenter, Lori Seawel, and Kristin Teig-Torres were able to meet with most of the Iowa congressional aides to introduce themselves. In addition, Christine was able to mentor other individuals about what BPT does.

IOWA CANCER REPORT 2025 FOCUSES ON SURVIVOR NEEDS

More Iowans are surviving cancer than ever before, and their unique needs require specialized support from health care providers, communities, and caregivers, according to the 2025 Cancer in Iowa report from the Iowa Cancer Registry.

Survivor needs can include:

- Screening for cancer recurrence and new cancers.
- Addressing late effects and delayed symptoms of cancer treatment.
- Quality-of-life considerations, with emphasis on nutrition, physical activity/movement, tobacco use cessation, and mental health and social support services.

The Iowa Cancer Plan serves as a guidebook for entities, services and individuals who want to help cancer survivors. It is available online at canceriowa.org.

“That plan has overarching priorities and specific strategies that anybody interested in supporting Iowa’s cancer survivors can look to,” explains Sarah Nash, assistant professor in epidemiology in the College of Public Health at the University of Iowa and director of research at the Iowa Cancer Registry.

Research also helps improve the kind of care cancer survivors need. Jess Gorzelitz, assistant professor in the Department of Health and Human Physiology at Iowa, operates a lab in which she investigates how cancer survivors who are introduced to muscle strengthening

and aerobic exercise can improve their functional strength and quality of life.

“We know that people, after they finish cancer treatment, have reductions in their strength and function, and that can be a risk factor for other health conditions and premature death,” says Gorzelitz. “So, we think it’s really important to use exercise as a supplementary strategy to help people live their best lives and ultimately to reduce the burden of cancer.”

Her findings so far have been promising: Up to 70% of research participants in her lab have improved their fitness at a clinically significant clip, translating into these cancer survivors having up to a 40% lower risk of mortality.

“Most people don’t think, ‘I go lift today so that I can live another two years,’” Gorzelitz says. “But from the epidemiological perspective, it’s quite a powerful medicine.”

The Cancer in Iowa report includes county-by-county statistics, summaries of new research projects, and a special section focused on cancer survivorship. You can read a copy online at shri.public-health.uiowa.edu or call 319-335-8609 to request the report.

The Iowa Cancer Registry will hold 99 county meetings this year to discuss specific cancer findings for each county. To find upcoming dates and locations, visit shri.public-health.uiowa.edu and search for 99 counties project.

FUNDRAISERS

Black Hawk County Sheriff
Cedar Falls Public Safety
Community Main Street
- Give Back
Farrell’s
Hudson High Leo Club

Peoples Savings Bank
SCHEELS
- 2025 Pink Ribbon Run
UAW Local 838
Visions Hair Studio
Waverly Health Center



KEY FINDINGS FROM THE IOWA CANCER REPORT 2025

- Breast cancer continues to be the most often diagnosed cancer in Iowa, followed by prostate and lung.
- The state of Iowa continues to have the second-highest rate of newly diagnosed cancers, when adjusted for differences in age among the states.
- Iowa is one of only two states with a rising age-adjusted rate of new cancers (Kentucky is the other).
- 20,000+ Iowans will be diagnosed with cancer this year.
- The cancer death rate in Iowa is declining due to effective detection, treatment and support, which leads to more survivors.
- Nearly 172,000 cancer survivors live in Iowa (5.4% of the population).

DONATIONS

The following monies were received between December 1, 2024, through February 28, 2025. Thank you everyone for thinking of the Beyond Pink TEAM with these gifts.

A-Line EDS - Christman Donation
Anne Barloon
Bambino's
Bunger Family Foundation
Christine Carpenter
Cedar Falls Business Professional Women
CF Police Protective Assoc.
Jeff Coons
Troy Davis
Stacy Glascock
Mary Lou Gutting
Lee Homeister
Kara Howard
Jean Hoy
Tammy Hughes
Mary Jo Juel

THANK YOU

to these individuals, businesses, and corporations for their support of the Beyond Pink TEAM mission through their donations and support.

Carol Kallenbach
Kaitin Kammeyer
Amber Krebsbach
John Luxem
Linda Lynch
Anne McCabe
Jodi Muller
Marty Mullnix
New Hampton Community School District
Crystal Schmitz
Lori Seawel
Sheri Snow
Mary Wallace
Sandra Williams
Cynthia Wilson

Memorials and Honorariums

In Memory of Aileen Anderson
Gene & Jane Groth

In Memory of Lynette Bond
Kara Rosebaum

In Memory of Anne Christensen Doyle
C. David & Glenda Christensen

In Memory of Leian Kammeyer
Joyce Guthrie
Donna McConeghey

In Memory of Judy Weston
Jeanne Koontz

In Memory of Debbie & Jodi Paul Fitzgerald

In Memory of Sister Pat Homeister

In Honor of Janice Akin
Greater CV USBS

DATES TO REMEMBER APRIL - JULY 2025

April 1, 1:30 pm

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

April 7, 1:30 pm

Touch of Courage
Breast Cancer Support Group
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-610-4424 for info & location

April 15, 2023, 5:00-7:00 pm

BPT All Cancer Survivor Group
Cedar Valley Unitarian Universalists Church
3912 Cedar Heights Drive, Cedar Falls
Angela 319-231-3143 for info & location

May 5, 1:30 pm

Touch of Courage
Breast Cancer Support Group
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-610-4424 for info & location

May 6, 1:30 pm

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

June 2, 1:30 pm

Touch of Courage
Breast Cancer Support Group
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-610-4424 for info & location

June 3, 1:30 pm

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

June 15, 2023, 5:00-7:00 pm

BPT All Cancer Survivor Group
Cedar Valley Unitarian Universalists Church
3912 Cedar Heights Drive, Cedar Falls
Angela 319-231-3143 for info & location

July 2, 2023, 1:30 pm

Touch of Courage
Breast Cancer Support Group
Community Foundation of NE Iowa
3117 Greenhill Circle, Cedar Falls
Pat 319-961-4424 for info & location

July 3, 1:30 pm

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

**FREE 9-week
Survivorship 101 Course
coming this fall!**


September 3 - November 5

Watch for details on
Facebook, BPT website,
and the July Touch of
Courage newsletter.

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

 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'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 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 provides 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 provides short 3–5-minute videos featuring survivors, doctors, social workers, and advocates who share their experiences of diagnosis, treatment, after-treatment, 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.

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
- Becoming part of the Breast Cancer Advocacy Network
- Becoming 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)
- Advocating by contacting Congress/Ignite the Cancer Conversation
- Assist with Support Groups
- Educating by hosting tables at Health Fairs, presenting, helping with newsletters
- Development (Publicity)
- Donating. Make checks payable to Beyond Pink TEAM designating specific fund, if you wish. (All donations are tax deductible)
- BPT Fund
- Advocacy Fund
- Area of Need

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

Scan here for more information on the Beyond Pink TEAM.



BeyondPinkTEAM.org