

# Touch of Courage Connection

Newsletter

### **April** 2021

Celebrating over 30 years in the Cedar Valley

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# Safety of COVID-19 vaccines for Cancer Patients And Survivors

By Joe Dangor, Mayo Clinic News Network



As two new COVID-19 vaccines become more widely available, patients with cancer and cancer survivors may wonder if it's safe to be vaccinated.

"Because cancer patients and survivors are at higher risk for severe effects from COVID-19 infection, we recommend they get vaccinated as soon as they can," says Robert M.D., McWilliams, а medical oncologist at Mayo Clinic. "Patients who are immunosuppressed due to active cancer treatment may not get the same effective response as someone without immune compromise, but it should still be safe for them to receive the vaccine."

There is no definitive data on the efficacy of the COVID-19 vaccines from Pfizer/BioNTech and Moderna in patients with cancer or cancer survivors. "However, the few patients with cancer who were studied as part of the clinical trials leading to the approval of these vaccines did not

experience any unique side effects," says Joleen Hubbard, M.D., a medical oncologist at Mayo Clinic.

The good news for patients with cancer and cancer survivors is that the Pfizer/BioNTech and Moderna COVID-19 vaccines are not live virus vaccines. That makes them less likely effects cause side immunosuppressed patients. "Both vaccines are mRNA (messenger RNA) vaccines, which means they teach our bodies how to make a protein that will trigger an immune response without the use of a live virus that causes COVID-19," says Dr. Hubbard. "Once triggered by the protein, our immune system makes antibodies to protect us if we are exposed to the virus."

Patients should discuss any concerns they have about being vaccinated with their healthcare provider.

Information in this article was accurate at the time of publication. Due to the fluid nature of the COVID-19 pandemic, scientific understanding, along with guidelines and recommendations, may have changed since the original publication date.

#### MAMMOGRAM NOTICE

The Society of Breast Imaging has recommended that women do not have a mammogram for at least a month after getting vaccinated. This is so any swelling in the axillary lymph nodes (lymph nodes in the armpit) has time to go away, preventing a false positive for cancer.

# **Survivor Story**

# Need to Be Your Own Advocate!

By Regena Huffman, Survivor

I was diagnosed with stage 2 IBC (inflammatory breast cancer) back in December of 2015. After chemo, surgery, and radiation, I was 6 months away from my 5-year milestone when I discovered the cancer had metastasized to my bone in 3 places. I am currently on oral chemo and appear to be responding favorably.

The newest cancer was discovered during an MRI that I had to advocate strongly to have... I would like to share with survivors the importance of being your own advocate and asking what tests are available to you for early diagnosis!

Here is my story - When I went in for my regular annual checkup at the breast surgeon's office last May, I shared how someone I knew had a recurrence of cancer on the side they had already had a mastectomy on. I asked how we would know if that was my situation or not given that I still got an annual mammogram, but I could only have one side of my body checked. How would we know if all was good on the reconstructed side? My doctor said that for those of us who have only one breast removed during treatment, the medical field is starting to see the value in doing an annual mammogram, but then following it up with an MRI 6 months later so they can identify anything that might be occurring on the reconstructed side. He told me that most insurance companies fight doing this because of the cost of the MRI, and I asked him to submit a request to move forward with the MRI. He said it might take a time or two to get approval, but I told him to keep requesting until we were approved, which he did.

When I went to his office to review the results of the MRI, his exact words to me were "Your case is exactly the reason why I think it is so important for us to do these MRI's for survivors... we had something show up in your results that we need to investigate further."

A PET scan was then ordered, and that scan showed that I now had cancer in my bones in 3 areas of my body, 2 cervical joints in my neck, one rib, and a spot on my pelvis. If I had not insisted on that MRI, I might not know about the recurrence yet! I am a firm believer that we need to not be afraid of what the doctors or insurance companies might think of us, we are fighting for our lives here!!! I am now on oral chemotherapy and had 5 radiation treatments to my neck back in July. My most recent PET scan (which my oncologist had to submit for three months in a row before we got approval!) showed that the affected areas are responding and for that I am grateful!

Thanks so much for all the Beyond Pink TEAM does for those of us who are living with this daily, and for the time spent educating and encouraging those of us who live with breast cancer.

### **Living Green**

# Spring Has Arrived! And with It...Lawn Care

By Dawn Keller



We are a country long obsessed with having the "perfect lawn" and that must change. We must change our definition of what a "perfect lawn" is. For most people, it is green grass, perfectly manicured, not a weed or an insect in sight. Bland. Empty. Devoid of life. Toxic. To me, a perfect lawn is a place where I can walk barefoot without being concerned about the chemicals I am stepping on or breathing in. A place where insects, birds, and others can feed while pollinating interesting plants that many refer to as weeds. A place I do not have to water because the soil is healthy and can withstand dry times. And a place where I even pick some of those "weeds" to eat, as they make delicious salads and side dishes that are full of nutrients. Some of the plants I eat are dandelion, stinging nettles, plantain, duck, wild onions, and mushroom. Rather than spending countless hours mowing, spraying, and weeding, let your grass grow a little taller, leave the so-called weeds, and do not use any chemicals. And then, take your shoes off, walk through your lawn and appreciate this new definition.



## Kristin Teig Torres, MA, CNP, an 11-year Survivor

11 years ago, this past December 18 - I was diagnosed with Breast Cancer.

I had the biopsy the day prior and went to see Dr. Duven for the results...I already knew...I knew as soon as I picked up the phone three days before when my OBGYN said she was referring me to a Breast Cancer Specialist. I was working full time, had just started graduate school and my children, Jack and Ava, were 6 and 3 years old.

The morning of December 18 - after I got the news and was immediately taken over to radiology to have an MRI - I went to work. It was Allen College Graduation at Nazareth Lutheran Church - I always announced the processional and I was to sing with the Allen College Chorus, which I started as part of my role as alumni relations director. I walked in and they all thought I must have received good news... after all, I was at work... my response to their questions... no, I have breast cancer and we got to work. After my treatment, which included lumpectomy, chemotherapy, and radiation, I took a few months for myself, I was still working full time and in graduate school. I wanted to become stronger physically and began training for the Chicago Marathon.

My friend, Anne Christensen Doyle, reached out to me a month after my diagnosis asking for advice. She had noticed a lump in her armpit and was concerned. It turned out that Anne



Kristin and Jacque Bakker with Dr. Slamon. Both Kristin and Jacque are HER2+.

had triple negative breast cancer. This is a form of breast cancer that is very lethal, with no known targeted therapies. My tumor type was HER2+ for which I received the drug Herceptin. Five years prior to my diagnosis my type would have been very lethal, but with assistance from patient advocates and initial research funding by the National Breast Cancer Coalition, the drug Herceptin was developed by Dr. Dennis Slamon. Anne, once diagnosed, immediately began working with the Beyond Pink TEAM, knowing she needed to find answers sooner rather than later. Anne was just a month behind me in treatment, but every experience I had seemed to be so much worse for her. I would have mild side effects, Anne would have a severe reaction, I exited treatment, Anne's cancer recurred, or maybe never left her body. Early on September 1, 2012 Anne passed away from metastatic breast cancer. I knew I needed to pick up her mission to end the disease - she was my mantra during the 26.2 miles of the marathon I ran the following month.

I attended my first National Breast Cancer Coalition Advocacy Summit in May 2013. Since then, I have not missed a single Summit, where we learn the basic science of breast cancer, the latest treatments, and how to be a strong grassroots advocate to change the landscape of breast cancer research and funding. Breast Cancer is a political issue and I learned how to affectively lobby my legislators. I attended NBCC's Project LEAD the same year, taking a deep dive into the science of breast cancer and have been invited back by NBCC for Advanced LEAD sessions and have served as a Mentor for Project LEAD attendees in 2018 and 2019. I have been fortunate to meet Dr. Dennis Slamon on two different occasions, the man who potentially saved my life - thanks to NBCC, and I have been inspired by those past patient advocates to step up and make a difference for others. For the Beyond Pink TEAM, I have served on the advocacy arm of organization, helping conceive of, and plan the Ignite the Cancer Conversation Events. To bring diverse communities together and activate the conversation that will initiate and develop concrete steps to conquer cancer.

Over these past 11 years I watched friends die of this disease - too many friends. You think that I am always positive and have a good attitude - that I never really appeared ill... well, many times I was just showing you what a good actor I am.

This diagnosis is never far from my mind.

There is no cure for Breast Cancer.

No such thing as early detection.

We must end this disease.



The Torres Family



#### Be Bold Together: Advocates in Action to End Breast Cancer!

Join with fellow survivors, advocates, and members of the breast cancer community, who are lending their voice and transforming breast cancer research and public policy and ensuring quality healthcare for all. Exciting plenaries and skill-building workshops will focus on the most critical areas of breast cancer research, science, and public policy. Attendees will have opportunities to network with other breast cancer survivors and advocates and connect with leading researchers in the field.

Join online Thursday, May 13 – Saturday, May 15, 2021. Our annual Lobby Day will follow the Summit on May 18, with Lobby Day Briefing and Preparation, Monday, May 17.



Registration is now open for the virtual National Breast Cancer Coalition's (NBCC) Advocate Leadership Summit. Go to stopbreastcancer.org and scroll down to the very bottom right and click on 2021 Virtual Advocate Leadership Summit. Registration fee is \$150. If you bring a new advocate leader with you to the Summit, you

both receive \$25 off your registration bringing the cost to \$125 per person. Beyond Pink TEAM offers need-based partial scholarships. Contact Christine Carpenter for a scholarship application or additional information at *Christine.carpenter@cfu.net* 

NBCC has revolutionized breast cancer since it was formed in 1991 to address the critical need for a coalition of breast organizations to work together and end breast cancer through action and advocacy. This was a revolutionary vision at the time, and NBCC's track record of success demonstrates the effectiveness of this strategy. Our bold, determined, and strategic advocacy has changed the breast cancer landscape, and continues to shape crucial breast cancer public policy and research. Beyond Pink TEAM is a member organization of NBCC.

### BPT "Ignites" Interest in Pesticide Use in Local School

By Dr. Julie Husband, Professor, Dept of Language & Literature, UNI

"What can you do in your community to reduce the incidence of cancer?" This was the culminating question organizers asked small groups of attendees at the second annual Ignite the Cancer Conversation event in 2017. This "Environmental Edition" of Ignite brought together speakers on water quality, radon testing in homes, and pesticides. Dr. Kamyar Enshayan, Director of the University of Northern Iowa's Center for Energy Environmental Education (CEEE), gave a hard-hitting talk on how pesticides damage people and especially children.

Because children play on grass and because they eat, drink, and inhale more pesticides per pound than adults, they are especially vulnerable. Scientific studies show pesticides are linked to a range of negative outcomes from birth defects to asthma to cancer. Eliminating or at least limiting pesticide use in public parks and schools can improve health for everyone, but especially children. As the mother of three, I decided this was the thing I could work on after the 2017 Ignite event.

My sixteen-year-old daughter Devin had been volunteering with Ignite. We had lost my mother to breast cancer in 2016 and this seemed like something Devin could do to understand her grandmother's illness and in tribute to her. I came and later joined Ignite for similar reasons. The beginning of an organizational effort led by Dr. Enshayan that was just then taking off.

The CEEE and its Good Neighbor Iowa program worked with UNI students and area parents to track current practices at public parks and schools, and then they shared them on their website. Parents fanned out to ask guestions of the Cedar Falls School District (CFSD) about when and where-inside schools and outside—pesticides were used. We asked, too, about notification processes so that parents with children who had asthma or other health conditions could make informed decisions about school attendance after spraying. As we gathered information, the school district agreed to form the Environmental Health Committee to investigate changes to their current practices.

Be an Advocate, continued on page 5, col 2



Join us for an evening with Dr. Cyrus Ghajar, Ph.D. from the Fred Hutch Institute this coming Fall, 2021 (date TBA). Dr. Ghajar's Cancer Conversation will be accessible for a broad audience and general community interested in cancer care and treatments.



Dr. Cyrus
Ghajar, Ph.D.
Associate
Professor
Public Health
Sciences and
Human
Biology
Division, Fred
Hutch

Dr. Ghajar researches metastasis, or the spread of cancer cells to distant sites, and how the microenvironments of these sites (including bones) can put cancer cells to sleep - or wake them up. During the early days of tumor formation, disseminated tumor cells, or DTCs, often break away and travel through the bloodstream to distant areas of the body. If they stay asleep, or these DTCs remain dormant, harmless. But if (or when) they wake up - which may happen months, years or even decades after a patient receives early-stage treatment such as chemotherapy – they can create metastatic tumors that are resistant to treatment and eventually kill the patient. Dr. Ghajar studies how the microenvironments within distant tissues regulate DTC dormancy and/or growth and whether these niches convey to dormant DTCs resistance to chemotherapy and immunotherapies.

Dr. Ghajar believes that solving these puzzles will allow the development of drugs that eradicate dormant DTCs before they can develop into full-blown metastases. He conducts this work within the Hutch's Laboratory for the Study of Metastatic Microenvironments and works with the National Breast Cancer Coalition on their Artemis Project, which he will discuss during his presentation.

#### **2020** Ignite Sponsors

We would like to thank the following for their support of the 2020 Ignite Event. Your support was greatly appreciated.

Allen Nursing Alumni Association
Anonymous
Bank Iowa - matching
BHC Care For Yourself
Bright Funds - matching
Bunger Family Foundation
Dee and Marty Hughes
MercyOne
Pancreatic Cancer Network
Pi Kappa Nursing Honor Society
Shawn and Janelle Smeins
Richard and Patricia Sulentic
Cheryl and Jim Thayer
Veridian Credit Union - matching

#### Be an Advocate, cont'd from page 4

December Between 2017 and Kate December 2019 parents Dunning, Jeremy Swanson, and Kristin Wood met with Rick Gersema, Supervisor of Buildings and Grounds (CFSD); Andy Superintendent (CFSD); Audrey Tran Lam, UNI Center for Energy and Environmental Education; and Pam Zeigler, Director of Elementary Education (CFSD). This Environmental Health Committee researched the medical literature on this issue, including information from the American Academy of Pediatrics, and examined how the schools might modify practices while still adhering to the Integrated Pest Management System in place. By consulting with other school districts, the CFSD learned that it might overseed rather than spray to reach similar results. They also analyzed overhead pictures of the outdoor grounds and shifted some of the zoning to keep spraying away from children. By taking soil samples and working with lowa Extension, the group found that the soil might be enhanced to promote better growth and further limit pesticides. Overall, the new system reduced spraying by 54% and saved the district \$5,000!

Parent Kate Dunning praised the response of the school district and especially its Supervisor of Buildings and Grounds: "Rick Gersema took learning seriously and became and remained very open to new approaches."

This is a great example of how advocacy can make changes on the local level that improve community health. Dr. Enshayan praised the Cedar Falls School District, saying it "is leading and setting a wonderful example by creating a healthy environment for children." If you are interested in contributing to these efforts or to another school district's program, contact Audrey Tran Lam, the Environmental Health Program Manager at the CEEE goodneighbor@uni.edu and check their website at: https://goodneighboriowa.org/

Call Ahead

#### DUE TO THE COVID-19 VIRUS, PLEASE CALL BEFORE ATTENDING ANY SUPPORT GROUP

#### Support Group Dates

#### April 5 1:30 p.m.

**Touch of Courage Breast Cancer Support Group** 

Location to be Determined Pat - 319-232-8691 for information

#### April 6, 1:30 p.m.

#### Care & Share Cancer Support Group

VIRTUAL MercyOne Waterloo Cancer Center 200 E Ridgeway Ave., Waterloo Jessica - 319-272-2816 for virtual meeting info

#### April 20, Time TBA

#### **BPT All Cancer Support Group -**Meet, Mingle and Learn

VIRTUAL Cedar Valley Unitarian Universalist 3912 Cedar Heights Dr., Cedar Falls Angela - 319-231-3143 for virtual meeting information

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

#### **Touch of Courage**

**Breast Cancer Support Group** Location to be Determined Pat - 319-232-8691 for information

Call Ahead

#### May 2, 1:30 p.m.

#### Care & Share Cancer Support Group

MercyOne Waterloo Cancer Center VIRTUAL 200 E Ridgeway Ave., Waterloo Jessica - 319-272-2816 for Virtual meeting info

#### May 13

#### Splash of Color – Women of Color **Breast Cancer Support Group**

Call Cathy Ketton - 319-504-2703 for details

#### June 1, 1:30 p.m.

#### Care & Share Cancer Support Group

VIRTUAL MercyOne Waterloo Cancer Center 200 E Ridgeway Ave., Waterloo Jessica - 319-272-2816 for virtual meeting info

#### June 7, 1:30 p.m.

#### **Touch of Courage**

**Breast Cancer Support Group** 

Location to be Determined Pat - 319-232-8691 for information

#### June 22, Time TBA

#### **BPT All Cancer Support Group -**Meet, Mingle and Learn

Cedar Valley Unitarian Universalist 3912 Cedar Heights Dr., Cedar Falls Angela - 319-231-3143 for meeting information (outdoors or virtual)

VIRTUAL

#### July 5, 1:30 p.m.

#### **Touch of Courage Breast Cancer Support Group**

Location to be Determined Pat - 319-232-8691 for information

#### July 6, 1:30 p.m.

### Care & Share Cancer Support

VIRTUAL MercyOne Waterloo Cancer Center 200 E Ridgeway Ave., Waterloo Jessica - 319-272-2816 for virtual meeting info



BPT was the recipient of the CBE Companies Casual for a Cause 2020 for November. Kirsten Conley, CBE, is presenting Dee Hughes, BPT, a check for \$4,109.27!



Jeremia Matz, Scheels, made a check presentation to Marty Mullnix, BPT for \$1,000.00 along with their \$1,000.00 sponsorship for the 2021 Pink Ribbon Run.

#### **Donations from December 1,** 2020 through February 28, 2021. Thank you for all your support!

Deborah Allender

Shanna Bovee

**Brecher Family** 

CBE Group Employees

Cedar Valley Cyclists

CFHS Food Service

C David Christensen

Marlene Ciorba

Rita Clark

Mary Curran

Maureen Daley

Susan Dobie

Aaron Dowdal-Osborn

Lindsay Erickson

Flowerama

**Barb Forbes** 

Mo Hardy & Visions Salon

Paul & Patricia Homeister

Teri Hook

Jennifer Hughes

Jill Jensen

Mary Jo Juel

Jordan Kettner

Sheila Krejci

Christina Kremer

Troy & Susan Love

Regina Lowery

Peggy Mangrich

Kimberly Meek

Jodie Muller

Donna O'Brien

Jeanne Olson

Panera Bread

Kathy Patterson

Mary Petersen

Pillar to Post Home Inspections

Maureen Rasmussen

Susan Robertson

Aaron & Christine Sannes

Rhonda Shaw

Sherri Snow

Joy Thorson

James Vervaecke

Doris Webber

Traci Weber

Jammi & Robert Welter

Roger White

Natalie Wulfekuhle

### University of Iowa Offers a Clinical Trial to Some Breast Cancer Survivors

About 15% of all invasive breast cancers diagnosed in the United States each year are triple-negative. Inherited gene mutations (like BRCA 1 or 2) are responsible for about 5 to 10% of breast cancers in the United Triple-negative breast States. cancers (TNBC's) do not have the hormone receptors other types of breast cancers do. These tumors are estrogen receptor (ER) negative, progesterone receptor (PR) negative, and human epidermal growth factor 2 (HER-2) negative. Because of this, we do not have specific targeted therapies for TNBC and thus have fewer options for treatment. The primary treatment for TNBC is still chemotherapy. Looking for new targets for treatment is of utmost importance.

At the University of Iowa, we have a clinical trial aimed at this goal. This trial evaluates the safety and effectiveness of a new targeted drug combination, talazoparib gedatolisib. Talazoparib is a PARP The PARP enzyme is inhibitor. involved in cell processes such as DNA repair. In cancer, blocking PARP may prevent cancer cells from repairing damaged DNA, causing the cells to die. Gedatolisib is another type of targeted therapy. It blocks two proteins, PI<sub>3</sub>K and mTOR. When these proteins are activated, cancer cells grow, survive, and become resistant to chemotherapy and radiotherapy. By blocking PI<sub>3</sub>K and mTOR, gedatolisib may cause cell death.

To qualify for this study, patients must be adults age 18 or older with metastatic triple-negative breast cancer or BRCA 1 / 2 - positive HER2negative metastatic breast cancer. All patients enrolled on the trial will receive investigational both treatments, and there is no placebo. For more information about this research study, including full requirements, eligibility visit www.clinicaltrials.gov (study #NCT03911973). Support for this study is provided by Pfizer Inc.

Did you know you can now donate to the Beyond Pink TEAM by Venmo and AmazonSmile. Click the "DONATE" button on our website for more information on these and other options, as well.

Dr. Sneha Phadke, an Ignite speaker and Medical Oncologist from the University of Iowa Holden Comprehensive Cancer Center has answered some questions about this clinical trial for those interested.

Does your clinical trial have easy to understand, informed consent? Yes, the IRB recommends the consents should be written at a 6th grade reading level. We try to maintain the wording at that level as much as possible.

What treatment is being tested? Talazoparib (an FDA approved treatment for patients with metastatic breast cancer and a BRCA mutation) gedatolisib (investigational agent that targeted toward a protein called PI<sub>3</sub>K which drives tumor cell growth). This is a new combination that is being tested and is unique in that it does not use chemotherapy (which is currently the mainstay of treatment in triple negative breast cancer).

will the trial benefit How patients? We do not know if any individual patient will benefit, since this is a new investigational treatment. If this study shows that this is a promising treatment, it may open αυ а new nonchemotherapy treatment option for patients with metastatic triple negative breast cancer.



The Beyond Pink
TEAM website has
been under
construction. Check
out the new look at

www.beyondpinkTEAM.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.

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

**Beyond Pink TEAM** is a local breast cancer organization providing a variety of services. Our website lists services we provide as well as other services available in the Cedar Valley. **www.beyondpinkTEAM.org** 

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

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

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

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

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

**National Breast Cancer Coalition** the NBCC's mission is to eradicate breast cancer by focusing the government, research institutions, and consumer advocates on breast cancer. It encourages advocacy for action and change. **www.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. www.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. **www.cancer.gov** 

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

<b>Connect with us</b> 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			Zip	
Email								
I would like to participate with the Beyond Pink TEAM by:								
<ul><li>Writing a survivor story for the newsletter</li><li>Become part of the Breast Cancer Advocacy Network</li></ul>			☐ Beco					
Volunte	ering: ((check all that apply) Assist with Support Groups Development (Publicity) Events (Fundraisers, Projects and	d More)		n (Health Fairs/Pr y — Contact Congr	,	ewsletters) Cancer Conversation		
☐ Donate.	onate. Make checks payable to Beyond Pink TEAM. (All donations are tax deductible)							
О	BPT Fund	☐ Advo	ocacy Fund		Area of Need	d 		

### **Touch of Courage . . . Connection**

Quarterly Newsletter of Beyond Pink TEAM

Cedar Valley Cancer Committee Dba Beyond Pink TEAM 3453 Kingswood Place Waterloo, IA 50701 www.beyondpinkteam.org