



Cedar Valley Cancer Committee

TOUCH OF COURAGE

CONNECTION NEWSLETTER

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LYMPHEDEMA AFTER BREAST CANCER

BY KATIE BOALDIN, PT, DPT

PHYSICAL THERAPIST, ROCK VALLEY PHYSICAL THERAPY

Lymphedema is the abnormal accumulation of lymphatic fluid in the body's tissues. It can occur when there has been trauma to the lymphatic system, such as surgery or radiation for breast cancer. These interventions can result in lymph nodes being removed or damaged, which decreases the ability for that area of the body to sufficiently transport fluid. After breast cancer treatment, lymphedema typically occurs in the involved arm, trunk, or breast. Symptoms may occur early on or may present a few months or even years later. Signs and symptoms of lymphedema include swelling in the affected area, skin tightness, a sensation of fullness, and/or tight clothing or jewelry.

Lymphedema is a condition that can worsen without treatment. Unfortunately, there is no cure. However, it can be managed successfully with collaboration between the patient and their medical team including the physician, therapist, and certified garment fitter. Treatment for lymphedema is called complete decongestive therapy and includes a combination of manual lymphatic drainage (a very gentle massage), compression, exercise, and skin care. The earlier treatment begins, the more successful the management may be. The primary goal of treating lymphedema is to first decrease the swelling and then learn strategies to keep it minimized.

A person at-risk for developing lymphedema should be aware of certain precautions:

- Avoid extreme heat or too much sun. Wear sunscreen to prevent sunburn.
- Avoid skin injuries on the involved side as this provides an opportunity for bacteria to enter.
 - Avoid injections, IVs, and blood draws in the involved arm.
 - Prevent bug bites.
 - Wear gloves when gardening to prevent unnecessary nicks, cuts, and scrapes.
 - Use an electric razor to shave in the underarm area.
- Avoid blood pressure checks in the affected arm.
- Avoid constrictive clothing or jewelry.
- Practice good skin care techniques including keeping skin clean and moist using an alcohol-free, fragrance-free lotion.
- Wear your compression garments while traveling, particularly long distances or on an airplane.

Lymphedema is a very manageable condition in which early detection and treatment leads to the best outcomes. The first step is education and awareness. If you think lymphedema is affecting you, please consult your physician or reach out to Katie Boaldin at Rock Valley Physical Therapy at (319) 233-6995.

IT WON'T HAPPEN TO ME - BUT IT DID

A SURVIVOR STORY BY CHERI NELSON

I am sure most people can relate with the phrase, "It won't happen to me." That was what I thought. I thought cancer is what other people get, not me. December 2020, I was diagnosed with squamous cell skin cancer. When I heard the word "cancer," everything went blank. I could not comprehend what the nurse was saying after that. Luckily, all I needed to do was to get the area cut out and keep a careful watch for any other marks that show up on my skin. My thought then was that I had my scare with cancer and there was no way I would get any other kind of cancer. December 2021, a year later, I was diagnosed with triple positive breast cancer. I first saw the results on MyChart. That day was the longest day waiting for the doctor to call me back. My son, his wife and daughter were all visiting. I spent the day pretending I wasn't worried or scared because I didn't want to ruin our day of fun.

After talking to the doctor later that evening, it really hit me. I had just started going back to school and signed up for a full load for the second semester. I didn't know what to expect. Would I be able to still keep a full load of classes, or would I have to cut back? Would I even be able to finish the semester? I didn't know what approach we were going to do so I didn't know how I would be feeling. It was the "not knowing" that was hardest for me. I wanted to know what was going to happen and how I was going to feel during this. After a lot of thinking I decided it would be best if I cut my class load in half.

After several doctor appointments, we finally came up with a plan. Since the tumor was over 2 cm, we started with chemo first. I was so scared to start chemo. I have watched too many movies where someone was fighting cancer and got really sick with chemo. My first appointment with chemo was very long but went pretty smoothly. I was able to Zoom my class time so I could still hear the lectures.

I had six rounds of chemo. I felt pretty good until after my fourth round. That one really wiped me out. I was very tired and didn't have any energy. I was not able to make it to school anymore but was able to stay connected with my instructors. I had great instructors that helped me finish my semester from home.

On June 10, 2022, I had a double mastectomy with reconstruction. The surgery went well, and I was feeling pretty good about things. Since I was done with chemo, I was started on a medicine called Kadcyla every 3 weeks. After the second dose, my eyesight started to get blurry. For the next 3 days my eyesight kept getting worse. I was able to get in with an eye doctor who told me that the medicine, Kadcyla, was causing this problem. There is only one other reported case of this happening with this medicine. Needless to say, we immediately stopped

that medicine and started a different one. I had to wait for the Kadcyla to work itself out and I slowly regained most of my eyesight back.

In November, I started radiation. I was starting to feel better and was able to have an exercise routine. Unfortunately, by Thanksgiving time, my health started to slowly decline. I was getting short of breath very easily. I would bring this up to all my doctors when I had appointments, but they would just tell me that I need to give it time. My health kept declining. I was so short of breath that I could no longer walk for more than a couple of minutes. My muscles were sore and getting weaker and my joints were hurting so bad. I had chronic fatigue and headaches all the time. My right breast had gotten hard. My hair was not growing back very well. I pushed my doctors to send me to a specialist. I went from one specialist to another, and no one could figure out what was wrong. I ended up seeing a pulmonologist, a cardiologist, and a neuromuscular specialist. They all ran all sorts of tests, but they could not figure out what was wrong. When I would get up and walk, my oxygen level would go down, but my lungs were fine. My heart, muscles, and nerves were all good also. Still, my health kept deteriorating. I did not think I was going to survive this.

I decided to try going to a breast cancer meeting. I was hoping that someone there might have gone through this same thing or at least have some advice. The women at this meeting were very compassionate and supportive. I knew these women were going to become important in my life. Unfortunately, no one there had gone through this, but they were all very helpful. They gave me different ideas to try. During one of our meetings, The Beyond Pink TEAM was brought up and the Pink Ribbon Run. I attended the run even though I could not participate. I loved watching all the people there. It was amazing how so many people came to one place for one reason....to support breast cancer. I decided I wanted to be part of The Beyond Pink TEAM. I didn't know what I would be able to do but I really wanted to be a part of this.

After reading Stacy Glascock's story in the beyond Pink TEAM January 2024 quarterly newsletter about "going flat" and breast implant illness, I made an appointment with my surgeon. I had all the symptoms of breast implant illness, and I figured it wouldn't hurt to ask my surgeon about it. After telling me I had a better chance of winning the lottery than having breast implant illness, he finally



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BPT VOLUNTEERS ARE RECOGNIZED

CONGRATULATIONS TO DONNA O'BRIEN – THE 2024 YWCA WOMEN OF PERSIMMON AWARD WINNER IN THE VOLUNTEER CATEGORY

Donna is the creator of Bambinos, The Stacked Cookie That Gives Back, and owner of Bambinos Bakery. While going through breast cancer treatment in 2007 here in Waterloo, Donna found baking to be very therapeutic. She developed the Bambino cookie, baking them in her home, with the help of family and friends, for the Beyond Pink TEAM events and special orders. She began shipping corporate orders to many parts of the country, donating her proceeds to the Beyond Pink TEAM.

Donna was fortunate to have a very supportive husband, family and friends during her difficult battle through her cancer treatment and multiple surgeries. At the cancer center, she realized that many others were not as fortunate as she, but they were getting support and financial assistance from the Beyond Pink TEAM. Donna's enthusiasm to give back was infectious and many wanted to share their baking talents to further Donna's mission to help BPT provide that financial support.

Besides being an entrepreneur, Donna is a philanthropist. She takes no proceeds from the business for herself, but generously gives her proceeds to the Beyond Pink TEAM. In 2023 she gifted \$23,000 to the Beyond Pink TEAM and she will not stop until she presents the BPT with a check for \$100,000.00. (In 2023, the Beyond Pink TEAM helped 110 individuals in Black Hawk and 13 surrounding counties with \$133,970.84 for medical and essential living expenses for those in breast cancer treatment.)

Congratulations, Donna! And thank you for all you do for the Beyond Pink TEAM!



CONGRATULATIONS TO NIKKI LADAGE – 2024 WINNER OF THE CEDAR VALLEY MAYORS' VOLUNTEER AWARD

Nikki Ladage is a busy wife and mother, a competitive athlete, and a dedicated John Deere employee. She has also, for the past five years, been the volunteer race director for the Beyond Pink TEAM Pink Ribbon Run – the nonprofit organization's largest fundraiser that brings more than 1,000 participants to downtown Cedar Falls and requires several months of preparation, from securing sponsorships to dealing with unpredictable weather for the outdoor event.

"Planning the Pink Ribbon Run takes countless hours of coordination, logistics, and energy. Fortunately for the Beyond Pink TEAM, Nikki is organized, enthusiastic, and an avid runner, making her an excellent person to guide this event," said Gabbi DeWitt, Beyond Pink TEAM member and a Pink Ribbon Run committee member.

Fundraising for and participation in the Pink Ribbon Run has increased each of the past five years (except for 2020 when it was virtual- but still raised over \$30,000). Most recently, the 2023 event had more than 1,200 participants and raised over \$71,000.

"The Beyond Pink TEAM would not be as visible or able to provide financial assistance during breast cancer treatment without the funds the Pink Ribbon Run raises for us," explains Dee Hughes, chair of the organization. "In 2023 we granted almost \$134,000.00 to 110 women and men in the Cedar Valley and northeast Iowa during their treatment. All of these funds are donations from our extremely generous community, with at least half coming from the Pink Ribbon Run. We are so grateful to the Pink Ribbon Run and Nikki's exceptional leadership."

Congratulations, Nikki! And thank you for all you do for the Beyond Pink TEAM especially the Pink Ribbon Run.



CONTINUED FROM PAGE 2

agreed that taking the implants out would be a good option for me. On March 22, 2024, I had my implants removed and went flat. I could instantly feel a difference after my surgery. My muscles and joints were not as achy, and I felt like I could breathe a little better. In 2 weeks, I

went from walking less than 1,000 steps a day to walking 6,000 steps. I was able to walk through the grocery store instead of riding the motorized cart. For the first time in the last 16 months, I felt hopeful and excited about life.

WHAT IS THE NBCC ANNUAL SUMMIT ALL ABOUT ANYWAY?

JOY THORSON, BPT MEMBER ADVOCATE AND SURVIVOR



That's what I was wondering for several years. I wasn't sure what the NBCC Summit was and if this national event held in Washington DC each May was something I was qualified to attend or how I could contribute. I just didn't understand.

I'd been invited to go in the past, but my insecurities held me back... until this year. In

February I read Barack Obama's quote, "Change will not come if we wait for some other person, or if we wait for some other time. We are the ones we've been waiting for. We are the change we seek." It was at that moment that I knew I needed to be an advocate for eliminating breast cancer. God has blessed me with fairly good health as I live with Metastatic Breast Cancer for the past seven years and He asked me to attend the NBCC Summit representing women who cannot represent themselves and for those who will be diagnosed in the future.

I still had some questions...

1. What is "NBCC" (National Breast Cancer Coalition)?

NBCC is a national organization that has been in existence for over 30 years and "combines the power of advocacy, education, policy, and research to unite around one goal: **ending breast cancer.**"

~ Well, I can get onboard with that!

2. What does it mean to be an ADVOCATE?

An advocate is someone who supports, defends, or pleads on behalf of others. Regarding NBCC, an advocate is someone who asks and pleads for

continued research in the prevention and elimination of breast cancer. Making sure that in the meantime there is all kinds of assistance for women dealing with breast cancer.

~ Hmm, that's something I am passionate about!

3. What is the NBCC Summit?

NBCC's Summit is an annual gathering of breast cancer advocates from across the country. People who want to make a difference. Participants attend sessions given by researchers in the field and prominent public policy experts regarding the latest scientific research and learn how to be an effective advocate. All given in language anyone can understand.

~ It will empower me to become a convincing advocate for the elimination of breast cancer. Count me in!

You might be asking, "What did you learn?"

~ I learned so much about the science and research surrounding breast cancer. I couldn't learn everything, but I now know way more than I did before!

~ I learned skills helping me feel confident in meeting with politicians (or their aides) on Capitol Hill when I'm passionate about a cause. And I learned that I'm not doing this alone...we are an amazing army of women who want to end breast cancer.

This was my first-year attending. Will next year be your year? **JOIN ME!** What are YOUR questions? Please ask me at jthorson@cfu.net

I'd love to visit with you!



WHAT IS THE NATIONAL BREAST CANCER COALITION (NBCC)

Founded in 1991, NBCC is a collaboration of activists, survivors, researchers, policymakers, grassroots groups, and national organizations that have come together as disruptive innovators for social change with a mission to end breast cancer. Breast cancer patients and those at risk of getting the disease must lead and participate in all decision-making affecting breast cancer research, health care, and public policy. NBCC's comprehensive breast cancer education and training programs equip these advocates, survivors, and others

affected by breast cancer with the knowledge they need to confidently participate in their health care, help set scientific priorities, inform research protocols, review science for relevance and merit, and communicate accurate and accessible information to the public.

NBCC's programs such as the Project LEAD Institute® are considered the highest-quality education and training programs available and serve as models for patient advocacy organizations worldwide.

REPORT FROM THE 2024 NATIONAL BREAST CANCER COALITION'S SUMMIT

CHRISTINE CARPENTER, BPT ADVOCATE AND MEMBER

In May, six members of the Beyond Pink TEAM joined other breast cancer advocates from around the country in Washington, DC, for the National Breast Cancer Coalition (NBCC) Leadership Summit. They learned the latest in research and science about the disease. A few of the topics covered included: Drug Cost, Value, and Accessibility – Policy Levers for Advancing Equitable-Quality Care in Oncology; Patient-Centered Oncology Research-Designing Research to Answer Questions About Outcomes that Matter for Patients; Patient-Centered Oncology Research; and Election 2024: What Impact Will Women and Healthcare Have?

After three days of extensive training at the National Breast Cancer Coalition's Summit, members of the Beyond Pink TEAM used their strengthened political advocacy skills to lobby Iowa's Rep. Ashley Hinson (R-1st District), Rep. Mariannette Miller-Meeks (R-2nd District), Rep. Zach Nunn (R-3rd District), Rep. Randy Feenstra (R-4th District), Sen. Charles "Chuck" Grassley (R-Iowa), and Sen. Joni Ernst (R-Iowa) on the National Breast Cancer Coalition's 2024 legislative priorities.

"We held meetings on Capitol Hill to discuss breast cancer public policy issues with our members of Congress and we urged them to support the NBCC agenda," stated Lori Seawel from the Beyond Pink TEAM.

Key priorities covered include 1) \$150 million/Level Funding for the Department Defense (DOD) Breast Cancer Research Program (BCRP) for FY2025. As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 to end breast cancer for Service Members, Veterans, and the general public by funding innovative, high-impact research through a partnership of scientists and consumers. The DOD BCRP is widely

viewed as an innovative, unique, and efficient medical research model which has proven to be accountable to the public and has produced extraordinary results. NBCC seeks continued level funding. And 2) Metastatic Breast Cancer Access to Care Act - this legislation would waive the 24-month waiting period for Medicare and the five-month waiting period for Social Security Disability Insurance benefits for eligible individuals with Metastatic Breast Cancer.

Just a few of the ideas BPT advocates have brought from the NBCC Summit to the Cedar Valley include the Beyond Pink Fund, cutting edge cancer researchers, social-emotional health during cancer, and a website for those with cancer and their loved ones, with expert advice entitled The Cancer Journey.

Start thinking now about joining Beyond Pink TEAM advocates at the May 3-6, 2025, NBCC Leadership Summit. You can help end this disease.



COPING WITH YOUR FEELINGS

FROM NCI – NATIONAL CANCER INSTITUTE

You may have just learned that you have cancer. Or you may be in treatment, finishing treatment, or have a friend or family member with cancer. Having cancer changes your life and the lives of those around you. The symptoms and side effects of the disease and its treatment may cause certain physical changes, but they can also affect the way you feel and how you live.

It is important to know that everything you are feeling is ok. Here is a resource you may find helpful:



National Cancer Institute's Coping with Cancer- cancer.gov/about-cancer/coping

This website offers topics including managing emotions, sex and sexuality, adjusting to life after a diagnosis, questions to ask your doctor, and more.



LACE UP FOR THE 18TH ANNUAL PINK RIBBON RUN



On Saturday, October 5th, downtown Cedar Falls will be hosting the 18th Annual Pink Ribbon Run. We are excited to share our Warrior Sponsors (\$5,000 and up) for this year. GreenState Credit Union, Oakridge Real Estate, both presenting sponsors, Community Auto Group, the Survivor Sponsor, and Bambino's. These sponsorships cover survivor registrations, race costs, etc. allowing all money raised from the race to go back to The Beyond Pink TEAM.

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.

Follow us on Facebook – Pink Ribbon Run/Walk-Cedar Falls Downtown District for updates and more information.

Major Pink Ribbon Run Dates:

August 1st - Online registrations will open – The link will be shared at www.beyondpinkteam.org.

September 15th – Registration deadline to be guaranteed a t-shirt and registration price goes up!

October 4th – Packet Pick up – 3:00-7:00 pm, Community Main Street Office, 310 4th Street, Cedar Falls

October 5th – Packet Pick up – 6:30-7:30 am, Community Main Street Office, 310 4th Street, Cedar Falls

October 5th – Pre-race survivor photo at 8:00 a.m., with the run starting at 8:30 a.m. All pre-race activities including pre-race announcements will be at the River Plaza, 200 E 2nd Street, Cedar Falls.



PESTICIDE BE GONE

BRITTANY LATCH, GOOD NEIGHBOR IOWA PROGRAM MANAGER

It is that time of year when signs begin showing up in yards stating weed killers were recently sprayed. However, did you know that those chemicals are dangerous to children, pets, pollinators, and water quality? Pesticide exposure has been associated with childhood cancers, neurodevelopmental delays, chronic illnesses, and behavioral disorders per the American Academy of Pediatrics report, Pesticide Exposure in Children. Your furry friends are at risk, too. Research shows there are higher rates of bladder and testicular cancers in dogs due to herbicide-treated yards, as well as an increased risk of developing mammary cancer or lymphomas. Unfortunately, due to pesticide drift, dogs can play on an untreated lawn and still be exposed.

NOTE:

Good Neighbor Iowa, a statewide public health education initiative, at UNI's Center for Energy & Environmental

Education, urges everyone to manage their grounds naturally for the sake of all species. For more information go to goodneighboriowa.org or call 319-273-7150.



DONATIONS

Donations, Memorials, and Fundraiser monies received from March 1, 2024 through May 31, 2024.

Anne Barloon
Bunger Family Foundation
Jeff Cooks
Pat Homeister

Marty Mullinx
Kate Paredes
PEO Chapter OG



FUNDRAISERS

UNI Volleyball
Waterloo Firefighters IAFF Local #68



THANK YOU

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

Memorials and Honorariums

In Memory of Judy Scatturo
by Debra Burger

In Memory of Diana Pollaratty
by Trish Pedersen

SURVIVORSHIP 101 COURSE

SPONSORED BY UNITYPOINT HEALTH ALLEN HOSPITAL, WATERLOO COMMUNITY CANCER CENTER

Beginning September 9, 2024, the FREE 9-week Survivorship 101 course will be held for cancer survivors and their caregivers. This course provides practical guidance for your next steps, including research-based advice on topics like nutrition, exercise, intimacy and reducing anxiety.

Survivors of any type of cancer are welcome to register. To get more information or to be added to the contact list for future offerings, please contact Mary Kobliska, Social Worker, Allen Hospital Community Cancer Center at 319-236-4721.

DATES TO REMEMBER JULY - OCTOBER 2024

July 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 more info

July 2, 1:30 pm

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

August 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 more info

August 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

September 3, 1:30 pm

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

September 9, 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 more info

September 17, 5:00-7:00

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

October 7, 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 more 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

 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.

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

The Cancer Journey 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
- Become part of the Breast Cancer Advocacy Network
- Volunteering: (check all that apply)
 - Assist with Support Groups
 - Development (Publicity)
 - Events (Fundraisers, Projects and More)
- Donate. Make checks payable to Beyond Pink TEAM. (All donations are tax deductible)
 - BPT Fund
 - Advocacy Fund
 - 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