Welcome to the Breast Cancer Coalition, now in our TWENTY-FIFTH YEAR!

Whether you are new to our organization or have been a longtime participant in any of our programs, utilized our services, served on one of our committees, or volunteered, we are always delighted to welcome you to the Coalition. If you have not connected with us, PLEASE DO.

Every one of us at the Coalition strives to meet your short and long-term survivorship goals. Many of the programs and services available in the community were pioneered by us and tested by you, our survivor community. SURVIVORS. THRIVERS. Surviving and thriving. The Coalition was the very first to offer a variety of survivorship-focused programs in our region. Our commitment to you is unparalleled. Just a few of our hallmark programs:

• Educational Seminars (since 2000)
• Breast Cancer 101 (since 2001)
• Brown Bag Friday (since 2002)
• Peer Advocates Lending Support (PALS) (since 2002)
• Common Ground: Living with Advanced Breast or Gynecologic Cancer (since 2002)
• Variety of Networking Groups: Weekly and Monthly (since 2004)
• Gentle Yoga (since 2005)
• Quickly followed by Qi Gong, Tai Chi, Mindfulness and other Healing Arts offerings
• Young Survivor Gatherings (since 2006)
• Gynecologic Cancer 101 (since 2014)
• Surviving & Thriving on Aromatase Inhibitors (since 2015)
• Sisters of Color (*NEW* this year!)

Have you yet to participate in any of these programs, or others? (See pages 12-13 for more information.)

We develop our offerings after completing a community assessment of what’s already offered (and going well) in our community so we aren’t unnecessarily duplicating services. All of our programs are evidence-based and survivor-informed. What does this mean, exactly? After carefully reviewing well-designed studies and considering the values and desires of the survivors we serve, and prior to launching any new program, we conduct focus groups. These are held in the morning, afternoon, evenings, and on weekends to maximize input from the broadest population. Our latest focus groups allowed us to connect in depth with those who’ve faced gynecologic cancer. Thanks to a generous funder, we received means to expand our offerings to this historically underserved group. Stay tuned to hear about what the individuals at these focus groups taught us and where we’ll go from here.

We have always prioritized collaboration over competition. The leaders of area nonprofit cancer organizations frequently talk to each other and often meet in person to share ideas, experiences, and expertise. We make every effort to keep each other informed as we prepare to launch new programs. This collaboration is important as we at the Coalition strive to serve our breast and gynecologic cancer survivor community.

Providing opportunities for survivors to network with each other is a top priority. The Coalition is the ideal place to meet others and forge meaningful, often long-lasting relationships. We know what is needed because we ask you what is needed.

What are you waiting for? Join us!
A PERSONAL JOURNEY: RACHEL S., EMERGING LEADER

Turning Pain To Purpose: THE MAKING OF AN ADVOCATE

In January of 2020, I was in the middle of a meeting at work when a phone call came that shifted the axis of my world. I had been diagnosed with breast cancer. About a month earlier, my boyfriend, Michael, had found a lump in my breast. At my mammogram, I alerted the technician about it and she took specific images of the area. This led to a biopsy, which led to an MRI that showed a clearer picture – and a second tumor. I was terrified, but I didn’t let my terror make me freeze – I jumped into action. After calling Michael, I called my OB-GYN, who was out of town that week. I learned they only refer to one surgeon, and patients are generally happy with him. I also spoke with a number of friends who had already gone through a breast cancer diagnosis, surgery, and treatment. Three of them recommended a specific surgeon, so I scheduled a second opinion with her.

The first surgeon strongly advised a bilateral mastectomy (removal of both breasts) with implant reconstruction. I have allergies and sensitivities to many things and knew my body would not do well with implants. A couple of weeks later, we met with the second surgeon and her team. We were presented with options and asked about quality of life scenarios to determine a plan of action. She also explained possible treatment options and made it clear that things could change once we had the pathology report after surgery. I chose her and was assigned medical and radiology oncologists. Then I was asked if those physicians were okay. I just wanted the best people for the job and, in hindsight, I got them!

I had a partial mastectomy, which removes more tissue than a lumpectomy but leaves most of the breast intact. This was on March 10, 2020, a few days before the COVID shutdown and it was the last time Michael was able to be with me for an appointment. Unfortunately, we did not get clean margins, meaning cancer was found at the edges of the tissue that was removed. A re-excision surgery would be needed; I had been told this was a possibility. The re-excision was somehow considered elective, and I was not able to schedule it. I met with my medical oncologist by Zoom to discuss options for moving forward during his time of uncertainty. We decided that I would start taking an aromatase inhibitor along with Lupron injections; this combination would suppress the estrogen that had been feeding my tumors.

On May 4, I learned that the hospital was opening to elective surgeries again and I called my surgeon’s office. Two days later, I had my re-excision, and this time we got clean margins. This surgery was different, though. Michael dropped me off at an abandoned-looking hospital at 5 AM. The lobby and hallways...
Merriam-Webster defines a support group “...as a group of people with common experiences and concerns who provide emotional and moral support for one another.” Some research shows that participating in a support group improves quality of life. And it may even improve survival.* Connecting with others who “get it” in a safe, confidential group setting can help participants combat isolation, identify and work through difficult emotions, find solutions to practical problems, and learn strategies to help them cope with the challenges they face.

At the Coalition, our groups go beyond that dictionary definition to encompass much more, and we add the term “networking.” We encourage and empower our group participants to connect with one another during meetings and any time they need a listening ear. We know that it takes a village to see any individual from their cancer diagnosis through treatment and beyond, and our groups provide opportunities to build support networks among individuals who have “been there;” whose shared experiences can provide inspiration, insight, and encouragement.

The Coalition stands solidly on four pillars: Advocacy, Education, Research, and Support. It may seem that our support/networking groups rest squarely and solely on the support pillar, but in practice, they touch all four.

**SUPPORT**

Group attendees exchange informed sympathy and true empathy; through shared experience, they are able and willing to put themselves in another’s place. The caring and understanding exchanged is freely given and sincerely meant. All emotions are encouraged to be expressed — the good, the bad, and the ugly — which results in feelings of validation and being ‘heard’. Group participation provides a healthy outlet for honesty, struggle, and humor. Sometimes a good laugh is just what’s needed to lighten the load a bit and allow a pause for a deep, cleansing breath.

“In our support group setting,” shares Theo, “I sense the relief when participants recognize, ‘You felt that way TOO? I’m not going crazy?!’ And we can see the special bond when a few are having very similar experiences, whether they be medical or cultural or something to do with their families. We also celebrate how unique each person is and how much they deserve to be treated as individuals.”

It can be complicated to speak with family and friends about treatment details and feelings that accompany a life-threatening disease. Whether a group meets in a physical or virtual room, participants can let their guard down, sometimes even figuring out in the safety of the group how to talk with their families, friends, colleagues, casual contacts, and health care providers.

Our group attendees understand that cancer affects the whole family, and are sympathetic to that. They also listen to each other’s dilemmas that are not cancer-related. Understanding that having cancer doesn’t protect a person from other adversities (such as other serious illnesses in their families or themselves, car accidents, or financial concerns), we can and do talk about anything: sex, death, money, and more. What happens in the political arena, not so much — unless the discussion turns to...

**ADVOCACY**

Advocacy happens on many levels. People diagnosed with cancer advocate for themselves when they honor their interdependence with others. Connecting with those who extend a helping hand and supportive listening ear along the way can help in a myriad of ways. The flip side of this coin is that longer-term survivors...
in groups become advocates for the newly diagnosed.

Some group participants have joined in the Coalition’s advocacy efforts at the local, state, and national levels. Legislation to reduce exposures to environmental chemicals that are known or suspected to cause cancer is a priority. Funding for research into the causes of and primary prevention for breast and gynecologic cancers is an ongoing need. And more timely disability coverage for those with metastatic disease is also on the Congressional table – for the fourth year in a row. Enough! We demand change!

EDUCATION

Access to up-to-date, evidence-based information is essential for those diagnosed with cancer and their supporters. At the Coalition, we strive to keep our survivor community empowered with the latest, evidence-based information. Well-informed survivors sharing their experiences at group meetings are in a perfect position to pass valuable information to their more recently diagnosed peers while offering support and reassurance.

During support/networking groups, a great deal of information is exchanged. Not only do participants share a multitude of treatment details, they talk about complementary therapies that helped (or didn’t) and other comfort measures. They will “go there” about the annoyances of tiny veins, constipation, neuropathy care, itching, diet, vitamins, and side effects. We hear questions like: “What is really known about occasional alcohol use?” “Who is willing to talk about treatment for depression and anxiety?” “What are the best websites to consult?” “Where can I get more information about a plant-based diet?” And so on. Survivors are a wealth of information, and their input drives our educational programming.

RESEARCH

Cancer survivors have much at stake in the research process, and many group participants are participating – or have participated – in research studies at their treatment centers. Some have even traveled to institutions far from home to explore clinical trials for which they qualify. The newest treatments bring hope. It’s also meaningful to be pioneers, advancing scientific inquiry so that more people will experience the benefits of a new approach to treatment. A few have become active on the Coalition’s Research Committee to lend their voices as survivors to the process of awarding research grants.

A SENSE OF BELONGING

A support group is a democratic phenomenon. With a facilitator present to watch over the conversation, the time, and the group guidelines, it is important to remember that person is “on tap, not on top.” It is the participants who are invaluable; those who bring their questions, fears, triumphs, and challenges to the table. Sometimes it is the quietest person present, or an otherwise unlikely contributor, who will have just the perfect thing to say in the moment.

Drawing on her deep and longtime experience in grief work, Theo shares her favorite quote: "When it comes to grief, all people are like all others, like some others and like no others.” The same is true for support group attendees, who experience a mix of raw emotions, including grief.

For those who say “a support group isn’t for me,” we ask you to consider it again. And come in just a couple of times to check the process out. You may be surprised at the sense of belonging you feel.

https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/support-groups

" A support group is a democratic phenomenon. With a facilitator present to watch over the conversation, the time, and the group guidelines... It is the participants who are invaluable; those who bring their questions, fears, triumphs, and challenges to the table."
It’s quite a thing to believe that you are at the end of a hard journey only to discover you are at the beginning of an even harder one. By December of 2022, I had made it through an acrimonious divorce, an extended period of couch surfing, a stage 3 breast cancer diagnosis, a year of cancer treatment during COVID, getting COVID myself during that terrifying first wave in NYC and then giving it to my beloved partner, and grappling with the emotional aftermath that many cancer survivors face once their treatment has ended. In my case, I fell into a deep depression that took nearly a year to crawl out of.

When I went for my second annual PET scan in December of 2022, I was feeling good. Sure, I had some ‘scanxiety’ and some side effects from the aromatase inhibitors that had been prescribed to reduce the amount of estrogen in my body. But overall, I felt amazing physically. I had started running again, was weightlifting, and was dropping weight without even trying. My chemo brain fog was starting to clear, and I felt able to contribute at work in ways that were hard during and immediately after my treatment.

Then, the day after my scan, my oncologist called. As soon as I saw his number flash across my phone, I knew the news wasn’t good. “We’ve found a large area of concern,” he said. “I’m going to schedule you for a CT scan and blood work.” The month that followed was a whirlwind of appointments and diagnostic tests, ultimately resulting in what was supposed to be laparoscopic surgery to determine whether a growth on my ovary was ovarian cancer or metastasized breast cancer. My gynecologic surgeon said, “I hope it’s breast cancer because you’ll have more treatment options.” And my breast oncologist told me, “I hope it’s ovarian cancer because that way you might have the possibility of being cured.” I didn’t know what to hope for except that maybe this was all a bad dream and I would soon wake up.

Instead, I woke up from surgery and learned that the tumors on both ovaries were so large, it took a c-section to remove them. Three days later, I boarded a plane for a previously scheduled trip to visit my partner’s mom for the holidays. It was there, walking in the Arizona desert, that I learned I had metastatic breast cancer (MBC).

Continued on next page.
In the weeks that followed, I felt okay. I rallied my community, who immediately jumped into action to make sure I had accompaniment on every medical visit. I dove into taking care of all my estate and financial planning. I researched as much as I could about my condition and my treatment. I joined support groups, including Common Ground at the Coalition since - even though I live in New York City - I had a longstanding connection to the organization and to Holly Anderson. I was in action mode and focused on my death, which seemed imminent. When I finally slowed down, feelings of fear, sadness, and anger set in.

Now four months into this diagnosis, I am more focused on living with MBC, and I am learning (and struggling) to manage the uncertainty that such a diagnosis brings. I am unbelievably fortunate in almost every way: I have a loving and supportive partner, an amazing community of friends, solid health insurance, and a job that is meaningful and willing to accommodate me as I struggle with fatigue and other treatment side effects. I belong to a spiritual community that has offered support and guidance. I am tolerating my first line of treatment well overall and am able to stay active. And I have found real community and support and among other people living with MBC. I have seen how they have learned to live, even with varying degrees of health and illness. The folks I have met walking with the burden of a terminal illness like MBC are brave – not because they are fighting a battle they never asked for, but because they are living in authenticity and vulnerability. They are willing to examine death and in doing so, find ways to even more deeply embrace life and each other. I continue to be on a journey I would not have chosen for myself or anyone, but I am on it with a community of friends and with people who are teaching me that in facing our mortality, we can become more fully alive.

Save The Date!

THE 20TH ANNUAL CINDY L. DERTINGER ADVANCED BREAST CANCER SEMINAR

Tools for the Journey

LIVING WITH METASTATIC BREAST CANCER

FRIDAY, OCTOBER 13, 2023
1:00 - 5:00PM

CARE PROVIDER SPEAKERS:

- Jennifer Serventi, PA, URMC Wilmot Cancer Center, “Advance Planning Continuum: Starting the Conversation”
- Amy Bodrog, MD, Rochester Regional Health, “Medical Oncology Updates in the Treatment of Advanced Breast Cancer”

SURVIVOR SPEAKERS:

- Lori M
- Jules N

Learn more and register today:
www.BreastCancerCoalition.org/advanced-breast-cancer-seminar/
Endometrial cancer – cancer of the lining of the uterus – is the most commonly diagnosed gynecologic cancer. It is also the most common form of uterine cancer, a disease found in more than 65,000 women in the United States in 2022.¹ (Uterine sarcoma, another type of uterine cancer, is much less common and is treated differently than endometrial cancer.²)

**STAGES OF ENDOMETRIAL CANCER**

For those diagnosed with endometrial cancer, individual treatment considerations will vary depending on the stage of the disease — whether it is only in the endometrium or has spread to other parts of the uterus, the pelvis, or the body.⁴

<table>
<thead>
<tr>
<th>STAGE I</th>
<th>STAGE II</th>
<th>STAGE III</th>
<th>STAGE IV</th>
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<tbody>
<tr>
<td>The cancer is in the uterus only. It is divided into stages IA and IB, based on how far the disease has spread within the inner and outer lining of the uterus.</td>
<td>The cancer has spread to the cervix, but not outside the uterus.</td>
<td>The cancer has spread beyond the uterus and cervix, but not beyond the pelvis. It is further divided into stages IIIA, IIIB, and IIIC, depending on how far the disease has spread.</td>
<td>The cancer has spread to other parts of the body (metastatic disease). It is divided into stages IVA and IVB, based on how far the disease has spread.⁵</td>
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For many, surgery alone is enough to treat their endometrial cancer. If additional treatment is needed, it is likely to include one or more of the following: radiation, chemotherapy, hormonal therapy, targeted therapy, or in some cases, immunotherapy.

**YOU’RE NOT ALONE**

If you have been diagnosed with endometrial cancer – or ANY gynecologic cancer – connecting with others who have faced a similar scenario can offer a sense of connection and community while enhancing your circle of support immeasurably. Call us. We’re here for you!

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¹ seer.cancer.gov/statfacts/html/corp.html  
² www.cancer.gov/types/uterine/research  
³ my.clevelandclinic.org/health/diseases/16409-uterine-cancer  
⁴ www.hopkinsmedicine.org/health/conditions-and-diseases/endometrial-cancer  
⁵ www.cancer.gov/publications/dictionaries/cancer-terms
Immunotherapy in Advanced Endometrial Cancer

A RECENT TRIAL WITH A LOCAL CONNECTION

By Pat Battaglia

According to the results of a recently completed clinical trial, adding pembrolizumab to chemotherapy improved progression-free survival in patients with advanced or recurrent endometrial cancer.¹ The study’s authors include a name familiar to us at the Coalition: Richard Moore, M.D., Director of the Gynecologic Oncology Division at the University of Rochester. Pembrolizumab (brand name Keytruda) is a type of immunotherapy; an immune checkpoint inhibitor, which blocks certain proteins that prevent the immune system from recognizing and killing cancer cells. It has been used to treat a variety of malignancies, including certain forms of breast and gynecologic cancer.

In this double-blind, placebo-controlled, randomized, phase 3 trial, a racially diverse population of 816 patients with stage III or IV endometrial cancer were assigned in a 1:1 ratio to receive either pembrolizumab or placebo along with their standard-of-care chemotherapy regimen. These patients were further divided into two cohorts according to whether they had mismatch-repair-deficient (dMMR) disease or mismatch repair proficient (pMMR) disease.²

DNA mismatch repair deficiency is detected through testing of tumor samples, and is associated with an increased risk of developing several types of cancer. It is the most common cause of hereditary endometrial cancer. About 20-30% of endometrial malignancies are discovered to be mismatch repair deficient.³

Dr. Moore and the team of researchers found that adding pembrolizumab to standard chemotherapy, followed by maintenance with pembrolizumab alone, resulted in a 70% lower risk of disease progression or death in the dMMR cohort and a 46% lower risk in the pMMR cohort, as compared with those who received the placebo.

Pembrolizumab is currently approved for certain patients with advanced endometrial cancer that has progressed after other treatments. The most recent data suggest that incorporating pembrolizumab into first-line therapy for those with advanced or recurrent endometrial cancer may significantly improve their outcomes.

With a list price in the tens of thousands of dollars per month of treatment (varying according to the treatment schedule)⁴, the cost of pembrolizumab therapy could potentially be a factor for many. Even those who are insured may find their out-of-pocket costs to be high, depending on the type of coverage they have. For those in whom pembrolizumab is a treatment consideration, speaking with your insurance carrier may be a good first step. When copay assistance or other financial support is needed, an oncology social worker, financial counselor, or other patient advocate can connect patients with programs to help make their treatment affordable.

Pembrolizumab and other immunotherapies are becoming increasingly important tools in the continually evolving landscape of cancer treatment. Dr. Moore and the team of researchers who contributed to this recent study have opened the door to another first-line treatment option that may soon be available for those with stage III or IV endometrial cancer.

². www.ncbi.nlm.nih.gov/pmc/articles/PMC8268938/
⁴. www.keytruda.com/financial-support/
The Coalition’s Advocacy Committee meets monthly as a whole, while smaller groups meet in addition to strategize on different pieces of legislation or to build and sustain relationships with our legislators.

The committee is dedicated to moving a critical piece of legislation for New York State residents: S4265/A6969, which provides for the regulation of ingredients in personal care products and cosmetics. The bill has gained momentum in the New York State Senate and was introduced into the New York State Assembly by Assemblymember Deborah J. Glick of the 66th District, located in southwestern Manhattan. Co-sponsors include Jen Lunsford of the 135th District (east and south of Rochester); Linda Rosenthal of the 67th district (also in southwest Manhattan); William Colton of District 47 (in Brooklyn); and Phil Steck of District 110 (in the Schenectady/Albany area).

Our conscientious Advocacy committee members are continually expanding their knowledge of the effects of endocrine disrupting chemicals in humans. Research has repeatedly found links to the increases of numerous illnesses, including breast cancer, to these chemicals found in many personal care products and cosmetics. S4265/A6969 would place the timeframes during which designated chemicals are to be removed from all personal care products and cosmetics. Our committee members collaborate with different groups that also believe in removing these chemicals. These collaborators include the Finger Lakes Children’s Environmental Health Center, Breast Cancer Prevention Partners, and Clean and Healthy New York.

For more information about this legislation or ways you can be involved, please contact the Breast Cancer Coalition.

Christina Thompson, Advocacy Chairperson, Associate Director

Be an agent of change for our community – join the Advocacy Committee!

For information about our Advocacy Committee, contact Christina at the Coalition:

(585) 473-8177
info@bccr.org

Elected Officials Representing the 27-County Region We Serve

**UNITED STATES SENATE**
Kirsten Gillibrand
Charles Schumer

**UNITED STATES HOUSE OF REPRESENTATIVES**
19th district: Marc Molinaro
21st district: Elise Stefanik
22nd district: Brandon Williams
23rd district: Nick Langworthy
24th district: Claudia Tenney
25th district: Joe Morelle
26th district: Brian Higgins

**NEW YORK STATE SENATE**
54th district: Pam Helming
55th district: Samra Brouk
56th district: Jeremy Cooney
57th district: George Borrello
58th district: Tom O’Mara
60th district: Patrick Gallivan
62nd district: Rob Ort

**NEW YORK STATE ASSEMBLY**
130th district: Brian Manktelow
131st district: Jeff Gallahan
132nd district: Phil Palmesano
133rd district: Marjorie Byrnes
134th district: Josh Jensen
135th district: Jen Lunsford
136th district: Sarah Clark
137th district: Demond Meeks
138th district: Harry Bronson
139th district: Stephen Hawley

Whether you live inside or outside our region, you can find your elected officials, including their contact information, through the League of Women Voters: [www.lwv.org/take-action/find-your-elected-officials](http://www.lwv.org/take-action/find-your-elected-officials).
As a first-time participant at the Advocacy Leadership Summit held in Washington D.C. last May sponsored by the National Breast Cancer Coalition (NBCC)*, I've learned that breast cancer research, ending breast cancer, and access to care for all are primary goals of the organization. As a new breast cancer advocate, I've found that understanding genetics, etiology, and epidemiology of breast cancer are important. Moreover breast cancer research, as well as access to quality care including all populations, are of vital importance. This became clearer after hearing the session on Ancestry, Gene Expression, and Disparities in Breast Cancer: What this Means for Diversity in Clinical Trials, presented by Melissa Davis, PhD, of Weill Cornell Medicine and Monique Gary, DO, MSc, FACS, of the Grand View Health/Penn Cancer Network.

I have discovered that understanding genetics among all populations, including race and ethnicity, is essential in terms of providing best practices in testing, risk assessment and treatment options for patients. This work, in turn, can help educate the community about the importance of diversity in clinical trials and provide solutions that will help reduce inequities and correct disparities in breast cancer research.

Dr. Davis discussed in detail the importance of ancestry as a tool in understanding the behavior of breast cancer. She pointed out that studies have begun to identify differences in gene expression between those of African ancestry and European ancestry, and that origin is an area to pay attention to.

I have discovered that understanding genetics among all populations, including race and ethnicity, is essential in terms of providing best practices in testing, risk assessment and treatment options for patients. This work, in turn, can help educate the community about the importance of diversity in clinical trials and provide solutions that will help reduce inequities and correct disparities in breast cancer research.

Genome Wide Association Studies (GWAS) have been conducted. However, she acknowledged that these studies involved a larger percentage of people coming from European ancestry. This motivated Dr. Davis to partner with investigators to look more closely at why greater numbers of African American Women were dying of triple negative breast cancer (TNBC) compared to women of European descent. This included her collaboration with John’s Hopkins Director of Cancer Disparities, Dr. Clayton Yates, PhD, MS.

Dr. Davis and her team analyzed data in the Cancer Genome Atlas. They found cases in which African American women who had TNBC also had androgen receptor negative pathologies and termed this subset “quadruple negative.” These have distinctive signaling pathways and contribute to early onset breast cancer. Further investigations identified additional biological differences in women with African American ancestries compared to other groups. On a global scale, Dr. Davis learned that in countries where self-reporting took place, the African component had shown the highest rate of TNBC. Thus, we see the absolute need to include this population in studies in order to understand cancer behavior better. Fortunately, there is a growing body of data designed to examine this further in order to be clinically meaningful in trial recruitment and understanding how drugs are metabolized, as well as recommending medical therapies.

I will continue to work with NBCC’s educators as part of Project LEAD this summer. This is a six-day course designed to train breast cancer advocates in the science of breast cancer research. As a member of the Coalition’s Research Committee together with the education received though Project LEAD, I look forward to working with medical experts, scientists, and fellow advocates to help design breast cancer research focused on ending breast cancer and improving the lives of all.

*Despite the similarity in our names, the Breast Cancer Coalition is an independent, local organization unaffiliated with any national group, including NBCC. We choose to support NBCC’s public policy agenda because their goal is our goal: doing all we can to END breast cancer. We join hundreds of other grassroots, independent, community-based organizations in doing so because TOGETHER, we are stronger.
Our evidence-based Healing Arts Initiative is offered in block series of 4 - 6 weeks throughout the year. Call or email us today if you are interested in learning more about these beneficial offerings.

**Breast or GYN Cancer 101 & 201**

These are one-to-one sessions to assist newly diagnosed individuals in managing the complex tasks and emotions of a breast or gynecologic cancer diagnosis. We empower individuals to be self-advocates as they proceed through treatment, recovery, and survivorship. Our professional facilitators provide a safe, comfortable atmosphere where information can be absorbed and assimilated while the individual formulates a personal strategy for making informed decisions. Also valuable for a gynecologic or breast cancer survivor at any stage of their journey.

*Contact us for an appointment.*

**PALS Project**

In this peer mentoring program, individual breast and gynecologic cancer survivors reach out to those who are more recently diagnosed, providing the reassurance of one-to-one contact with someone who’s “been there,” helping them connect with needed resources, and instilling confidence during a difficult time.

*Call today to learn how to join the program and be paired with a mentor who has been there, or if you would like to become involved as a mentor.*

**HEALING ARTS INITIATIVE**

Our evidence-based Healing Arts Initiative is offered in block series of 4 - 6 weeks throughout the year. Call or email us today if you are interested in learning more about these beneficial offerings.

**Gentle Yoga**

Gentle Yoga includes breathing exercises, restorative yoga postures, and mindfulness exercises with the goal to relax, be mindful, and improve range of motion and flexibility. Classes are 1 hour and 15 minutes. Offered throughout the year on:
- Mondays at 10:00am with Susan
- Mondays at 5:30pm with Susan
- Tuesdays at 10:00am with Susan (IN PERSON)
- Tuesdays at 4:00pm with Susan
- Saturdays at 9:00am with Raksha
- Sundays at 10:00am with Sunni

**Qi Gong**

A traditional Chinese practice combining meditation, controlled breathing, and movement to balance the flow of energy (qi) within your body. The goal is to improve overall health, combat stress, and promote healing. Classes are 1 hour and 15 minutes.

Upcoming sessions begin (IN PERSON):
- Saturday, August 5 at 10:00am with Raphaela

**Tai Chi**

An ancient martial art that consists of a series of small, specific movements combined with deep, relaxation breathing. Tai Chi’s goal is to improve your ability to relax and de-stress, and has other benefits such as decreasing falls in the elderly and reducing arthritis. Classes are 1 hour and 15 minutes.

Upcoming session begins (IN PERSON):
- Saturday, October 28 (time TBD) with Jean

**Mindfulness & Meditation**

Connect with your mind and breath to bring calm to self with a goal to improve your ability to relax, concentrate, and be in the present moment. Classes are 1 hour and 15 minutes.

Upcoming sessions begin (VIRTUAL):
- Wednesday, July 12 at 6:00pm with Rick
- Wednesday, September 13 at 6:00pm with Rick
- Saturday, October 7 at 10:00am with Debra

**Movement & Motion**

Movements are designed to improve range of motion, balance, endurance, and strength. Benefits include increased lymphatic flow and decreased lymphatic swelling.

Upcoming sessions begin (IN PERSON):
- Thursday, July 27 at 2:00pm with Pamela

**Voices & Vision**

A writing class to think creatively while recording personal experiences, memories, feelings, and thoughts. Each week, you will respond to prompts that challenge you to reflect on the broader aspects of life. Classes are 2 hours.

Upcoming sessions begin (VIRTUAL):
- Tuesday, June 20 at 1:00pm; facilitators will rotate throughout series

Contact us today to learn more and to sign up for open registration notifications.
### GIVE AND GET SUPPORT

Support/Networking Groups can be an important resource for people diagnosed with breast or gynecologic cancer. Some support groups are led by professionals. Others are more informal and discussion based.

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Description</th>
<th>IN PERSON</th>
<th>VIRTUAL*</th>
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<tbody>
<tr>
<td><strong>Newly Diagnosed or In Active Treatment Networking Group</strong></td>
<td>A professionally facilitated group to discuss your experience/questions.</td>
<td>1st and 3rd Wednesdays at 10:00am</td>
<td></td>
</tr>
<tr>
<td><strong>Breast &amp; GYN Cancer Groups</strong></td>
<td>Gather, support, network, and discuss your journey with others. Professionally facilitated.</td>
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</tr>
<tr>
<td><strong>Partners/Spouses, Family &amp; Friends Networking Group</strong></td>
<td>Find camaraderie with others supporting a loved one diagnosed with cancer. Professionally facilitated.</td>
<td>1st Tuesdays at 5:30pm</td>
<td>3rd Tuesdays at 5:30pm</td>
</tr>
<tr>
<td><strong>Sisters of Color</strong></td>
<td>Professionally facilitated group to support women of color through all phases of their diagnosis and treatment. Alternating facilitators.</td>
<td>1st Mondays at 5:30pm</td>
<td></td>
</tr>
<tr>
<td><strong>Brown Bag Discussion Group</strong></td>
<td>A weekly discussion group over lunch!</td>
<td>Every Friday at 12:00noon</td>
<td></td>
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<tr>
<td><strong>Common Ground: Living with Metastatic Breast or Gynecologic Cancer</strong></td>
<td>Join others coping with a diagnosis of metastatic breast or gynecologic cancer. Professionally facilitated.</td>
<td>1st and 3rd Thursdays at 12:00noon</td>
<td></td>
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<tr>
<td><strong>Young Survivor Gatherings</strong></td>
<td>An informal and fun way to connect with others who walk a similar path.</td>
<td>Call or email to be added to our invitation list.</td>
<td></td>
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<tr>
<td><strong>Lymphedema Networking Group</strong></td>
<td>For those living with lymphedema, caregivers, therapists, and medical personnel. Professionally facilitated.</td>
<td>2nd Wednesday of the month at 6:00pm</td>
<td>VIRTUAL links online.</td>
</tr>
<tr>
<td><strong>Evening Education Webinar</strong></td>
<td>Evening Educational Webinars bring information to our survivors and community friends. Held on the 4th Wednesday of the month at 7:00pm. VIRTUAL, register online.</td>
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<tr>
<td><strong>Book Club</strong></td>
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* Virtual links online: [www.BreastCancerCoalition.org](http://www.BreastCancerCoalition.org)

### LEARN

Research has shown that education and community have a positive effect on emotional and physical health outcomes. Registration is easy and may be done through our website.

#### Evening Education Webinar

**June 28:** “Full Circle – Empowering Breast Cancer Survivors Through Mastectomy Tattoos,” featuring TeeJay Dill and Miriam Steinburg

**July 26:** “Fertility and Cancer: What Are The Options?” Panel with Erin Masaba, MD, Strong Fertility Center, Robert Kiltz, MD, CNY Fertility Rochester, and young survivors: Sarah M and Kara O

**August 23:** “Coping with Anger, Fear, Anxiety, Grief, Depression, and PTSD Following a Cancer Diagnosis,” presenter: Whitney Read, LMSW-R in PsychOnc at URMC

#### Lymphedema Networking Group

For those living with lymphedema, caregivers, therapists, and medical personnel. Professionally facilitated.

#### Book Club

4th Thursday of the month at 6:00pm. VIRTUAL links online.

**June 22:** "The Keeper of Lost Things," by Ruth Hogan, facilitator is Ashley Pinkeney

**July 27:** "Honor," by Thritos Umrigar, facilitator TBD

**August 24:** "Demon Copperhead," by Barbara Kingsolver, facilitator is Theo Munson

#### Surviving & Thriving on Aromatase Inhibitors

This program provides information, support, and empowerment for those prescribed aromatase inhibitors who are experiencing joint pain or other side effects. VIRTUAL, contact Christina@bccr.org to register.

Registrants must commit to all four sessions in a series.

- Wednesdays, August 30, September 6, 13, 20, 6:00-8:00pm
When you are a cancer patient, you want a doctor who is experienced, knowledgeable, confident in their abilities, compassionate, and forthcoming. The Rochester region is home to a good number of oncology providers who fit this bill, and many of us have been fortunate to find that person in Dr. Michelle Shayne. She has the skill to take a complicated cancer diagnosis, come up with a treatment plan based on current research and her own expertise, and individualize it for the person in her treatment room. She does this hundreds of times a month.

As her patient, Dr. Shayne has always made me feel like I was the only person who mattered during the time she was with me. She listens with an open mind and responds with research-based answers in a manner that one can understand. Her gift for sharing good and difficult news with kindness, compassion and respect is without measure. Dr. Shayne's leadership is remarkable; every person on her team exudes the same qualities as she does.

Dr. Shayne has dedicated herself to helping those of us who travel this path. With her retirement, Rochester and the surrounding communities are bidding farewell to a legend, and this loss will be felt deeply by those of us who have had the privilege of knowing her. Dr. Shayne, you deserve the world in your retirement. You have made an impact that goes beyond words on the lives of countless people. The love, gratitude, and good wishes of many are with you as you embrace new passions.

**DR. MICHELLE SHAYNE**

**A Fond Farewell to a Trusted Care Provider**

*By Lori McJury*

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Dormant Tumor Cells
By Silvia Gambacorta Hoffman, Research Administrator

Each spring, I look forward to the Advocate Leadership Summit sponsored by the National Breast Cancer Coalition (NBCC) in Washington DC; I am particularly interested in updates on the Artemis Project.

The Artemis project is an NBCC initiative that brings researchers, advocates, and other key stakeholders around the table to set priorities, design, and implement research focused on the prevention of breast cancer and/or prevention of metastasis.

Cyrus Ghajar, PhD, one of the researchers on the project, is a Professor at Fred Hutchinson Cancer Center in Seattle, WA, with an interest in metastasis and tumor dormancy. His presentation focused on dormant disseminated tumor cells (DTCs), cell dormancy, cell growth, and resistance to chemotherapy or immunotherapies.

90% of the deaths in breast cancer are due to metastasis, when cells break away from the primary tumor and travel to distant parts of the body. These cells can stay dormant for many months, years, and even decades, but if they wake up, they can become metastatic breast cancer. There is evidence that the cells travel early and by the time the primary tumor is detected, tumor cells may have already disseminated in some cases.

Scientists have studied breast cancer patients with early stage disease and discovered breast tumor cells in the bone marrow of 30-40% of them. They found a single cell or a small cluster of cells, even when there was no evidence of invasion. The presence of these cells in the bone marrow increases the chances of developing local recurrences and metastasis.

Why do dormant DTCs escape immune system surveillance? Dr. Ghajar theorizes that because dormant cells are very rare – one in a million – they can easily evade detection by the immune system. Furthermore, because the cells are asleep and not dividing, they are protected from the effect of chemotherapy, which targets rapidly dividing cells.

Understanding cell dormancy could lead to the development of new tumor-specific drugs to prevent local recurrences and metastasis in breast cancer patients.

The goal of Dr. Ghajar and his research team is to understand how cancer cells escape from dormancy, and to develop a therapeutic regimen to keep them dormant or to remove them. One way to eradicate them is to boost the number of tumor antigen-specific T-cells.

When mice with dormant cells in the lungs were treated with antigen-specific CAR T-cells, scientists found a 98% kill of dormant cells in the lungs. This suggests, said Dr. Ghajar, that the rarity of dormant DTCs can be overcome by flooding the system with antigen-specific T-cells.

However, more studies need to be done to understand the biology of tumor dormancy in people. A study is in progress with the collaboration of several institutions: the University of Utah, Washington University in St. Louis, and the Fred Hutchinson Cancer Center. Patients’ breast tumor and bone marrow samples taken at the time of surgery are analyzed. A profile of the primary tumor is performed to identify all the mutations, and concurrently, T-cells in the primary tumor are sequenced to determine all the T-cell receptors. The goals are to test the hypothesis that dormant tumor cells are rare, and determine whether the immune cells specific against the tumor are present in the bone marrow.

Understanding cell dormancy could lead to the development of new tumor-specific drugs to prevent local recurrences and metastasis in breast cancer patients.

1. The Breast Cancer Coalition is an independent, local organization unaffiliated with any national group, including the National Breast Cancer Coalition. Many of our goals are the same; thus, we support NBCC’s public policy agenda.
2. A type of white blood cell. T-cells are part of the immune system and develop from stem cells in the bone marrow. They help protect the body from infection and may help fight cancer. Source: www.cancer.gov/publications/dictionaries/cancer-terms/def/t-cell
3. Made by collecting T-cells from the patient and re-engineering them in the laboratory to produce proteins on their surface called chimeric antigen receptors, or CARs. The CARs recognize and bind to specific proteins, or antigens, on the surface of cancer cells. Source: www.cancer.gov/about-cancer/treatment/research/car-t-cells
What a Celebration!

by Meredith Utman, Director of Special Events

On a gorgeous, sunny day, more than 1,490 people turned out for our Pink & Teal Challenge at Monroe Community College. This event was the perfect kick-off to the Coalition’s celebration of its 25th anniversary! The pink and teal attire abounded as everyone ran, walked, and helped to raise more than $220,000! A huge THANK YOU not just to our walkers and runners, but to the families and friends who supported them, and of course, our AMAZING sponsors.

Monroe Community College served as a phenomenal all-in-one venue. Participants were able to gather inside the gymnasium to peruse the Vendor Village, check out the Kids Activity Table and listen to Deanna Dewberry, news anchor at WHEC-TV News10NBC, who reprised her role as our dynamic emcee. We are also grateful to Vault fitness studio for leading the crowd in a quick stretch and warm-up before everyone headed to the start line. After participants finished their walk or run, many headed back to the gym for refreshments and a performance by MCC’s acapella group, The Tributones. And a special shout-out goes to the Netsins Ice Cream truck for serving up frosty treats near the finish line and generously donating a percentage of their sales that morning to the Coalition!

All funds raised from this event stay local, enabling the Breast Cancer Coalition to continue providing critical programs and services at no cost to breast and gynecologic survivors in our region. At the Coalition, we like to say that it takes a community to serve a community. We are truly fortunate to have such a dedicated community of partners helping us to continue empowering breast and/or gynecologic cancer survivors through support, education, advocacy and research.

Many thanks to all who helped make the Pink & Teal Challenge a true success!

Our Fabulous Committee!

Holly Anderson
Michelle Arbore
Deb Bishop
Claire Bopp
Sharon Brogna
Michele Chantra
Gina DiMonda
Nikki Evers
Melinda Goldberg
Jill Gress
Ashley Infantino
Dawn Lee
Diane Micheal
Julie Overbeck
Cori Palazzolo
Breana Pollett
Michaela Raes
Jerry Roberts
Alyssa Santana
Rachel Studley
Meredith Utman
Christina Thompson

Special congratulations to the winners of the women’s only 5k run:

Overall winner: Lindsay Piraino

Age Bracket Winners:
5-15: Anna Blodgett
16-25: Macy Letendre
26-35: Maria Garcia
36-45: Amy Konopka
46-55: Christine Parnell
56+: Joanne DiNoto
Photo Feature: Tina McKean (above) has run every race since event’s inception in 2002!
were eerily empty. Luckily, I didn’t have to wait long once I signed in, completed the paperwork, changed, and got in the bed. The procedure was over before I knew it. Healing the first time seemed like a breeze. After the second surgery, I lived in a snug sports bra for a few months before the soreness went away.

As my surgeon had suggested, my post-surgery pathology report led my medical oncologist to recommend chemotherapy. In preparation, I stopped taking the aromatase inhibitor while continuing Lupron injections to protect my reproductive system. Chemo took place from June through August. Afterward, I had a break before beginning radiation, which went from early September to early October. Around six or eight weeks after radiation ended, I went back on the aromatase inhibitor.

I started to notice stiffness in my shoulder and right side in general. By December, I had a fully frozen shoulder. To get my range of motion back, help with the inflammation, and improve my lymphatic system, I started occupational and physical therapy, and then I added in some specialty fascia work as well. A year and a half later, I have about 90% range of motion back.

Through my surgery and treatment, many people – my doctors, their nursing staffs, infusion nurses, and more – handed me brochures for the Coalition. However, a number of my friends had gone through breast cancer surgery and treatment, and I already had a great support system. But as supportive and caring as they were, none of them had gone through the same scenario as me. By the time I finally made the call to the Coalition, I was in the midst of chemo and planning for radiation. A radiology nurse asked if I had called the Coalition yet. I said “No.” She asked if more support was a bad thing. “No, no,” I laughed. “It’s the exact opposite!”

After speaking with the Coalition staff, I signed up for a few of the Healing Arts classes. I took Gentle Yoga, Mindfulness & Meditation, and a Voices & Vision Writing Workshop. That’s also when I inquired about the PALS program and was matched with Katherine, a peer mentor whose diagnosis and treatment were similar. And I attended some Evening Educational Webinars and a virtual Young Survivor Gathering. Once my radiation treatments ended and I resumed the aromatase inhibitor, I joined the class on Surviving & Thriving on Aromatase Inhibitors.

Going through cancer treatment during the pandemic was a double-edged sword. I felt isolated most of the time even though friends would come over and sit outside with me or check in by Zoom. The way that the Coalition dropped materials off at my house for classes and events and converted everything else to Zoom helped immensely by making connections that eased my recovery process.

In 2022, I spoke with Holly, the Director, about my desire to become more involved with the Coalition. Soon, I joined the first group of Emerging Leaders, a new initiative of the Coalition. I had been wanting to somehow make a difference, and this was the perfect opportunity to make my pain my purpose, as the saying goes. After being paired with a mentor who is an accomplished member of the Advocacy Committee and attending training sessions, I had an eye-opening experience in May of 2022, when I attended the Advocate Leadership Summit in Washington, D.C.

After that, joining the Advocacy Committee seemed like the next logical step. I want my voice to be heard on issues that matter to survivors. And if I can make a difference in getting rid of even some of the chemicals in the environment that may have contributed to my cancer, that would be a win.”
heard on issues that matter to survivors. And if I can make a difference in getting rid of even some of the chemicals in the environment that may have contributed to my cancer, that would be a win. Far too many people are still being diagnosed. We have a lot of work to do. I’m happy to have this Coalition crew to work with!

My hope is to represent the Coalition as an advocate for their services and the causes this organization champions. I also want to continue to foster the relationships I’ve built and create new relationships with young survivors who want to get involved. It’s a different kind of connection when you’ve gone through similar experiences – physical and emotional. We also fight for those who can’t and give a voice to those who no longer have one. I’ve lost friends to breast, lung, and other cancers. I want to do whatever I can to stop this from happening.

I’ve always been a private person and someone who doesn’t like to ask for help. That has all changed. Through my involvement with the Coalition, I’ve learned the importance of community and leaning on others for support; the importance of making my mess my message. And doing so has also opened up discussions I never thought I’d have. Sharing my story - the good, bad, and ugly - has encouraged others to get to know their bodies and to be their own advocates. I’m happy people feel comfortable coming to me with their questions.

The relationships I’ve developed at the Coalition have brought me so much joy. I never had the patience for nonsense, and now more than ever, I try not to listen to negative noise. I want to enjoy every day and focus on the people, things, and activities that make me happy. I like giving back. It feels good to help those who helped me, and to help make sure that people who are newly diagnosed have the support and information they need for the best possible outcome one can have in this situation. Even when you think you have plenty of support, you’d be surprised at how much you need.

One of the first questions I ask when I hear that someone has been diagnosed is: “Have you reached out to the Coalition?” I share my story and caution others not to wait like I did. But regardless of when you call the Coalition, it’s never too late for anyone to join us. The more, the merrier!

She shows up at our fundraisers. She shows up at our community outreach events. She shows up for her fellow survivors at our support/networking groups. Since her breast cancer diagnosis in 2018, Karen F. has been a solid, steady, and compassionate presence in our organization. A nurse who works in the surgical recovery unit at Highland Hospital, Karen had long experience in connecting with breast cancer patients as they recovered from their procedures; experience that predates her own diagnosis.

As she made her way through her treatment and recovery, Karen became a regular at our Brown Bag table. She shared her own story with honesty and clarity while offering her finely tuned and attentive listening ear to others, always responding with insightful feedback. This soon morphed into PALS mentoring. After completing her mentor training, Karen has connected one-to-one with many newly diagnosed individuals, extending the level of support and reassurance only a survivor can offer. While her training as a nurse affords her a high level of background knowledge, Karen’s interactions with her mentees and those at our support/networking groups are those of a fellow survivor.

Karen’s presence at our fundraisers and community-wide events matches her commitment to our survivor community. Wherever she goes, her warm smile and kind, thoughtful comments have endeared her to everyone she meets.

Not all heroes wear capes. There are those whose calm, steadfast manner provides a place of tranquility in a storm. Karen is such a person. And the knowledge base from which she operates makes her a uniquely effective peer advocate for her fellow survivors. We at the Coalition are grateful for her dedication, her bravery, and for showing up, time and time again. Thank you, Karen!

“Sometimes the bravest and most important thing you can do is just show up.”

~Brené Brown
Kathryn  Mossbrook  Zimmerman

By  Pat  Battaglia

She  called  herself  the  “Bag  Lady”  after  freeing  herself  of  most  of  her  belongings  to  explore  the  world  on  her  bicycle.  An  honest,  wise,  often  hilarious,  unfailingly  kind  and  articulate  self-advocate,  Kathryn  Zimmerman  chronicled  her  journeys  in  Facebook  videos,  amassing  a  throng  of  devoted  friends  throughout  the  world.

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Mary  Kniep  Hardy

The  following  memories  are  among  the  many  shared  with  Mary’s  family  by  members  of  the  Common  Ground  “Peeps,”  the  Coalition’s  group  for  those  living  with  metastatic  breast  or  gynecologic  cancers.  Mary  was  an  integral  part  of  this  group.

“Mary  was  so  balanced  and  steady  in  her  approach  to  life  with  cancer.  She  was  practical,  straightforward  with  her  emotions,  insightful,  and  witty.  She  often  surprised  me  with  some  of  her  funny  comments.  Her  insight  was  always  helpful  and  welcome.  I  appreciated  her  confidence  in  how  she  wanted  to  live.”

“Mary  always  thought  outside  of  herself.  With  a  steady  voice;  she  gave  warm,  wise  support  to  us -  even  when  she  was  suffering.  She  was  a  true  caregiver,  through  and  through.”

“Mary  stopped  me  one  day  after  a  Peeps  lunch,  as  I  was  on  my  way  to  the  car.  She  told  me  she  felt  bad  that  I  was  sick  from  chemo  and  because  I  live  alone,  probably  didn’t  want  to  cook  for  myself.  Out  of  her  car,  she  got  a  container  of  chicken  soup  from  the  Jewish  deli.  That  was  such  a  sweet  gesture.”

“Mary  challenged  us  to  look  beyond  laughter  and  fun  times;  she  wanted  our  discussions  to  go  deeper.  Based  on  this,  the  Coalition  held  the  first  ‘Death  Café’  to  give  us  a  forum  for  such  discussions.  She  shared  insights  that  comforted,  enlightened,  and  opened  the  doors  for  sharing  those  ‘tougher’  topics.”

“When  Mary  decided  to  stop  treatment,  she  was  very  willing  to  discuss  it  with  us.  She  demonstrated  taking  charge  of  HER  plan  for  living  a  life  of  quality  over  quantity.”

“Thank  you,  Hardy  family,  for  sharing  Mary  with  us;  each  of  us  has  been  blessed  by  her.”

Friends  Remembered

We  celebrate  all  who  set  an  unwilling  foot  on  this  path,  along  with  our  friends  and  supporters.

Almina  Adams  Rochelle  “Shelly”  Braiman  Carol  Cafalone  Corrine  Chizuk  Patricia  “Pat”  Foucht  MJ  Iuppa  Lisa  Liberatore  Kathryn  Schmanke  Robert  “Bob”  Rinken  Marlene  Vetusto  Barbour  Warren,  PhD  Shelli  Wheeler  Mary  Kniep  Hardy

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Since the inception of PALS, Pat Battaglia has played a major role in virtually every aspect of the program and has had a huge impact on it. When I started working at the Coalition in 2017, I was amazed at everything that went into creating PALS matches and was extremely impressed by everything Pat did to make just the right match. As I look forward to continuing this incredible program and making meaningful matches, I am so thankful Pat will continue to be a part of the team that meets to discuss PALS connections. I will continue to rely on her for guidance and strive to keep the program running at the high level that she has maintained.

In planning my first newsletter article, I reached out to all of the mentors and ask them to share what impact Pat has had on them as their PALS Coordinator. As you can imagine, I was inundated with thoughtful, meaningful messages. There is not enough room on this page to share all of them, but here are just a few excerpts. I will definitely be sharing the full list of messages with Pat.

Thank you, Pat, for all the time and energy you have given to the program, and I look forward to taking the reins. Our next PALS mentor training session will be held on September 23 at the Coalition. Reach out to Ali for more information at ali@breastcancercoalition.org

BreastCancerCoalition.org
Everyone has their own way to recharge their inner batteries – to do something that makes them feel good physically and, in turn, emotionally. For me, getting outdoors for a walk around the neighborhood helps hit that “reset” button. A hike in a beautiful, natural setting is even better, when I can make it happen. Walking helps lift my mood and clear my mind.

No matter what form of movement you prefer, there is abundant evidence to suggest that engaging in regular physical activity is one of the most important things you can do for your health. According to the Centers for Disease Control (CDC), being physically active can improve your brain health, help manage weight, strengthen bones and muscles, improve your ability to do everyday activities, and even reduce the risk of certain diseases.1

Research shows that for most, exercise is safe and beneficial before, during, and after cancer treatment. Physical activity can even help people cope with the side effects of their treatment.2 Citing a large number of systematic reviews, the American Society of Clinical Oncologists (ASCO) has issued guidelines for health care professionals that state, in part, “Oncology providers should recommend aerobic and resistance exercise during active treatment... to mitigate side effects of cancer treatment.”2

HOW MUCH ACTIVITY IS ENOUGH?

Ideally, adults should get 150-300 minutes per week of moderate intensity activity (such as walking, yoga, or mowing the lawn) or 75-150 minutes per week of vigorous activity (such as running, swimming, or singles tennis). Balancing different activity levels is fine. Those who are just beginning a physical movement program will still see benefits below these recommended levels and can gradually increase their activity levels.4 No matter which forms of movement we choose, every effort counts and will have positive effects on the mind and body.

MAKING MOVEMENT A PART OF LIFE

What gets you up and moving? Whether it’s the thought of going to the gym, taking a walk, hopping on your bicycle, hitting the golf course, a planting session in the garden, connecting with like-minded peers in yoga class, or any number of pursuits, you will reap the benefits. Taking an easy hike, swimming a few laps, a beginner tai chi session, and other low-impact activities share many of the same advantages as more intense workouts. Engaging in activities that help us feel stronger, raise our heart rate, and relieve stress is ultimately empowering.

My cancer diagnosis resulted in feelings of being curiously out of sync with my body. This may not be everyone’s experience; there is no right or wrong way to feel after learning you have cancer. Movement is my way of “coming home.” It’s one thing I can control. What motivates YOU?

3. ascopubs.org/doi/full/10.1200/ JCO.22.00687
Ten Easy Ways to Get Moving

Summer provides ample opportunity to choose the form of movement that works for you. Always check with your health care team before starting a new activity or exercise program. And when spending time in the great outdoors, don’t forget to wear sunscreen. A wide-brimmed hat and sunglasses are also essential protection from the sun’s UV rays. Remember, all forms of movement count! What sounds good to you? Here are a few ideas to get those creative thoughts flowing. Feel free to add your own ideas to this list.

1. BEACHCOMBING
   What could be better than taking a stroll along a beach to see what you can find? Shells, sea glass, rocks, driftwood... there’s a world of treasure on our shores.

2. BICYCLING
   Explore your area on a bike! If you don’t have one, borrow or rent one. Don’t forget to bring a bottle of water. You might even pack a picnic lunch or bring along snacks.

3. DANCING
   Whether you bust a move in your living room or on the dance floor, you’re engaging muscles throughout your body and raising your heart rate. Sweet move!

4. FRUIT PICKING
   Pick-your-own fruit farms abound in our region. Online resources such as [www.pickyourown.org/NY.htm](http://www.pickyourown.org/NY.htm) can help you find them. Spend an afternoon gathering yummy treats.

5. GARDENING
   Many people find gardening energizing and relaxing. Add to the beauty of your surroundings and/or enjoy some freshly grown vegetables.

6. GOLFING
   Golfers are onto something. Hitting the links is a great way to keep the body moving and the mind sharp.

7. HIKING / WALKING
   You might take a short and sweet jaunt around the neighborhood or take a day trip and explore one of the many hiking trails in our region. In either case, you will benefit!

8. KAYAKING OR CANOEING
   Paddling can be as active or as relaxing as you like. If you’re new to the experience, begin with some professional help or an experienced guide.

9. SIGN UP FOR A CLASS
   The Coalition’s Healing Arts Initiative offers a wealth of opportunities for survivors to move in a safe, supportive setting. Check page 12 for offerings and registration information.

10. SWIMMING
    Whether in a backyard pool, your local gym, or one of the local outdoor swimming holes, swimming engages all your muscles. And it’s a low-impact cardio workout.

Beet Lemonade

¾ cup fresh lemon juice (about 4 – 6 lemons depending on the size)
2/3 cup granulated sugar (or honey)
½ cup finely grated raw beet*
6 cups cold water

*I used a box grater to shred a medium, raw, unpeeled beet. You can also use a food processor with the shredder attachment.

In a blender (or food processor) blend together the lemon juice, sugar and shredded beet. Blend for 1 minute until the mixture is bright pink and well combined. The beets will never be fully smooth – that’s ok! Let the mixture sit for 30 – 45 minutes.

Strain the mixture through a fine mesh strainer and into a medium bowl. Use the back of a spoon to press any remaining juice out of the beets and into the lemonade.

Transfer strained mixture to a pitcher and discard the beet pulp. Add the water to the pitcher and stir. Taste and add more lemon or sugar as necessary. Store in the refrigerator and serve chilled with lemon slices.

Submitted by Deb Bishop.
Prescription Discount Cards, Too Good to Be True?

Heather L. Lee, MSN, FNP-C

It’s no secret that prescription medications are getting more expensive every year. In fact, the Congressional Budget Office released a report in January 2022 that revealed nationwide spending on prescription drugs had skyrocketed from $30 billion in 1980 to $335 billion in 2018. Even with medical insurance, the out-of-pocket costs can be alarming. Prescription discount cards could provide some relief. That’s why it’s important to understand what they can and cannot do.

HOW IT WORKS:

1. A pharmacy and a prescription discount company partner up.
2. A customer uses a discount company website or app to find a lower price on their medication.
3. The customer goes to the pharmacy, presents a coupon, and pays a lower price.
4. The pharmacy pays a small fee to the discount company for bringing the customer in.

FIND THE BEST PROGRAM FOR YOU:

• Most prescription discount programs are free. If they charge a fee, walk away.
• Make sure your local pharmacies accept the discount card. You may have to shop around for the best price as two pharmacies on the same street can have different prices for the same medication.
• Is the card easy to use? Is it a physical card, an app on your phone, or do you have to print out the coupons before using them?
• What does the company do with your information? Making sure the company is compliant with the Health Information Portability and Accountability Act (HIPAA) will protect your privacy. Read the terms and conditions closely.

WHERE TO START:

• SingleCare is for any US citizen over age 13. The Better Business Bureau (BBB) gave them an A+ rating.
• America’s Pharmacy offers discounts for your family and pets, too.
• GoodRx is widely available and offers health information written by health care providers on their website.
• New York Rx card for NYS residents, that can be used anywhere in the country. No personal information required.

For more information you can visit https://www.pharmacytimes.com/view/overview-of-prescription-discount-programs.
Thank You Friends

Each year the Coalition benefits from hundreds of individuals participating in multiple fundraising events created for us by people like you. Your donation will help us continue to provide our programs and services free of charge! Contact us today at info@bccr.org or (585) 473-8177 for more information.

FUNDRAISING FRIENDS EXTRAORDINAIRE

CooperVision’s Scottsville Manufacturing Operations employees know how to put the FUN in FUNdraising! 18 teams put together a variety of themed baskets for a raffle that was open to all employees. Not only were these baskets filled to the brim with unique and imaginative items, but they raised $1,190! Special thank you to Jody Dietz for helping to organize this event!

HAPPY BIRTHDAY, ANDIE!

To celebrate her 14th birthday this year and pay tribute to a friend, Andie decided to raise money for the Coalition. We could not be more grateful for her generosity. Through the month of March, she raised $410 in honor of a family friend, Angie Martin, who passed away. Thank you, Andie. Our hearts are with you.

MORE FUNDRAISING FUN!

As a part of an employee fundraiser last autumn, Barilla America NY donated $954 to the Coalition. Members of their FUN Committee, which consists of employees who arrange events and activities that are held throughout the year, decided to sell pink shirts to honor the Breast Cancer Awareness month October. We’re honored and grateful they chose the Coalition to receive this donation! Grazie!

THE GIFT THAT KEEPS ON GIVING

James Kaczmarsky attended the 2022 Batavia Downs Fundraiser to benefit the Coalition and placed the winning bid ($280) on a Thurman Thomas Jersey and signed football. Instead of keeping these collector items, he decided to raffle them off and raise MORE money for the Coalition! Selling raffle tickets at three of his favorite hangouts, he raised $2000. Frank Calabra, who purchased the winning ticket, decided to donate the jersey and football back to the Coalition so we could use them once again to raise more money. Wow! We are in awe of the kindness and selfless support of these gentlemen!

NEIGHBORS SUPPORTING NEIGHBORS

Tyler and Kaley Sutphen, owners of Crossfit Park Ave – a neighbor of the Coalition – organized a workout competition event in early March, 2023. Participants were encouraged to donate to the Coalition, and raised an impressive $1,389! We truly appreciate the CrossFit community’s passion for fitness that has translated into support of our mission! Many thanks, neighbor!

NAMASTE

Joann Klinkner and Young Lion Brewing had the brilliant and very original idea of combining yoga and beer with fundraising. Yoga at Young Lion in March 2023 raised $340 for the Coalition! We are so thankful!
GOAL!!!

Last year, the Rush-Henrietta Soccer Club hosted their annual Pink Day, a fundraiser to support breast cancer research. We’re honored they chose the Coalition to receive the proceeds. Wearing pink to show their support, their teams and visitors raised an astounding $1,200! Beyond soccer, Pink Day included a raffle, food trucks and a very popular “Cream Your Coach” (pictured). We are beyond grateful for this GENEROUS donation that will support the vital research needed to END this disease!

KICKING CANCER TO THE CURB

The Chili Fusion Youth Soccer group hosted its 8th Annual Pink the Field tournament in Oct 2022. Approximately 90 teams participated - up from 4 teams their first year! Amy Wood has organized the tourney every year with the help of the team members, their families, and other kind volunteers. Keeping the funds local, the Fusion tournament raised an incredible $9000 for the Coalition! We are humbled by their hard work and generosity. BIG thanks to all for this wonderful gift!

STICKING IT TO CANCER

Greece Storm Lacrosse Team Parent volunteer and breast cancer survivor, Karen Hill, helped to coordinate the Stick It To Cancer lacrosse game on May 2. Thank you team for the $600 donation. Sticking it to cancer sounds good to us!

Longtime Friends in Sodus Bay

Continuing a tradition that has lasted over 20 years, the Sodus Bay Heights Golf Club once again held their 2022 Charity Golf Tournament in the Coalition’s honor. Under the adept guidance of Sharon Lilla and with the support of dynamic co-chairs Donna Krehling, Mary Jo Deichmiller, and Nan VanEe, the tournament resulted in a marvelous $19,000 gift to the Coalition! We are honored and humbled to be the recipients of such generosity for so many years. “Thank you” doesn’t adequately express our gratitude, but it’s a beginning. Thank you, Sodus Bay Heights Golf Club. You are aces in our book!
Van Bortel Subaru “Shares the Love”
…and we feel it!

As one of two hometown charities chosen by Van Bortel Subaru to receive donations through Subaru’s 2022 Share the Love event, Coalition staff members were on hand to receive a check in the amount of $108,062 from our longtime friend and supporter, Kitty Van Bortel. Standing side by side with representatives from It’s About Caring for Kids, who were also recipients of Van Bortel’s generosity, the check presentation was an opportunity for an in-person “thank you” to Kitty for her enduring commitment to our organization.

For fifteen years, Subaru of America, Inc. has held its Share the Love event, contributing $250 to charity for every vehicle purchased or leased. Kitty Van Bortel generously matched every donation from Subaru to a hometown charity during the most recent Share the Love event, which ran from November 17, 2022 through January 3, 2023.

We are grateful to Kitty and her customers who chose to Share the Love with the Coalition. You are helping us make a difference for people right here in our region.

When you share the love, you change lives.

Making Sense and Making a Difference

When she learned she had been selected as the Leaders Conference Charity Ambassador for the Make Sense Foundation, a group whose mission is to support women and children in need, Rachel Johnson was honored. And she found herself in the position of choosing a nonprofit in New York State to receive a $10,000 grant from the Foundation. With the conference taking place in October of 2022 – Breast Cancer Awareness month – it ‘made sense’ to Rachel to select the Breast Cancer Coalition as the grant recipient. We are truly grateful to this thoughtful, caring young woman and to the Make Sense Foundation for making the world a better place for women and children – and for us! Thank you!
We are truly amazed at the many ways our generous donors support our work at the Coalition. Some host fundraisers among their peers on social media or in person; others donate directly through their payroll with the help of an employer and/or the United Way. And there are those who respond to our annual fund campaigns, honor a loved one with an honorary or memorial gift, or simply return the donation envelope enclosed in this newsletter.

We are grateful to all donors for their valuable contributions and their commitment to our mission. Every effort has been made to ensure the accuracy of this list. We apologize for any errors. Please join us in thanking the following individuals, companies, and organizations for their contributions between January 1 - March 31, 2023.

IN HONOR OF:

The staff at BCCR
Terri Sharpe

All women who have had breast cancer
Carol Loughner ♥

Young Survivors
Jacqueline Moffett

Holly Anderson & Valerie Pasquarella
Annie Murphy ♥

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Mary Valerio
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Bobbiejo Wright’s Birthday
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Paula Mendies

IN MEMORY OF:

All the breast cancer warriors
Elaine Martinez

My mother
Norene White ♥

Terri and EJ
Wendy Bachhuber ♥

Miriam Ackley
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BreastCancerCoalition.org

Summer 2023 • 29
### Platinum Power Players ($5,000 and Above)
- Holly Anderson
- Maya Polashenski, What Would Pam Do team
- Cori Palazzolo, Marvelous Ovengers

### Power Players ($2,500-$4,999)
- Patti Cataldi
- Andrea Reynolds
- Patricia Battaglia
- Ann & Emily Leonard
- Jody L. Dietz

### Elite Level ($1,000-$2,499)
- Celeste Frohm
- Kathleen Cook
- Nicolette Ferguson
- Christina Thompson
- Terry Mulee / Team Terry
- Julie Overbeck
- Mary Carafos
- Sonya Russell
- Carol Giffi
- Leslie Gallea
- Marianne Stanchus
- Rachel Studley
- Dawn Lee
- Cori Palazzolo
- Amanda Atkinson
- Marianne Sargent
- Leni Rayburn
- Georgia Carney
- Jessica Cataldi
- DJ Wells
- Michele Chandra
- Ali Dennison
- Kathy Guglielmi
- Remembering Pat Haralambides
- Sue Delp
- Betsy Crumity

### Professional Level ($500-$999)
- Diane Micheal
- Wendy Gottorff
- Kate Rowland
- Rose VanTyne
- Amber Ford
- Jill Gress
- Cindy Dykes
- Mary Germano
- Eileen McConville
- Esther Tanzman
- Ron Skuse
- Laura Despard
- Nancy Kolb
- Wendy Bachhuber
- Jessica Gooch
- Jane Oswald
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- Mary Reed
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- Teri Drew
- Colleen Molina

### Semi-Pro Level ($100-$499)
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- Heidi Versprille
- Lenora Colarutolo
- Caitlin Crilly
- Charlotte McCabe
- Paula Baum
- Julie Jeffries
- Maya Polashenski
- Amanda Marshall
- Vina’s Walk for Pink Sisters
- Tina Brown
- Jen Schum
- Linda J Taylor
- Christina Michaels
- Hannah Heffernan
- Briggs Crew
- Kathleen Cunningham
- Aimee Whyte
- Robin Finley
- Kelly Zintel
- Becki Vincent
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- Marj Cunningham
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- Stacy Forrett
- Anne Clark
- Jason Goudreau
- Tallis Polashenski
- Molly Dillon
- Colleen Bogart
- Adriann Strauss
- Susan Miller
- Mallory Manning
- Sarah (Farney) Mack
- Kimberly Ellis
- Bambi Talley
- Michelle Arbore
- Jennifer Goldenberg
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- Shawn Maxson
- Stacy Mayou
- Jenna Samudio
- Tammy McGraw
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- Susan Hoh
- Patricia Honch
- Christen Groeling

### Rookie Level ($50-$99)
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- Rosemarie Morrison
- Kristen Donovan
- Corie Holding
- Kristina Wilkins
- Gianna Chandra
- Marcy Horn
- Amy Hernandez
- Megan Griffin-Adams
- Amy Warcup
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- Melissa Hagen
- Cate DiNoto
- Virginia Ruff

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**Thank You Donors**

**PINK RIBBON WALK & RUN FUNDRAISERS**

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*Continue on next page.*
Thank You Donors

PINK RIBBON WALK & RUN FUNDRAISERS

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President’s Circle
The Coalition recognizes individuals who have made leadership level annual fund or United Way gifts of $1,000 or more in the calendar year through the President’s Circle.

Coalition GEMs are a special group of dedicated supporters who help the Coalition throughout the year by making a monthly gift. Monthly gifts offer a steady and cost-effective source of income.

Coalition Loyal are individuals who make an annual fund or United Way gift – of any amount – for two or more consecutive years are part of our Coalition Loyal Giving Society.

Wish List
- Breast Cancer postage stamps
- Burt’s Bees Lip Balm (sealed, no mint)
- Coloring books (pocket or travel size preferred)
- Computer paper, white, 20 lb.
- Joann Fabrics gift cards
- Lotion: Aveeno
- Post-it Notes - square, 2” x 2” or 3” x 3”
- Sleeping masks, lavender or unscented
- Gin Gins
- Tea (small boxes of 20)
- Tissues - pocket pack size

People

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BreastCancerCoalition.org

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Breast Cancer Coalition Mission Statement

To cultivate community among those touched by breast or gynecologic cancer; to empower informed decision-making through education, support, and advocacy; and to advance research in our region with the goal of eradicating breast cancer.

Voices of the Ribbon is published quarterly by the Breast Cancer Coalition to provide encouragement and inspiration to those facing a breast or gynecologic cancer diagnoses, their supporters, and care providers.

In addition, it is intended to impart accurate, evidence-based information to enlighten and empower our readership.

Our in-house editor, graphic designer, writers, and support staff work together to ensure our publication is economically produced and our printers assure us that we are getting the best rates possible.

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To keep up to date on all BCCR happenings, follow us on social media:

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Breast Cancer Coalition Inclusion Statement:
Just as cancer does not discriminate, the Breast Cancer Coalition recognizes the importance of a culture that strives for diversity. We honor individual differences whether color, race, religion, political viewpoints, socioeconomic status, physical abilities, gender, gender identity, gender expression, and/or sexual orientation. We are committed to increasing the diversity within the Coalition and welcome you to our safe, inclusive community.

SAVE THE DATE!

Thursday, October 12, 2023
Comedy at the Carlson
Everyone is invited to celebrate the Breast Cancer Coalition’s 25 Years of Impact!