Breast Cancer Coalition

VOICES of the RIBBON

Celebrating

$1,000,000

to Regional Breast Cancer Research

FEATURE STORY:

A Conversation With Sangwoo Park, 2022 Recipient Of The Pamela Delp Polashenski M.D. Breast Cancer Research Trainee Grant

- Advanced Breast Cancer Seminar
- An Update: Breast Implant Associated Lymphoma
- Programming Updates
FROM THE DESK OF THE EXECUTIVE DIRECTOR

Pushing Out & Moving Forward

AUTUMN.

I must admit... this is my favorite time of year. The air turns crisp. Children are adjusting to their new schedules. Sandals and flip flops get packed away with the bathing suits and sleeveless tops. The scent of cinnamon-soaked pine cones, seemingly everywhere, reminds us that the days are getting shorter, and we have much to do before we turn the calendar page to a new year. Autumn is officially underway. And our plans for 2023 are already taking shape.

This is the time of year that we complete our budget for the upcoming year. It is the time of year that we plan programs, schedule presenters for our evening seminar series, coordinate facilitators for our networking groups, lock in dates with the instructors of our acclaimed Healing Arts program, assess our advocacy efforts, reflect on comments shared through program evaluations, and take stock of where we are and what needs to happen as we strive to meet the needs of a growing community of survivors of breast and gynecologic cancers. Have you heard? Our programs and services have expanded into twenty-seven counties in Central and Western New York. That’s a lot of turf for a small, community-based, grassroots nonprofit organization to cover!

What is on the horizon? Focus groups, for one.

Focus groups are often the best way to identify, assess, and confirm unmet needs. Throughout the year, we listen carefully to suggestions shared by program participants and comb through the written comments that have consistently trickled in for confirmation of what we are hearing. For example, implementing a new networking group takes a commitment from multiple parties, not the least of which are the participants themselves. There are multiple steps involved. Would you like to participate? Currently, we are in the planning phase of a series of focus groups that will help us determine the specific needs of two demographic groups:

- Black Women (breast or gynecologic cancer)
- Gynecologic Cancer

If you would like to be included in either or both groups, please reach out to us. These focus groups will commence in late October and early November.

As always, you can email me (holly@bccr.org) or reach us through info@bccr.org with your thoughts, ideas, or suggestions. We welcome, value, and respond to feedback.

Now... bring on the pumpkin spice!

Holly Anderson

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On the cover:
Marcus Cox, Maya Polashenski, M.D., Tallis Polashenski, Silvia Gambacorta-Hoffman, Walter Polashenski, M.D., Sangwoo Park, and Holly Anderson

Photo credit: Lisa Gresens
One of our Emerging Leaders*, Colleen M., turned to the Coalition after her breast cancer was diagnosed shortly before the COVID shutdown. She graciously agreed to share her story with our community.

In February of 2020, I was diagnosed with invasive ductal carcinoma. I was thirty-three years old and thirty-three weeks pregnant with my second child.

The previous November, at about five months pregnant, I noticed what I thought might be a clogged milk duct. I frequently had a clogged duct in that exact spot when I was nursing my daughter. (She had weaned at twelve months old and I found out I was pregnant with my second when she was thirteen months old.) About a month after discovering the suspicious area, I pointed it out to the Physician’s Assistant at my OB/GYN appointment. She agreed it was probably nothing to worry about and advised me to keep an eye on it. The area never got smaller or went away, even though I tried all the tricks I knew to get rid of a clogged duct. After dealing with a lingering illness, I went back into the OB/GYN and let her know I was not feeling well and the lump was still there. At that point she recommended I have it looked at, and I scheduled an ultrasound.

At the ultrasound, I knew something was wrong when the radiologist told me I needed a biopsy as soon as possible. I thought about coming back the next day as I was alone at the time and the office was about to close. However, the radiologist talked me through what the procedure would look and feel like, encouraging me to stay and do the biopsy that day. Physically, the biopsy was uncomfortable, and mentally it was terrifying. My radiologist was as comforting to me as she could possibly be while still performing multiple biopsies. Afterward, she gave me some ice and told me to take a few minutes to collect myself before I went home. They would call with the results in the next couple of days.

The next afternoon, I picked up my daughter from daycare after work, as usual. However, after buckling my little one into her car seat, I saw a missed call from the radiologist’s office. My husband worked across the street, so I drove to his parking lot before calling back. When I returned the call, the doctor said this was not the news we were hoping for; I had breast cancer. I listened in disbelief as she went through what my next steps would be, and before ending the call, she told me to call back if I needed anything. I then called my husband and told him to come out to the parking lot. When he saw the look on my face, he knew even before I told him that it was cancer. We stood in the parking lot for a few minutes holding onto one another in total shock.

We got into the car, and my eighteen-month-old daughter looked at me and wondered why I was crying. I told her I was okay, not knowing if I really would be okay. The silence on our twenty-five minute drive home was interrupted only by an occasional little voice asking for snacks or for help picking up a dropped toy.

Continued on page 19.

*Our Emerging Leaders Program, funded by the Marilyn Lichtman Foundation, has paired eight young survivors with eight experienced members of our Research and Advocacy Committees, who serve as mentors to the next generation of leaders.
The first recipient of the Coalition’s newly renamed Pamela Delp Polashenski M.D. Breast Cancer Research Trainee Grant, Sangwoo Park hails from South Korea. Currently a Ph.D. candidate at Cornell University, he kindly agreed to meet and discuss his Coalition-funded study, "Overcoming the glycocalyx barrier to engineered cellular therapeutics."

Thank you for taking the time to share your work with our survivor community. What originally motivated you to study breast cancer?

SP: As you know, I came from South Korea, where I served in the military as a firefighter for a few years. I was dispatched to many different accidents including fires and car crashes as a firefighter or Emergency Medical Technician. I still clearly remember the day when the person I was assisting had stage IV lung cancer, and while transporting the patient to the university hospital, there was nothing I could do for him other than supply oxygen or measure the blood pressure. At that point, I wanted to do something for cancer patients. Because my major was in physics, I wanted to help them with my physics background.

After I finished my military service, I went back to college in South Korea and joined the lab to study cancer research. I studied breast cancer and lung cancer. We developed a device that diagnoses breast cancer and lung cancer with a small blood sample. But I wanted to learn more about cancer biology and new techniques to find cancer treatment. That’s why I applied to the Cornell Biophysics program; to learn about cancer and to help cancer patients.

How would you describe your project that the Coalition is funding?

SP: Immune cells such as natural killer cells – NK cells – are our frontline guardians of the immune system. They can find the pathogens, viruses, and cancer cells, and kill them. But the results of immunotherapy in treating breast cancer have not been universal and remain unsatisfying. One of the recent immunotherapies is called the immune checkpoint blockade. That blocks immune suppressors and enhances immune activity against cancer cells. But only about 25% of patients across all indications respond to immune checkpoint blockade therapy. So a better understanding of the mechanisms of tumor inhibition may help.

We think one of these evasion mechanisms may involve the cancer cell glycocalyx acting as a barrier to immune cell engagement. Glycocalyx literally means sugar (glycol) and husk (calyx). One of the main components of this glycocalyx is called mucins. Cancer cells are often associated with dramatic overexpression of cell surface mucins, and they cause a thick glycocalyx structure. For example, Mucin 1 (Muc-1) is one of the membrane proteins belonging to mucins and is overexpressed in over 90% of breast cancers.
The physical length of this Muc-1 is usually 100-200 nanometers (nm: one-hundred-millionth of a meter). But immune cells such as NK cell need close cellular contact for immune recognition because the size of the immune receptor is only 30nm. So, Muc-1 is likely to act as a barrier to immune cell engagement with cancer cells.

We think the mucin-infused glycocalyx does something for immune engagement. We found that tiny changes in the glycocalyx thickness — as small as 10 nanometers — could affect the anti-tumor activity of the NK cells. Thus, new strategies to disrupt or penetrate the glycocalyx barrier are needed for improved cancer immunotherapy. We will develop strategies to engineer immune cells with new capabilities to breach the glycocalyx barrier and more effectively kill breast cancer cells. One of the strategies is equipping NK cells with enzymatic machinery that can chew away the cancer cell glycocalyx. And the other strategy is equipping NK cells with engineered receptors that can penetrate the glycocalyx and functionally link immune cells to targeted cancer cells.

**Q** Is the potential role of the glycocalyx in protecting cancer cells from detection by the immune system a recent discovery?

**SP:** The importance of the glycocalyx for immune response is a recent discovery. One reason we haven’t known about the biophysical role of the glycocalyx is because we couldn’t measure its thickness precisely before. But in our study, we were able to measure this thickness with a custom-developed microscope. It’s called Scanning Angle Interference Microscopy — SAIM — and with that approach, we can actually measure the glycocalyx thickness, reading in nanoscale resolution.

We have used genetic engineering techniques to create cell lines with different thicknesses of glycocalyx. By combining genetic engineering techniques with SAIM, we were able to understand the biophysical properties of the glycocalyx in these engineered cell lines. And then we measured how many engineered cells were killed by NK cell attack. Here, we found that tiny changes in thickness of the glycocalyx as small as 10 nanometers could affect NK cell response.

**Q** Is one of your aims, then, to enable the body’s natural defenses to recognize cancer cells after the thickness of the glycocalyx has been reduced?

**SP:** Yes, one of our aims is to reduce the thickness of only the cancer cell glycocalyx to help the body’s natural immune system.

As we discussed, the glycocalyx thickness is a main factor in immune engagement. Immune cells will recognize cancer cells and kill them more easily after reducing the cancer glycocalyx thickness.

StcE mucinase is one of the enzymes that can digest mucins. We can tether this anti-mucin enzyme, or mucinase, to the NK cell. By anchoring mucin-specific enzymes on the engineered NK cell, we found that most of mucin-expressing tumor cells were killed by engineered NK cells.

**Q** Are you doing this work on cells in petri dishes or in animals?

**SP:** We use cancer cell lines. Our NK engineering technique has been verified in petri dishes and we are planning to do animal studies with our technique in the near future.

The glycocalyx is a complex structure like a forest. A forest is full of different types of trees. Just like thinning trees in a forest, we will reduce the glycocalyx thickness by using different enzymes that can cut different mucins like trees.

Thus, my first aim is to make a universal platform that can capture different enzymes on NK cells and I hope these engine sets can then kill the cancer cells efficiently.

**Q** You're approaching the glycocalyx from different angles, chemically speaking, and intend to attack it on as many fronts as you can.

**SP:** Yes. What we’re saying is, ‘What if the structure of the glycocalyx is very important in developing immunotherapy?’ That’s a new way of looking at immunotherapy.

And the next aim is chimeric antigen

*Continued on page 25.*
A Blessing for the Courage to Try

Blessed are you, faced with the impossible.

You who do not take your eyes away from what threatens to swallow you whole.

You who stare down reality, though your heart quickens.

You for whom action comes swiftly, as you chart the next step or bulldoze a new path yourself.

You know how to turn hope into action.

And blessed are you who, when you’ve come to the end of what is possible, find the courage to live there too.

Blessed are we, who are learning how to hope. and how to let go. when to act. and when to stop.

Balancing the impossibility of so much love and so much to fear. Together.

By Kate Bowler, katebowler.com used with permission.

What Do Those Living With Metastatic Breast Cancer Wish Others Knew?

By Pat Battaglia

From Erin B:

I’d like everyone to know there is a bipartisan bill in Congress now with over 200 co-sponsors. The Metastatic Breast Cancer Access to Care Act (HR 3183) expedites payments for those who have been diagnosed with metastatic breast cancer (MBC). This is especially helpful for young people diagnosed with MBC as well as many others.

THE METASTATIC BREAST CANCER ACCESS TO CARE ACT (MBC-ATC Act)

This bill eliminates the five-month waiting period for Social Security Disability (SSDI) benefits and subsequent twenty-four-month waiting period for Medicare coverage for individuals with MBC, or breast cancer that has spread to areas of the body outside the breast and surrounding lymph nodes. Under current law, most individuals, including those with MBC, must wait five months after the onset of disability to begin receiving SSDI benefits and an additional twenty-four months to become eligible for Medicare.

This MBC-ATC Act is now before Congress for the third consecutive year. In the current congressional session, it was introduced by U.S. Representatives Kathy Castor from Florida and John Katko from New York, along with thirty-six other members of Congress from both sides of the aisle.

Why is the MBC-ATC Act important? While MBC is treatable, there is no cure. Living with MBC often limits a person’s ability to maintain their employment and receive health benefits. Those who must retire early need funds to cover their living expenses and access to life-prolonging treatment. Waiting nearly two-and-a-half years to receive benefits is a significant burden for them. While many with MBC live for years, or even decades, after their diagnoses, survival rates vary. Some have died of the disease while waiting for their benefits to begin.

What can YOU do to help? Thank your congressional representative in your district for supporting the MBC-ATC Act. We are pleased to report that ALL congressional representatives from Central and Western New York have signed on as co-sponsors of this bill.

How do you find your representatives? Go to www.house.gov/representatives/find-your-representative and type your zip code into the search bar. Their names and contact information will appear. Phone calls, emails, and written letters all have an impact, and combining them multiplies that impact.

You can make a difference!

For more information: www.congress.gov/bill/117th-congress/house-bill/3183

BreastCancerCoalition.org
THE 19TH ANNUAL CINDY L. DERTINGER
ADVANCED BREAST CANCER SEMINAR

Tools for the Journey

LIVING WITH METASTATIC BREAST CANCER

THURSDAY, OCTOBER 13, 2022
1:00 - 5:00PM
Held virtually, via Zoom

MODERATOR:

MARCIA KREBS, MD, Medical Oncologist, University of Rochester Medical Center

PRESENTERS:

MARILYN LING, MD, Radiation Oncologist, University of Rochester Medical Center

“Management of Side Effects of Radiation”

AJAY DHAKAL, MD, Medical Oncologist, University of Rochester Medical Center

“Medical Updates in Advanced Breast Cancer”

SABRINA VOGLER, CPC, CEC, CGSS, Wellness Coach, Heart in the Moment

Mindfulness Coaching

“How Can We Manage Scanxiety?”

SURVIVOR SPEAKERS:

KELLIE ANDERSON • SUSAN COWDERY, MD

Special thank you to our community co-sponsors:

M&T Bank

M&T Bank provides funding for this event in memory of their friend and
colleague, Cindy L. Dertinger.

BreastCancerCoalition.org
In the waning days of the summer of 2020, Kathy Q experienced increasing pelvic pain that became so severe, she was admitted to the hospital. When imaging revealed an eight-centimeter mass on her ovary, the attending physician’s verdict was ovarian cancer. Surgery would be needed to remove the growth. However, when her OB/GYN examined Kathy the next day and ran some tests, this doctor did not feel the mass was cancerous. Still, she agreed it should be removed. Kathy opted for a complete hysterectomy, including removal of the ovaries.

The aftermath of her surgery brought unexpected news. Kathy’s pathology results revealed endometrial adenocarcinoma, also known as uterine cancer. It was stage 3A1, which means the cancer had spread to the outer layer of the uterus and potentially into areas immediately surrounding it.

“I was shocked because I thought it was not cancer according to the test my doctor did. Then I was scared because I lost my mom in 2015 to ovarian cancer,” Kathy recalls. “I thought, ‘I do not want to die.’”

“I was lucky that my sister Karen is a surgical scrub tech in obstetrics,” Kathy notes. “She had personally worked with my doctor and my oncologist so I knew both were great doctors who would take good care of me.” Kathy and her health care team put together a treatment plan consisting of chemotherapy, radiation treatments, and brachytherapy, a form of targeted radiation treatment. Kathy tolerated her treatments well. “The symptoms I had were bone pain, neuropathy, dizziness, and nausea, but I am doing great now over a year out of treatment. I’m still a little fatigued, but I am getting there.”

Throughout her treatment, Kathy’s family and friends rallied around her. “My brother Kevin, sisters Karen and Kim, and my dad have been here this entire time supporting me. My sister-in-law Karleen was awesome; she cooked for us, sat with me when I was not feeling well, and shopped for us. I have great friends who helped – too many to name – and my best friend Doris never left my side. She came over or called every day.”

Kathy’s work life was also impacted by her diagnosis. “I had just started a new job nine months before so I feared what might happen with that. But my co-workers were awesome and took great care me. Because of the pandemic, my employer laid me off but kept my health insurance, so I was able to do my treatments and safely recover at home.”

“I never knew the Coalition helped with gynecologic cancers. When I saw they did, I called and spoke to Ali, who set me up with a GYN101 session ... The programs are great and have helped me so much.”

Kathy Q.
“During my first oncology visit, I was given a lot of information, including information on the Coalition,” Kathy continues. “I never knew the Coalition helped with gynecologic cancers. When I saw they did, I called and spoke to Ali, who set me up with a GYN101 session and it went from there. The programs are great and have helped me so much. I have attended the support groups and still do, and some of the educational seminars, the Brown Bag lunch, participated in the PALS* program, and this was my first-year volunteering for the Mother’s Day Weekend Pink Ribbon Walk.” A recently trained PALS mentor, Kathy has extended a compassionate listening ear to those facing a recent diagnosis similar to her own, and we’re pleased to have her on board with us.

To those who find themselves facing endometrial cancer – or any cancer – Kathy suggests, “Take it one day at a time and remember to breathe.” As simple as it sounds, taking that next breath can be difficult in the aftermath of a life-altering diagnosis. “It’s scary when you hear you have cancer, and the unknown can give you a lot of anxiety.”

Yet hope still abounds. “The fact that I am over a year out of treatment and still in remission gives me hope. My faith in God helps. I pray for myself and “my cancer family” often. Staying positive helps also; I always tell people that is key for getting through this entire process.”

Kathy’s hope and optimism are rooted in having faced her fears, asked the hard questions, gathered her inner resources, and relied on her support network. She has, in turn, become a treasured member of the Coalition’s survivor community, extending a compassionate listening ear to others along the way. We are grateful to have her with us!

*Please see pages 12 - 13 for more information on Brown Bag, PALS, and all our programs.

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Johnson & Johnson to Discontinue Talc-based Baby Powder

By Pat Battaglia

On August 11, 2022, the Johnson & Johnson (J&J) company announced that they will end worldwide sales of their talcum-based baby powder and switch to a formula based on corn starch by 2023. For many years, health and justice organizations, government agencies, investigative journalists, cancer survivors and advocates, and other concerned people have called for this change, citing studies that suggest using talcum powder (also called talc) in the genital area can increase a woman’s chances of developing ovarian cancer.

Talc deposits in the earth are often found in the same places as asbestos deposits, and talc can become contaminated during the mining process. Testing done by J&J from 1972 -1975 confirmed this contamination, as did FDA testing in 2019. Asbestos has been classified as a known human carcinogen.

J&J’s iconic, talc-based baby powder has been marketed and sold for a variety of uses in children and adults, as well as to communities of color. Numerous lawsuits have been filed to hold the company accountable for the sales of this product and the marketing practices that have fueled those sales.

As advocates, we are hailing the withdrawal of J&J’s talc-based baby powder as a long-awaited victory.

For more information, go to Women’s Voices of the Earth: www.womensvoices.org/media

2. www.center4research.org/talc-and-ovarian-cancer
Advocacy Chair Update

Making A Difference

By Christina Thompson

This is a very exciting time of year for all things advocacy-related, and the Breast Cancer Coalition’s Advocacy Committee has been hard at work! Midterm elections provide the opportunity for our committee members to introduce our organization to those running for office. And while legislative sessions are in recess, we get busy planning for when our representatives return!

During the summer, we continued to meet monthly to strategize and plan ways to drive momentum on two major pieces of legislation: the New York State Safe Cosmetics Act¹, or S3331B/A143 and HR 3183, the Metastatic Breast Cancer Access to Care Act² (MBC-ATC Act). Our strategies include meeting with local legislators to thank them for their support and query as to the best approaches leading into the upcoming term. At the state level, 135th District Assemblymember Jennifer Lunsford and her legislative aide, Heather Neu, joined a virtual meeting to discuss S3331B/A143 and chat about who may be named committee chairs in the upcoming term. At the federal level, we met with 25th District Congressman Joe Morelle while he was in Rochester to thank him for supporting HR 3183 and discuss ways to bring in the remaining two New York State Congressional members who have yet to sign on, downstate Representatives Meng and Ocasio-Cortez.

The Coalition’s Advocacy Committee consists of empowered members who care deeply about the legislation that supports cancer survivors. Our members share their personal stories and discuss how the legislation impacts them directly.

Mary Ellen Capineri has taken a leadership role and acts as a liaison to the advocacy committee regarding the NYS Safe Cosmetics legislation. Thank you, Mary Ellen!

Rebecca Solomon has served as the senior team leader liaison between the National Breast Cancer Coalition (NBCC)* which includes support for MBC-ATC Act. Thank you, Rebecca!

Are you interested in learning more about these bills and other pending legislation? Would you like to make your voice heard following your own diagnosis of breast or gynecologic cancer? Has someone in your life experienced a diagnosis and you’d like to join our efforts? Please contact the Coalition for Advocacy Committee meeting information.

“Despite the similarity in our names, the Breast Cancer Coalition is an independent, local organization unaffiliated with any national group, including the National Breast Cancer Coalition. We chose 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’re stronger.

1. “The purpose of this bill is to regulate ingredients in personal care products, to better assess its impact on the environment and on public health.” nysenate.gov/legislation/bills/2021/s3331

Would you like to make your voice heard following your own diagnosis of breast or gynecologic cancer? Has someone in your life experienced a diagnosis and you’d like to join our efforts? Please contact the Coalition today at info@bccr.org.
As a mentor in our Emerging Leaders Program, I was fortunate to attend this year’s Advocate Leadership Summit in Washington D.C. The Summit is offered annually by the National Breast Cancer Coalition*. Our group of Emerging Leaders left Rochester bright and early the first Saturday in May. Over the next three days, we attended multiple educational plenary sessions.

One plenary session that stood out to me was The Crazy Confluence of Congress, Liquid Biopsies, Medicare, and Health Inequities, presented by Gilbert Welch, M.D. During his presentation, Dr. Welch discussed liquid biopsies, which are simple blood tests that can detect multiple types of cancer early, even before a person has any symptoms. He explained the pros and cons of this type of testing. As attendees learned, the idea of finding cancer early, before it has any symptoms, sounds great. But when you take a closer look at the data – or lack of data – it seems we are trying to run before we walk.

After listening to Dr. Welch, I realize more research needs to be done before we can begin to utilize this type of testing. Numerous questions still need to be answered first. Just a few examples include:
- Will liquid biopsies work as claimed to diagnose cancers early?
- If so, will they work accurately enough to make them worthwhile?
- What is the cost of this screening test?
- How will this testing improve health inequities?

A bill called The Medicare Multi-Cancer Early Detection Screening Coverage Act of 2021 was introduced into Congress last year and is gaining a good deal of bipartisan support. This law would require Medicare to cover the cost of these screening blood tests. However, legislators need answers to the questions surrounding these tests before they consider signing on to this bill. For now, it is apparent that more randomized controlled clinical trials are needed to provide clarity on the effectiveness of liquid biopsies.

*More about NBCC can be found on p 10.

Liquid Biopsies: Important Questions Remain

By Ali Dennison

Anaplastic large-cell lymphoma (ALCL) of the breast is a rare form of cancer, comprising about three percent of all breast lymphomas, and has been implicated as an adverse effect of breast implants. A report published on July 21, 2022, in JAMA (Journal of the American Medical Association) Oncology indicates that the incidence of this rare malignancy may be higher than previously estimated. A cohort study using data from the SEER (Surveillance, Epidemiology, and End Results) database provided by the National Institute of Health, estimated between 14.5 and 19.6 cases of breast ALCL per 100 million people occurred between 2012 and 2018 in the United States. While still quite low, these rates are higher that a previously-issued estimate by the Food and Drug Administration (FDA) of three cases per 100 million people, which was based on SEER data from 2001 to 2007.1

Breast-implant-associated ALCL (BIA-ALCL) is strongly associated with textured breast implants. In 2019, Allergan announced a voluntary worldwide recall of their Biocell textured tissue expanders and breast implants, effectively removing a large number of these devices from the market.2 A warning on all breast implants was issued by the FDA in 2011 and strengthened in 2021.3

Treatment decisions in the aftermath of a breast cancer diagnosis are varied, complex, and highly personal. Breast reconstruction using implants is a viable option for many. Plastic surgeons who perform breast reconstruction will review the updated FDA guidelines with those considering implants, informing their patients of the benefits, the risks, and long-term monitoring recommendations so they are in the best position to make empowered decisions regarding their care.

3. fda.gov/medical-devices/breast-implants/labeling-approved-breast-implants

Breast Implant Associated Lymphoma: An Update

By Pat Battaglia
Although we have remained open throughout the COVID-19 pandemic, safety remains our primary concern. For this reason, our programs are being held in a hybrid format (some virtual/some in person). Please visit our website or social media pages for updates. Our programs will remain fluid as we adjust to current NYS DOH and CDC guidelines.

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 survivors at any stage of their journey.

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.

Gentle Yoga
Gentle Yoga includes breathing exercises, restorative yoga postures, and mindfulness exercises. Yoga activates a relaxation response and can help relieve feelings of anxiety. The goal of the class is to relax, be mindful, and to improve range of motion and flexibility. Participants benefit most when they are present for the full duration of each class. Classes are 1 hour and 15 minutes.

Offered throughout the year on:
• Monday mornings
• Monday afternoons
• Monday evenings
• Tuesday mornings*
• Tuesday afternoons*
• Wednesday mornings
• Saturday mornings
• Sunday mornings

*Tuesday Yoga programs are offered thanks to the generosity of Reenie Feingold.

Mindfulness & Meditation
A way of connecting with your natural state of mind and breath to calm the mind. The goal is to improve your ability to relax, concentrate, and be aware of the present moment. Classes are 1 hour and 15 minutes.

Offered throughout the year on:
• Wednesday evenings
• Saturday mornings

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

Offered throughout the year on:
• Thursday afternoons
• Saturday mornings

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.

Offered throughout the year on:
• Saturday mornings

Voices & Vision
An engaging writing class for those interested in thinking 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’s journey. For those interested, there will be opportunities to share your writing with the group. Classes are 1 hour and 30 minutes.

Please visit www.breastcancercoalition.org to view our program calendar for a current listing of available classes.

Call us at (585) 473-8177 or email us at info@BreastCancerCoalition.org if you have any questions, want to enroll in a class, or want to be added to our mailing list.

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BreastCancerCoalition.org
**GIVE AND GET SUPPORT**

Our 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.

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| **Breast & GYN Cancer Group** | Gather, support, network, and discuss your journey with others diagnosed with breast or gynecologic cancer. Professionally facilitated.  
**VIRTUAL Discussion Groups:**  
- 2nd and 4th Mondays at 5:30pm  
- 2nd and 4th Tuesdays at 5:30pm  
**Virtual links online.**  
**IN PERSON Discussion Group:**  
- 1st and 3rd Thursdays at 5:30  |
| **Newly Diagnosed or In Active Treatment Networking Group** | A professionally facilitated group to discuss your experience/questions.  
**VIRTUAL Discussion Group:**  
- 1st and 3rd Wednesdays at 10:00am  
**Virtual links online.**  |
| **Partners/Spouses, Family & Friends Networking Group** | Find camaraderie with others supporting a loved one diagnosed with breast or gynecologic cancer. Professionally facilitated.  
**• IN PERSON:**  
- 1st Tuesdays at 5:30  
**• VIRTUAL:**  
- 3rd Tuesdays at 5:30  
**Virtual links online.**  |
| **Brown Bag Discussion Group** | A weekly discussion group over lunch!  
**VIRTUAL Discussion Group:**  
- 1st Fridays at 12:00noon  
**Virtual links online.**  
**IN PERSON Lunch Group:**  
- 2nd, 3rd, and 4th Fridays at 12:00noon. Bring your lunch; dessert is on us!  |
| **We are grateful to our Brown Bag sponsors!** |
| **Common Ground:** | Living with Metastatic Breast or Gynecologic Cancer  
Join others coping with a diagnosis of metastatic breast or gynecologic cancer. Professionally facilitated.  
**Register** with Christina@bccr.org.  
**IN PERSON Lunch:**  
- 1st and 3rd Thursdays at 12:00noon  
**VIRTUAL Discussion Group:**  
- 2nd and 4th Thursday at 1:00pm  |
| **Young Survivor Gatherings** | An informal and fun way to connect with others who walk a similar path.  
**• Call or email to be added to our invitation list.** |
| **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 Seminar** | Evening Educational Seminars bring information and education to our survivors and community friends. Held on the 4th Wednesday of the month at 7pm. VIRTUAL; register online.  
**We are working on the 2023 schedule. Check our website and social media for updates!**  |
| **Lymphedema Networking Group** | For those living with lymphedema, caregivers, therapists, medical personnel, and those at risk for developing lymphedema. Professionally facilitated. VIRTUAL links online.  
- 2nd Wednesday of the month, 6:00pm  |
| **Book Club** | Every 4th Thursday of the month at 6:00pm. VIRTUAL links online.  
- October 27: *The Book of Longings* by Sue Monk Kidd, facilitated by Carol Moldt.  |
| **Surviving & Thriving on Aromatase Inhibitors** | Through increased movement, stretching exercises, and nutrition, 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.  
- Wednesdays in January 2023, Registrants must commit to all four sessions in a series.  |
| *This series is supported with funds from the State of New York Department of Health.* |  |
Virtual programs became a lifeline for our survivor community in March of 2020 due to the Covid-19 pandemic. As we have begun to peek out from under our physically-distanced rocks, it is exciting to imagine coming back together in person!

This year, The Breast Cancer Coalition will host the 22nd Annual Lives Touched, Lives Celebrated... in person for the first time since 2019! This beloved program is a special evening that traditionally features a candlelit walk through Neighborhood of the Arts; live, uplifting music; poetry and reflection readings; and contemplative words from a community spiritual leader. The objective for Lives Touched, Lives Celebrated is to honor and pay tribute to the lives of all who have been touched by a diagnosis of breast or gynecologic cancer.

On Wednesday, October 26th, at 7pm, the traditional candlelit walk will start us off, after which we will welcome musicians from the Rochester Philharmonic Orchestra in collaboration with the RPO’s Community Partnerships. Original poetry written by survivor participants from our Voices and Vision program will be shared, and commemorations submitted by our larger community will be read. This event is a unique, inspiring celebration, and we look forward to sharing it in person with our survivor community. Advance registration is required; look for information in your email! Not on our email list? Sign up at Info@bccr.org.

What is a Death Café? Death Café provides an open, confidential, and respectful space to discuss thoughts, feelings, concerns, and more about dying. The format is flexible, lightweight and straightforward. What makes it special is the discussion about death; there is no need for bells and whistles. Food is always a feature – and cake! It is also important to know what Death Café is not. It is not a bereavement support or grief counseling setting. Death Café doesn’t work for people who, for any reason, aren’t able to discuss death comfortably and openly. Death Café is not an opportunity to give people information about death and dying - regardless of how good or important it is. Rather, we create time to discuss death without expectations. Death Café is offered all over the world, and we have hosted several sessions at the Breast Cancer Coalition. Look for upcoming dates in your email!

Have you been diagnosed with gynecologic cancer? This umbrella of cancers includes: ovarian, endometrial/uterine, fallopian tube, vulvar/vaginal, and cervical cancers. Are you interested in being part of focus groups conducted by the Coalition regarding how to best serve the needs of our gynecologic cancer survivors? The Coalition has been serving gynecologic cancer survivors since 2014 and we would like to hear from YOU! Please contact the Coalition via email: info@bccr.org.

Welcome to the Team!

The Coalition staff and Board of Directors extend a warm and hearty welcome to our newest staff members, Karissa Kuhl and Breanna Pollet. We’re already enjoying your company immensely and look forward to working with you in the time to come!
Does anyone else measure their life as Before Breast Cancer and After Breast Cancer? BBC and ABC? I found many others who do that at the Breast Cancer Coalition – it’s not so strange.

I was 62 when my malignancy was spotted during a routine mammogram, amazing the surgeon who admired the skill of the radiologist. Even though the lesion was small, it had broken through the duct, and Dr. H wasn’t comfortable doing less than a mastectomy. She partnered with the plastic surgeon: they operated in tandem. When I awoke, I was already being put back together. Physically, at least.

My 30+ career has centered on developing and facilitating support groups. I had begun a group at the Cancer Center at Strong, then worked with the Breast Cancer Support Group at Cancer Action, then had the opportunity to develop the Bereavement Program at Lifetime Care Hospice. I had a naturally occurring support system among my colleagues at work; many of us were diagnosed with breast cancer in a span of two or three years. And family and friends truly showed up for me – a crash course in how to be a loving friend!

I came late to the Coalition through a side door. My path had crossed with Holly Anderson’s several times, most recently through a course I taught called The Best Care Possible At the End of Life. She invited me to speak with Coalition staff about “Grief and Grieving.” After this, opportunities to be a substitute facilitator arose. I welcomed this development and eagerly said “yes” when an opening came to work with women sharing Common Ground. In addition to all the best things support groups can offer (i.e. practical tips, ease of conversation, true understanding, subjects that even the most loving family and friends may be tiring of, and topics that feel taboo in our wider culture), they provide a simple opportunity to put feelings into words. Simple, but the premier counseling technique!

A surprise to me is how much I benefit from these exchanges, even 14 years after my diagnosis and surgery. While my brush with breast cancer was minimal compared with many, I do relate to the anxiety, the body changes, the struggles with the unknown, the challenge to intimate relationships, the waiting for results and oncology consultations, and our sometimes seemingly unfeeling medical system. The Coalition is a “haven in a heartless world”. I must also praise the compassionate, smart and dedicated staff who set the tone and execute the many programs. When I was still working in bereavement care, I was impressed with the book The Body Keeps the Score by Dr. Basel van der Kolk. The title speaks loudly to me: I (we) have been through something quite traumatic. Our body, mind and soul “remember.” Therefore, it continues to be important to share – even wordlessly. The chance to be with “sisters” (and occasionally brothers) is hugely healing. Thank you!

"...I do relate to the anxiety, the body changes, the struggles with the unknown, the challenge to intimate relationships, the waiting for results and oncology consultations, and our sometimes seemingly unfeeling medical system."

- Theo Munson
On August 1, the Breast Cancer Coalition hosted the 20TH ANNUAL TEE’D OFF AT BREAST CANCER GOLF TOURNAMENT at Midvale Country Club. The morning golfers took to the links as early as 7:30 am, with the perfect temperature and overcast skies. The sun began to peek through the clouds as groups of golfers arrived throughout the day, until the last foursome headed out at 2:40 pm.

The day continued with the musical stylings of Amy’s Wish, a local folk band that performs in memory of Amy Schnitzler, a dear friend of the Coalition who died in 2019 from metastatic breast cancer. The night concluded with the presentation of awards:

1st Place, Men’s Team: Score 56
- Jim Edmister
- Matt Sawyer
- Shamus Stack
- Sean Killeen

1st Place, Mixed Team: Score 64
- Donna Patton
- Ben Carlson
- Sam Burgess
- Laura Beganny

1st Place, Women’s Team: Score 72
- Michele Romano
- Bridget Leipold
- Sarah Klein
- Marybeth Barbar

With an impressive 212 golfers, 43 sponsors, and over 100 silent auction items, it is no surprise that this event raised more funds than ever before – a net amount of well over $37,000! We’d like to extend a very special thank you to our Presenting Sponsor, Roc Auto Service & Tires, for their commitment to our mission.
20th TEE’D OFF
AT BREAST CANCER
GOLF TOURNAMENT

DEVELOPMENT/SPECIAL EVENTS

Thank you!

Golf Planning Committee
Holly Anderson
Lee Cordero
Colleen Dupuis
Carla Edmister
Carly Euler
Douglas Goldberg
Karissa Kuhl

Michelle Lindsay
Sean Patton
Susie Smith

Golf Tournament Volunteers
Aaron Cook
Aileen Gatti
Colleen Dupuis
Dawn Robinson

Deb Barr
Deb Bishop
Evan Euler
Grace Allison
Jacob DeVolder
Julie Overbeck
Karissa Kuhl
Lauren Henry
Linda Geraci

Marcy Lazio
Mary Carafoes
Mary Gilligan
Michelle Lindsay
Mimi Hawkins
Nancy Decker
Pauline Kubica
Sheila Hayes
Taylor Malta

BreastCancerCoalition.org
The Coalition has awarded a young scientist with a grant in the amount of $25,000 to support breast cancer research. As of this year, our organization has awarded more than $1,000,000 in funding to researchers in Upstate and Western New York since our Research Initiative was launched in 2003.

Sangwoo Park is the first recipient of the Pamela Delp Polashenski M.D. Breast Cancer Research Trainee Grant for his proposal titled Overcoming the glycocalyx barrier to engineered cellular therapeutics. The grant was re-named in 2022 in memory of Dr. Polashenski, who died of breast cancer in December 2021.

Park is a PhD candidate at Cornell University. He spent a number of years working on breast cancer research at the Korea Advanced Institute of Science and Technology in Deajeon, South Korea, where he earned his Bachelor of Science degree in Physics before his acceptance to Cornell University. His current project examines ways to develop new strategies that enable the immune system to detect and destroy cancer cells.

The Coalition’s Research Review Panel selected Park’s proposal because of its “out of the box” approach to the treatment of breast cancer. Chimeric antigen receptors (CARs) are targets for a class of immunotherapy drugs that, unfortunately, have not worked well for breast cancer and other solid tumors. Park theorizes that this may be due to the physical shielding of cancer cells by a structure on the surface of cells called the glycocalyx. Targeting and disrupting this barrier is a logical and innovative strategy that may result in the development of a new line of therapeutics. It represents a novel approach in the treatment of breast cancer and, if successful, has the potential to significantly improve immunotherapy for the disease.

Employing cutting-edge techniques available in the laboratory of his mentor, Dr. Mathew Paszek, Park is using Scanning Angle Interference Microscopy (SAIM), which is capable of measuring the thickness of the glycocalyx barrier in nanometers.

The Review Panel was pleased with Park’s qualifications. In addition to his undergraduate work in South Korea, he has co-authored two method papers and is currently working on his thesis research in Dr. Paszek’s laboratory.

I look forward to following the progress of Sangwoo Park’s project with our Research Committee.
A PERSONAL JOURNEY: COLLEEN M., continued from page 3

My next call was to my parents. I dialed the phone knowing I was about to upend their entire world. After I told them the news, they came to my house that night and stayed for the better part of a year.

The next day, despite making endless phone calls, I was not able to get an appointment with an oncologist for at least a couple of weeks. At thirty-three weeks pregnant, this was not going to work for me. I remembered that the radiologist told me to call her if I needed anything, so I did. After giving me an incredible pep talk, she told me she would make some calls. About an hour later, she called back and said I had an appointment with an oncologist the following morning. I felt a lot better and was grateful to have someone so powerful on my side.

My husband and parents went with me the next day to my oncology appointment and we got the ball rolling. In the following days and weeks we met with the oncologist, the surgeon, the high-risk obstetrics team, a plastic surgeon, and sought second opinions with another oncologist and surgeon. Finally, I made my decision and my medical team was in place. I loved that everything was a team effort, not just between my oncologist and surgeon, but also with the obstetrics team. My biggest concern at that time was the health of my unborn baby. They answered all our questions and spent as much time with us as we needed. We ultimately decided to schedule a lumpectomy and port placement at thirty-seven weeks pregnant, and induce labor at thirty-nine weeks.

The baby cooperated and was born fourteen days after my surgery; a perfectly healthy baby boy. I had seven treatment-free weeks and was able to nurse him for that time. As it turned out, I needed a second surgery to be sure the cancer was gone, but thankfully it was much easier than the first.

The next step was chemotherapy: four infusions, three weeks apart. Then came radiation. I went once a day Monday through Friday for twenty-one days. I tolerated chemo and radiation relatively well. Fatigue was my biggest symptom, but I was not able to tell the difference between chemo fatigue and mother-of-a-newborn fatigue! I had good days and bad days but always had two little reasons to get up every day and play.

Because estrogen was found to contribute to the growth of my cancer, I now get an injection every twelve weeks to suppress my ovaries. I also take an aromatase inhibitor, a medication to further suppress estrogen. The side effects of these drugs were challenging at first but became more manageable after I took the Surviving and Thriving on Aromatase Inhibitors course through the Coalition.

My first encounter with the Coalition was at the suggestion of my oncology team. After my Breast Cancer 101 session, I attended an evening seminar on genetics with my mom. The timing was perfect because this was a topic I was dealing with at that time. It was wonderful to be more educated before making any decisions. That was the last in-person event I was able to attend for two years because of the COVID shutdown. But the Coalition made their services available via Zoom, so in addition to the Aromatase Inhibitor course, I participated in Gentle Yoga classes, and the PALS* program where I was connected with another young mother who was also diagnosed during her pregnancy. It was encouraging to know that someone had been in my shoes. I could ask her questions, see that she was doing well, and knew this cancer chapter in my life would not be my last. Eventually I was able to go back in person to the Coalition and became a PALS Mentor myself, then joined the Advocacy Committee. Being part of the Coalition has helped tremendously in my recovery and given me a new sense of purpose and a way to help others.

"Exhaust every resource you have to help yourself, then once you are on the other side, turn around and help someone else."

My life has changed in many ways since my diagnosis. I have more appreciation for life and am less anxious about the little things. I am able to look inward for answers I used to seek from others. I have more compassion for myself and for others. I understand that life is both painful and joyful, and you will miss so much of the joy if you are only worried about avoiding the pain.

The most significant thing that helped me through was my family, both immediate and extended. They are the biggest parts of my life. And my friends were always there for me. They showed up in some huge ways and may never know how much that meant to me. Therapy was invaluable to me during that time as well as meditation, reading, physical activity, and humor. My advice to anyone with a recent diagnosis would be to pause, breathe, process, get informed, and surround yourself with a supportive community. It can be family, friends, religious, professionals, medical, support groups, and of course, the Coalition. A support network can help you through; rely on them and do not feel guilty about it. Exhaust every resource you have to help yourself, then once you are on the other side, turn around and help someone else.

*Please see pages 12-13 for more information on PALS and all our programs. (We need to be consistent throughout the newsletter.)
The Advisory Council of the Breast Cancer Coalition is a group of experts from diverse fields who assist our organization in fulfilling its mission in the broadest possible way. Serving as independent, unbiased professional advisors to Coalition staff and members of the Board of Directors, they assist with specific questions, concerns, and issues related to their individual fields of expertise throughout the year. Once a year, members of our Advisory Council gather at the Coalition, along with our staff and survivors of breast or gynecologic cancer, to share experiences and expertise while reminding each other of the truth that it takes a community to serve a community. We at the Coalition are grateful to our Advisory Council for their vital role in our community and their commitment to our mission.

Love filled the VanBortel Subaru showroom earlier this summer as VanBortel shared the love with us...again! We're grateful for VanBortel's ongoing support throughout the years – truly making a difference in the lives of breast and gynecologic cancer survivors. We were overjoyed to be presented with two checks totaling $45,019 from the 2021-2022 Share the Love campaign!

Thank you to all of VanBortel's customers who chose to support the Coalition during the Share the Love event.

BreastCancerCoalition.org
In the aftermath of a breast or gynecologic cancer diagnosis, people are often faced with treatment decisions that can alter the landscape of their lives. Relying on the advice of medical providers is of primary importance in understanding which treatment options are open to an individual. Gathering information is helpful for many during this time, and the learning curve is frequently steep. Support from family, friends, co-workers, and faith communities is crucial. And, as the newly diagnosed individual gradually builds their circle of support, there is another member of this circle who can contribute in unique and important ways.

Peer Advocates Lending Support (PALS) mentors have walked these paths before. They have felt the emotional impact of a cancer diagnosis, gathered their resources, made their treatment decisions, and are living proof that there is life after cancer – or life WITH cancer in the cases of those with metastatic disease.

To those who are new to this experience and have reached out to the Coalition, we offer a connection with a trained PALS mentor who is carefully chosen based on similarities in their diagnosis and life situation. They offer a compassionate listening ear, the voice of experience, and wholehearted encouragement as the newly diagnosed person finds their way forward.

Listening is a powerful form of support, and feeling heard is empowering. Author Brené Brown says, “Empathy has no script. There is no right or wrong way to do it. It’s simply listening. It’s holding space, witholding judgement, emotionally connecting, and communicating that incredibly healing message of ‘You’re not alone.’”

No one needs to walk this walk alone. If you or someone you care about is facing a breast or gynecologic cancer diagnosis, call us at the Coalition. We’re here for you. We hear you.
Hit the Trails!

By Pat Battaglia

Picture it: the sun on your shoulders; the wind rustling through the trees overhead; the soft feel of the ground under your feet; the beautiful sights, soothing sounds, and earthy fragrance of the natural world. Not only are these experiences enjoyable, they're good for you. Hiking is a great, low-impact form of exercise, and the mental and emotional relief that comes from being in nature can be helpful during stressful times – or at any time!

Hiking has many proven benefits. In the short term, it can lower blood pressure, enhance the immune system, reduce stress levels, and restore attention. Regular hiking can help those wishing to lose weight reach their goals by enhancing overall wellness. Some regular hikers even experience decreased depression.*

The astounding beauty of the Upstate and Finger Lakes regions of New York State can never be overstated. Furthermore, our region is chock full of hiking trails through all kinds of terrain. From flat and even pathways to gently rolling hills to steep, rocky landscapes that challenge the most physically fit among us, there is something here for everyone.

*https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6993091/

STAFF PICKS

Several Coalition staff members are frequent hikers. Among the abundance of trails in our region, here are a few favorites:

- Holly, our Director, recently discovered Thousand Acre Swamp. "It’s an awesome set of trails- easy for any age! We did the mile loop and several offshoots. I can’t believe I’d never been there!" https://www.nature.org/en-us/get-involved/how-to-help/places-we-protect/central-thousand-acre-swamp/

- Christina, our Program Director, says “I recommend Watkins Glen State Park for a day trip with hiking and a great town to visit as well!” parks.ny.gov/parks/watkinsglen/maps.aspx

- From Pat, our Associate Program Director: “Channing Philbrick Park in Penfield is the perfect place for a soul-soothing walk surrounded by the sound of water tumbling through Irondequoit Creek.” penfield.org/detail_T12_R46.php

Ali, our Program Assistant, frequents several local trails. Her top picks are:

- Webster’s Whiting Road Nature Preserve - “The trails are color coded and clearly marked. Depending on the trails you pick, you can easily hike 1-4 miles.” webstertrails.org/maps/maps.php


FINDING TRAILS NEAR YOU

There are many apps and websites available to help you find everything from well-trodden paths to the hidden gems in our region. Here are a few ideas to get you started:

- AllTrails offers a free app and a website: www.alltrails.com

- Day Trips Around Rochester, NY is a Facebook community that frequently posts information about regional hiking trails, including photos.

- In Monroe County, go to www.monroecounty.gov/parks and click on any one of the parks listed to view trail maps. The same applies to any county in which you live or are near. This is a great way to explore our region!

- Go to www.iloveny.com/things-to-do/outdoor-adventures/hiking/

HAPPY HIKING!
Apple Galette

6 servings

What tastes like pie, is easier to prepare, and is just as delicious? A galette! This version takes advantage of the abundance of apples available in our region during the autumn.

FOR THE CRUST:
- 3/4 cup whole wheat pastry flour
- 1/2 cup all-purpose flour
- 1 tablespoon sugar
- 1/2 teaspoon salt
- 1/2 cup unsalted cold butter or non-dairy alternative, cut into small cubes
- 3–4 tablespoons ice water

FOR THE FILLING:
- 4 medium apples
- 3 - 4 tablespoons sugar
- 1 teaspoon cinnamon
- 1 tablespoon flour
- 2 tablespoons cold butter or non-dairy alternative, cut into small cubes

FINISHING:
- 1 beaten egg white
- 1-2 tablespoons sugar

FOR SERVING:
- 1 pint vanilla ice cream (optional but highly recommended)

INSTRUCTIONS:

Prepare the crust. Blend the flours, sugar, and salt in a bowl, then cut in the butter using a pastry cutter or your fingers. Add the ice water 1 tablespoon at a time until a crumbly dough begins to form. Turn the dough out onto a lightly floured surface and press it into a disc shape. Wrap the dough tightly and place it in the refrigerator for at least 1 hour, or up to 2 days.

Peel the apples, slice them thinly, and place them in a bowl. Add the sugar, flour, and cinnamon; toss gently until the apples are well coated.

Roll the chilled dough into a 12-to-14 inch circle and place it on a baking sheet. Set it in the freezer while you heat the oven to 400 degrees.

When the oven is hot, remove the pan from the freezer and arrange the apple slices in the center of the dough, leaving a 2-inch border around the edges. Drizzle any remaining juices over the apples, then dot with the butter cubes. Slowly start pulling the edges of the dough up and over the edge of the apple filling and pinch the dough together to secure it.

Brush the edge of the dough with egg white then sprinkle the whole galette with sugar. Bake uncovered for 25 minutes. Place a piece of aluminum foil lightly over the galette and continue to bake another 15 minutes. Remove the foil and bake an additional few minutes if needed. Watch carefully - the crust should be golden brown, the apples tender, and the juices bubbling.

Remove from the oven and cool on the baking sheet for 10 minutes. Slice and serve warm, topped with ice cream. Cool leftovers (if there are any) completely, cover them, and store in the fridge.

Recipe submitted by Pat Battaglia
We celebrate all who set an unwilling foot on this path, along with our friends and supporters.

The youngest of the “Weber five” children, Su Weber was born in Waco, Texas, in 1964. With Dad in the Air Force, the family moved frequently, eventually settling in North Syracuse-Cicero, NY. After earning her Bachelor of Arts degree from SUNY Cortland, Su’s artistic nature continued to grow and blossom.

In addition to being a talented artist and creator, Su was a published writer. She had a deep love for nature and gardening, and enjoyed having her hands in the dirt. An avid reader, Su also enjoyed knitting and canning. She loved her fur babies and was a wonderful caregiver.

Su explored the deeper meaning of life through prayer, meditation, and ritual. She will be remembered fondly by her Common Ground Peeps for her gentle smile, her peaceful presence, and thoughtful responses to her fellow travelers on this road. One of these fellow travelers, Nancy G., shares, “When we first met, I noticed an amazing, generous spirit which seemed to illuminate Su; particularly when she was in nature or reflecting on it. I was intrigued by her understanding of the universe, nature, and each place in it. I felt inspired when talking with her.”

Su is survived by her loving and supportive husband, David Blythe; her four siblings Doug, Lisa, John, and Rick, and by many family members and friends. Their lives – and our hearts at the Coalition – have been touched for the better by Su’s kindness and compassion.

By Lisa Rothrock and Pat Battaglia
receptor (CAR) engineering. CAR-T or CAR-NK therapy has been one of the most powerful immunotherapy techniques. Basically, CAR structures that target specific cancers, such as breast or lung cancer, can be anchored on immune cells to enhance immune activity. However, we showed that the thicker glycocalyx structure blocks CAR-T cell recognition and the efficacy of this treatment. So we thought, ‘What if we make the CAR structure longer so it can penetrate the glycocalyx more easily?’ That’s another idea we’re working on in this project.

**Q:** Would you say your goals are a better understanding of how to deal with the presence of the thickened glycocalyx, either by thinning it or using existing immunotherapy approaches that have been engineered to penetrate through that thickness?

**SP:** Immunotherapy targeting the biophysical properties of the glycocalyx has not yet been developed. Our goal is to develop better cancer immunotherapy by using our recent finding that glycocalyx structure is a major determinant of cellular resistance to immune cell attack.

The Breast Cancer Coalition’s support will get us a step closer to developing new immunotherapies that are highly specific and potentially able to cure breast cancer. Again, I’m very grateful for the Coalition’s support of my proposed work.

**Q:** We’re very happy to provide that support. As you know, the goals of our Research initiative are to address primary prevention of breast cancer, preventing it from metastasizing, halt progression and/or obtain regression should it metastasize, and ultimately, cure of the disease.

**SP:** To achieve the goal of curing breast cancer, animal studies must first be performed to optimize NK engineering techniques and to determine whether the proposed work will be effective in animals or humans. The Coalition’s support is very meaningful to me. As I explained earlier, I was hopeless at the time when I first witnessed cancer patients. However, as a scientist, I am so happy that there is something I can do for cancer patients with the new immuno-engineering technique.

**Q:** You didn’t get stuck feeling hopeless. Instead, you used that feeling to develop something that gives you, and all of us, hope. We’re grateful to you for the work you do and look forward to following your progress.

**SP:** Thank you very much for your kind words. I will do my best, and I really appreciate the Coalition’s support.

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**Muc1 highly overexpressed in most adenocarcinomas**

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**THE HUMAN PROTEIN ATLAS**

BreastCancerCoalition.org
Thank You Friends

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

LEONARD’S EXPRESS

We are always grateful to our friends at Leonard’s Express who started their pink truck campaign in 2015. The company donates a penny per mile traveled by their fleet of pink trucks, which are all driven by employees with relatives who are going through or have gone through breast cancer. During the 1st quarter of 2022 those trucks traveled 52,087 miles and raised $520.87 for the Coalition.

MONA MOON NATURALS

Mona Moon Naturals was created after owner, Mona Samaan-Ockenden’s, supported her sister through Breast Cancer diagnosis. Shortly after the creation of her products, she reached out to the Coalition to collaborate. In addition to supplying samples for all of our PALS Paks, Mona donates 10% of her profits to support the Breast Cancer Coalition. She recently delivered a check for $500 representing funds raised in 2021. Thank you!

WOMEN SUPPORTING WOMEN

The Women’s Association of Penfield Country Club’s Pink Ribbon Rally golf tournament was held June 8. A very special event, the tournament sold out on the first day of registration. We are grateful to receive $5000 from this wonderful event! They have supported the Breast Cancer Coalition since 2018. Kudos to all the amazing women golfers of PCC.

CHANNEL YOUR INNER FLAMINGO

We were thrilled when we received a letter with a picture of sweetly smiling ladies in pink. This small but mighty group of 24 women hold an annual golf tournament during their golf league season to raise money for a charity or family member in need. This year, through tournament entrance fees, golf games, raffles and a crazy hat contest, the group raised $720.00 for the Coalition! As the organizer Linda said, “Fun has been had every year, all for a good cause.” Thank YOU all for your generosity!

MY TERMINAL LIFE: CANCER HABITATION AND OTHER LIFE ADVENTURES

Avid blogger and beloved member of our Common Ground group, Amy Schnitzler was a light to the Coalition every time she walked through the door. After her passing, her mother, Judy Schnitzler, compiled her writings into a book that is now published. A portion of the proceeds from the sale of the book are donated to the Coalition. We are honored to be included in Amy’s legacy and grateful for the initial $52.49 received!

ACCELERATE THE GOOD

The hometown support that we receive is amazing. We were so excited to receive word from Matthews Kia letting us know that they wanted to sponsor us to receive funds through the Kia “Accelerate
“#RockStrong” t-shirts with the funds coming to the Coalition. So far sales to their family and friends have resulted in $560 in donations to the Coalition. #RockOn!

DANCE FOR BREAST CANCER

We always love spotlighting local youth and their efforts to raise awareness and funds for us. Local dance studios - Jameson Irish Dance Studio, DK Dance, The Floor Dance Company, Titan Dance and CRS Dance Team, joined together for some fun in early June to raise funds for our Research Initiative. Congratulations on raising $1,550!

LEMONADE FOR SALE!

Grandkids of our own Executive Director, Holly Anderson, took to the streets this fourth of July weekend selling lemonade to their neighbors in Port Bay, raising $80.85! Way to go!

GOAL!

Longtime supporter of the Coalition, SoccerSam Fantauzzo reached out to us in the spring with an idea to partner with the Coalition for the Rochester Lady Lancer’s 2022 season. In lieu of selling tickets, the team gave free tickets to fans with proof of a donation to the Coalition for their four home games. The initiative raised $1,574 for the Coalition. The team surprised us with an additional $4,000 – $1,000 for each of their four home games, bringing the total to $5,574! Grazie Molte!

Friends of the Coalition, Casey and Taylor Capuano, started a business called CAKESbody that sells reusable, washable, non-adhesive silicone inserts designed for workout, lounge and swimwear. On an ongoing basis $1 from each of these sales goes to the Coalition. This quarter they raised $1,710.00 for us!

THANK YOU MONGO!

We were thrilled to receive $163.83 from Krooked Tusker Distillery. They donate 1% of their cocktail sales to a nonprofit each month, and we were lucky enough to be a recipient in April! We just love their mascot, Mango the elephant!
IN HONOR OF:
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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 April 1, 2022 - June 30, 2022.

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### Wish List
- Breast cancer stamps
- Burt's Bees Lip Balm (sealed, no mint)
- Coloring books (pocket or travel size preferred)
- Sleeping masks, lavender or unscented only
- Computer paper, white, 20 lb
- Joann Fabrics gift cards
- Journals for writing
- Warm, fuzzy socks

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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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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.

22nd ANNUAL Lives Touched, Lives Celebrated

October 26, 2022 • 7:00PM at the Breast Cancer Coalition
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THIS IN PERSON PROGRAM WILL HONOR AND PAY TRIBUTE TO THE LIVES OF THOSE WHO HAVE BEEN TOUCHED BY A DIAGNOSIS OF BREAST OR GYNECOLOGIC CANCER.

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Gift baskets, restaurant gift cards, artwork, jewelry and more are available at BreastCancerCoalition.org.