Preparing Emerging Leaders

FEATURE STORY
After Breast Implant Reconstruction: Following Up on Informed Decisions

Gynecologic Cancer Seminar

Advocates in Washington

Research Initiative
FROM THE DESK OF THE EXECUTIVE DIRECTOR

FOCUSBING ON GROWTH

Summer is the season of growth and renewal. We see it in our gardens and window boxes. We see it in farm fields as we travel back and forth between cities. We see it in our children... our families... our friends... circles ever expanding, widening, and evolving.

Growth is my focus these days as well.

During these past two years, COVID has caused some of our favorite in-person events to be canceled or postponed, including our research award ceremonies, legislative receptions, and holiday gatherings. As events slowly return in a scaled-back way, we have found that many of our steady, beloved committee members have moved on; some have retired permanently to southern states. We have especially noted this on our Advocacy and Research Committees. These changes remind us that such evolution is always an opportunity to welcome new voices, fresh ideas, and diverse experiences to the table.

By Summer 2021, the median age of members of both our Advocacy and Research Committees was greater than 65 years. These dedicated advocates have a wealth of experience that would be lost if we didn’t address the obvious; we realized it was essential to narrow the age disparity as these long-established committee members retired and moved on. I began noodling on an idea for a training program that would prepare our young breast cancer survivors for leadership roles within the Coalition.

After discussions with our most experienced survivor-advocates, I confirmed their eagerness to help prepare the next generation of survivors for leadership. This meant actively recruiting and training younger survivors - of which, sadly, we had plenty.

In January, we launched our Emerging Leaders Program (ELP), funded by the Marilyn Lichtman Foundation. My goal was to recruit eight young survivors and pair them up with eight experienced mentors from our Advocacy and Research Committees. Ultimately, we exceeded my goal. The cover of this issue features photos of our ELP participants, both trainees and mentors.

In May, following training programs developed and conducted over the winter and spring months, five trainees and five mentors, along with four other trained survivor-advocates, traveled to Washington DC to attend a four-day Leadership Summit offered by NBCC.* This annual summit brought together the top breast oncologists and scientific researchers in the country where we learned the latest developments toward ending breast cancer. Additionally, at the end of the third day, these experts made themselves available for roundtable discussions with interested summit participants. This was one of the most exciting and engaging opportunities for our emerging leaders. On the fourth and final day, we traveled to Capitol Hill to share personal stories with the key staff members of our elected representatives. Here we were joined by other survivor advocates as our team leaders asked for support for research, screening and early detection programs, and the Metastatic Breast Cancer Access to Care Act.** We left deeply satisfied that seven out of eight of our regional representatives are fully on board.


*More information on this group can be found on page 10.
** Eliminates the waiting period for disability and Medicare benefits for those of any age with metastatic breast cancer.

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A PERSONAL JOURNEY: MICHELE C., an Emerging Leader
By Michele C.

Finding My Way after cancer

Sometimes I have trouble remembering my children’s birthdates, but I will never forget the date I first felt a lump in my breast. It was December 6, 2020. Or what I thought was a lump. Was it? Wasn’t it? Embarrassed to admit that I had not been doing monthly self-exams, I was not certain what to do, but knew I should call my doctor right away. I had turned 40 recently and was due for my first mammogram. A mammogram, ultrasound, and biopsy later, I received the news I never expected.

Aside from the craziness that the pandemic brought on, everything else about that year was great. It was a few weeks before Christmas, and we had been enjoying small, intimate holidays with our immediate family. I appreciated the way we were forced to slow down and “do less.” But learning that I had cancer stopped me in my tracks. Instantly, I had a whole new appreciation for everything.

There were a few weeks (that felt like months) while we waited to meet with all of the doctors. “We” means me; because of covid, my husband could only attend one appointment with me. Yes, one. In a matter of weeks, I had taken endless phone calls, made appointments, missed work without explanation, and met with a surgeon, medical oncologist, and radiation oncologist. It was a whirlwind, but I remember feeling relief after each appointment. There was a plan. We have great medical care in Rochester. I did my own research, and as terrified as I was to read about this disease, I was reassured that I was getting the right treatment.

Telling our families was the most difficult thing. How could I tell my parents? Our kids? At first, we kept quiet until we knew more. But each time I talked about it, I felt more relief. It was therapeutic to share my fears. And I was met with the most amazing support system. The meals we received, the cards, the calls and texts, front porch surprises; it all made a difference.

My surgeon was the first one to tell me I had triple negative breast cancer*. It grows fast, and is aggressive. Chemotherapy wasn’t something I had associated with breast cancer, and I really didn’t expect it since I was young and otherwise healthy. My treatment plan was chemo for six months, followed by surgery, and then radiation.

Chemo was difficult, both physically and mentally. I consider myself a strong person, and independent. But in a few months, I realized that I wanted to talk to someone else who had been through this. My family and friends were amazing, but it is different to share with

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AFTER BREAST IMPLANT RECONSTRUCTION:

Following Up on Informed Decisions

By Pat Battaglia
Breast cancer isn’t a single disease and no two people who face this diagnosis are the same; the treatment protocols and surgical options available to individual patients are complex, varied, and personal. Many, but not all, who undergo a mastectomy choose to have reconstructive surgery, and implant reconstruction is one of several techniques that plastic surgeons use to recreate the shape of breasts that have been removed.

Some reconstruction methods involve transferring tissue from another part of the body to the breast area; this is known as autologous reconstruction. Implant (or nonautologous) reconstruction is different. During this procedure, a plastic surgeon most often inserts a tissue expander, a temporary device that can be injected with saline solution, into the breast area. In a series of office visits that take place in the weeks and months afterward, the plastic surgeon (or a member of their team) gradually fills the expander. This allows the surrounding skin and muscle to slowly stretch and adjust, creating space for a permanent implant. When this process is complete, the expander is surgically removed and the implant inserted in its place.

Howard Langstein, M.D.
However, when it comes to breast implants, “permanent” is a relative term. “Breast implants are not considered lifetime devices,” said Dr. Howard Langstein, a plastic surgeon who spoke at a Coalition Evening Seminar in February of 2022 entitled Breast Implants: Understanding the Risks.* He shared the latest FDA guidelines on breast implants, issued on October 27, 2021, which state that, “Even if you have no symptoms, you should have your first ultrasound or MRI at 5-6 years after your initial implant surgery and then every 2-3 years thereafter. If you have symptoms at any time or uncertain ultrasound results for breast implant rupture, an MRI is recommended.”

Most implants will eventually need to be replaced, as Dr. Langstein noted in his presentation, and patients should be informed of that fact prior to their surgeries. The newly released FDA guidelines address breast implant details through several actions, including new labeling requirements and a checklist of potential complications for surgeons to review with their patients prior to surgery.1 As with all surgeries, the risks and benefits are carefully weighed to empower informed decision-making about these procedures.

Virtually all breast implants, whether used for reconstructive or cosmetic purposes, will cause the body to form a protective layer of scar tissue called a capsule around the device. This is normal. However, in some cases, the capsule thickens and tightens around the implant. This may cause it to change shape and, in a few instances, to rupture. The condition is called capsular contracture, and it is the most common complication following breast implant surgery. It is also one of the most common reasons for surgical replacement or removal of implants.2

Five years after her surgery, Kathy noticed rippling in one of her reconstructed breasts. After consulting with her surgeon, she underwent an MRI which showed that capsular contracture had caused her implant on that side to rupture and leak. Even though the other implant was still intact, Kathy and her surgeon decided it would be best to replace both of them. The surgery was scheduled and completed. Kathy healed well and, once again, life went on.

Another five years passed and she began to consider the monitoring protocol her plastic surgeon had advised; it was time to schedule an MRI to monitor the integrity of her implants. When Kathy called her imaging center, she learned that according to the center’s protocol, a mammogram would be scheduled first, and then an ultrasound if needed based on the mammography results. If more information was still needed, an MRI would be considered. “I hadn’t had a mammogram in ten years,” Kathy stated, recalling that her surgeon had advised her that these screenings were no longer necessary after her bilateral mastectomy. She was unsure about how to proceed.

Jennifer D.
Meanwhile, Jennifer (Jen) D. was experiencing a similar situation. “My OB/GYN felt a lump or bulge during a routine appointment and suggested that I see my plastic surgeon to determine what it was,” she shared.

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The Tower

Wood, clay, needle felting, acquired miniatures (24 x 24 x 46 inches)

Wells, the child of one of our beloved Common Ground Members, is an art student at Smith College. They created this intricate, imaginative, and powerful piece as a class project to honor their mother’s experience while acknowledging the impact metastatic breast cancer has had on the entire family. We are grateful to Wells for granting permission to include their powerful artistic statement here.

For me, exploring archives feels like play. Trying to piece together what someone was like or what their story was based only off of the objects that they left behind is a process that involves a lot of playing and imagination. I wanted to make this process more literal, creating an archive specifically for viewers to play with. As a child, my favorite form of play was making stories with my figurines, acting out interactions and scenarios as a form of exploration.

Like exploring an archive, this play constructs a narrative. Additionally, examining the definition of what an archive is has led me to the idea that spaces that people inhabit become archives of those people - living and changing archives. This informed my structure, a playset with figurines. But unlike a child playing with generic figurines, an archive has true narratives - what actually happened. My figurines needed to have a story behind them, some true narrative that viewers could potentially figure out - or completely miss. I have included a “true” narrative: this piece reflects the time I spent living at home with my mother, who is battling metastatic breast cancer. Each of the creatures in the tower represent a different aspect of living with cancer. Creating this piece has allowed me to confront the uncomfortable feelings that surround cancer, using play as a tool for processing.

I would like to thank all of my wonderful artist assistants; without you this project would not have been possible. Finally, I’d like to thank my mom, the Wizard, who was a huge inspiration for this piece and a massive support. I love you all!

THE TOWER by Wells

The Tower consists of a Wizard Tower and an Apprentice Tower. The Wizard (my mom) lives in a tower that is being attacked from below by the Cancer Beast, which is eating away at the tower supports. The Cancer Beast can only be kept at bay.

Shelf of Lore, with healing potions (not cures). Metastatic breast cancer is treatable, not curable, and the shelf is full of different options.

The Apprentice Tower with base too thick for the Cancer Beast to chew through. This is where I (and other family members) live.
Beast of Dietary Restriction; he guards the yummy fruit. My Mom has dietary challenges because of her cancer. This doesn’t happen to everyone, but it’s part of her story.

The Fatigue Beast and Wizard Throne for rest and hugs. Cancer fatigue is real, and when it’s there, the throne and Hug Beast are the best treatment.

Hug Beast, Fatigue Beast, and Wizard Throne

Hug Beast holding Wizard and Apprentice. Hugs are so important!
At 49 years old, I was living my best life. My children were doing well, and I was happy and having fun with my boyfriend of two years. I was one of many who believed the yearly Pap smear tested for all gynecologic cancers. The signs that something wasn’t right were subtle at first. For about four months, I experienced bloating, irregular periods, back pain, cramping, and eventually significant abdominal pain before I went to the OB/GYN.

Thinking I was going through menopause, I was put on birth control to alleviate my symptoms. However, those symptoms persisted and I came up with reasons for them all. My herniated discs explained the back pain; I was at the same age as my mother when she went through menopause; I went on a cruise, followed by holidays and birthdays, which explained the bloating – although, strangely, I was not gaining weight. When my mother saw the size of my tummy and said I looked pregnant, that was the moment I knew something was wrong. My primary care physician ordered some blood tests and an ultrasound, and thus began my 7.4 year journey with ovarian cancer.

Complete shock is an understatement. I had been diligent about my yearly OB/GYN appointments, so I couldn’t understand how this was undetected. I experienced every emotion you can imagine. In addition to shock, there was denial, fear, anger, hopelessness, sadness…and so on.

So many thoughts, so many scenarios swirled in my head. My family was greatly impacted by my diagnosis. My daughter was on top of her game, graduating Pittsford Sutherland High School with honors and in anticipation of attending School of Engineering at Clarkson University. My son was playing baseball, hanging with new friends, just being fourteen! My mother was devastated. My boyfriend went inward. He could not talk about it, just could not tolerate the feelings he was experiencing. I am fortunate to have a handful of “besties” and they were there by my side. I never attended an appointment alone; there was always a “cheerleader” with me.

Faced with many decisions, I was on autopilot, just following my oncologist’s plan of action. I was scheduled for a hysterectomy, to be followed by six months of chemotherapy. Surgery went as it should and I was fortunate to have mild to moderate side effects from chemo. I was grateful to still be able to take care of my family while working at a reduced capacity in my practice as a mental health therapist. It was encouraging to receive monthly confirmation from my oncologist that the chemo was working. At the end of treatment, I had No Evidence Of Disease – NED.

I was cancer free for almost five years and lived my life as normally as possible. Having put cancer in the ‘way back’ of my mind, I of course had an appreciation for life like never before and felt each day was a gift to be with my family, friends, and clients.

In October of 2020, the beast was back. I responded well to nine months of chemotherapy, but at the end of treatment I was not NED. I began taking a drug known as a PARP inhibitor, which seemed to be doing its job; the cancer was not growing. Unfortunately, my body could not tolerate the medication. The dosage was reduced twice, but the lower dose was ineffective. In March of 2022, I began a clinical trial, which I am currently on. The trial just fell into my lap, as an oncologist in the practice where I am being treated is a leader in that study. Like any trial, the hope is that the study medication works and can become a standard of treatment for others.

I learned of the Coalition when I was officiating a wedding of the daughter of one of my best friends. The groom turned out to be the nephew of Holly Anderson, and I soon became
I feel for all who find themselves as caregivers to us on this unintended walk with cancer. I often hear people say, “You’re so strong,” “You’re going to beat this,” “You’re so healthy otherwise,” “I know what you’re going through,” or “I know how you feel.” Those words are not usually helpful. Some helpful things to say to a person who is newly diagnosed are, “I’m not sure what to say, but I care and I am here,” or “We will get through this together,” or “How can I help?” Hug them, tell them you love them. Just “be” with them. Listen to them, sit next to them, validate their feelings, cry with them, or sit in silence. It can be hard for a friend or family member to just “be” with all of the emotions their loved one is feeling. But even attempts to do that are seen and appreciated.

Some helpful things to say to a person who is newly diagnosed are:

“I’m not sure what to say, but I care and I am here.”
“We will get through this together.”
“How can I help?”

To be honest, my hope has wavered of late. But I am trying. I try every day to be grateful that I am here and living and spending time with family and friends. Even though I don’t feel well many days, I have hope that my oncologist has a few more tricks up her sleeve. And I have given myself hope by beginning a journey to strengthen my mind-body connection through seeking knowledge of ways to help myself though healthy eating (including supplements) and meditation. I’m still here, still learning, still living my best life while finding out what that means for me now.
A group of empowered survivor-advocates from the Breast Cancer Coalition embarked on an early morning flight to Washington, D.C. on Saturday, April 30. Ours was the largest group attending the National Breast Cancer Coalition’s Annual Leadership Summit. Joining survivor advocates from across the United States, we gained new insights from experts on topics such as:

- Getting to Value Based Cancer Care
- Cancer Research News – Critical Appraisal Skills
- New Horizons in Breast Cancer Metastasis Research
- How Do Review Committees and Scientists Use Evidence to Launch Trials

Round table discussions followed some of the presentations, which allowed us to ask questions of the scientists. Additionally, workshops were held for our newer advocates:

- Building Your Relationships with New Members of Congress
- Advocacy is the New Normal
- Congress 101: Navigating Capitol Hill for Advocates

The days went quickly, and over dinner we compared notes from the seminars. The excitement was palpable among the advocate group! Immersing ourselves in the latest information helped to prepare us for what was coming next. After three days packed full of research, our final day was spent on Capitol Hill, visiting seven Congressional offices. All fourteen of us packed into each office, where some shared personal cancer experiences.

We were advocating for HR 3183, the Metastatic Breast Cancer Access to Care Act, and two annual appropriations:

- The Congressionally-directed allocation or $150 million to the Department of Defense Breast Cancer Research Program (the DoD-BCRP), and the
- Preservation of the Medicaid Breast and Cervical Cancer Treatment Program.

Enactment of HR 3183 would waive the 5-month wait period for SSDI and waive the 24-month wait period for Medicare for someone diagnosed with metastatic breast cancer under the age of sixty-five who can no longer work due to their disease. These waiting periods have already been waived for those with ALS (Lou Gehrig’s Disease) and End Stage Renal Disease.

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While in Washington, D.C. for the Leadership Summit, I attended the “Breast Cancer Disparities—Advancing Health Equity in Cancer Care” workshop session. This session included an incredible panel of five speakers and a panel discussion after.

This session started with a review of disparities in breast cancer between white women and women of color. I was surprised to hear what a large impact race has on breast cancer outcomes, although I was not completely shocked. It is widely known that the death rate during childbirth is much higher in black and brown women compared to their white counterparts, but I did not realize the same discrepancies are true across a wide range of medical conditions. Factors including, but not limited to, access to transportation, medical insurance, and medical facilities as well as socioeconomic standing, culture, air quality, water quality, fresh food proximity, and redlining all lead to serious disparities in health care.

I was most surprised to learn that participation of black and brown women in clinical trials, the cornerstone of so many medical advances, is significantly lower than in white women. Drugs, including side effects, were mostly tested on white women with the expectation that they would work similarly in black and brown patients. It was very interesting to listen to one doctor talk about the differences between the two groups at a biology/cellular level and what a difference there is in the effectiveness of some drugs. This is extremely important to know because many people are taught to believe everyone is the same regardless of color. However, when it comes to medical interventions, there are many real and important differences, and people need to be treated as individuals.

I was also surprised to hear that patients of color are often referred to certain hospitals, while white patients are referred to another, continuing the cycle of inequity. Many of these disparities are systemic and need to be eliminated one at a time before larger change can occur. Hospital systems, doctors, researchers, donors, and patients themselves can all be part of the solution.

As I start my advocacy journey, I will keep these things in mind and make sure I am advocating not just for myself, my ethnicity, or my subtype of cancer. I will advocate and fight for all, with a spotlight on people who may be disadvantaged and who need their concerns heard. I will be advocating for research for all types of breast cancer, advocating for all types of people to be included in clinical trials, and for access to quality health care for all women despite where they may live or how well-insured they are.

This session was eye-opening and I am glad it was included in the Leadership Summit. The more women we can bring together to fight for this cause, the better it will be for all of us and our children.

Fitting New Pieces into the Puzzle

By Julie Overbeck

The study of breast cancer, for me, is like trying to solve a 1,000 piece puzzle. In early May, at a Leadership Summit in Washington, D.C., I was able to pick up a few new puzzle pieces to see where they fit in the overall picture. One piece caught my attention because, as a retired medical technologist specializing in hematology, I love blood cells! I've turned this piece around and around to find its fit, and am fascinated by the technology now available to take “broken” T-cells (lymphocytes) from a patient, reprogram the DNA, and re-infuse the cells with new information to activate a restored normal cellular mechanism.

Dr. Simon Knott, Assistant Professor and Associate Director of the Center for Bioinformatics and Functional Genomics at Cedars-Sinai, presented background information on the types of genomic editing used in the past. He then introduced attendees at his session to CRISPR (Clustered Regularly Interspaced Short Palindromic

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HEALING ARTS

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.

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

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

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

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.

Contact us for an appointment.

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.

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.
# 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.

## 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

**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.

**IN PERSON:**
- 1st Tuesdays at 5:30
**VIRTUAL:**
- 3rd Tuesdays at 5:30

## 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.

## Book Club
Every 4th Thursday of the month at 6:00pm. VIRTUAL links online.
- **June 23:** *Hamnet*, by Maggie O’Farrell, facilitated by Jennifer Griggs, MD
- **July 28:** *Leave the World Behind* by Rumaan Alam, facilitated by Jessica Salamone
- **August 25:** *The Vanishing Half* by Britt Bennett, facilitated by Rachel David, MD

## 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

## LEARN

Research has shown that education and community have a positive effect on emotional and physical health outcomes.

### Evening Seminar
Evening Educational Seminars bring information and education to our survivors and community friends. Held on the 3rd Wednesday of the month at 7pm. VIRTUAL; register online.
- **July 27, 2022:** “Long Term Effects of Chemotherapy,” presented by Rachel David, MD
- **August 24, 2022:** “Cardiac Health and the Long Term Effects of Cancer Treatment,” presented by Anuradha Godishala, MD
- **September 28, 2022:** “Reducing Risk of Recurrence,” presented by Michelle Shayne, MD

### 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** with our last series beginning in September 2022, 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.
Programming Updates at the Coalition
by Christina Thompson

The Breast Cancer Coalition offers a large variety of programming at no charge to those with a breast or gynecologic cancer diagnosis. Perhaps you’ve taken part in a Mindfulness and Meditation session or have participated in a Voices and Vision workshop. Have you ever considered how the programs at the Breast Cancer Coalition evolved?

Surviving and Thriving on Aromatase Inhibitors is a flagship program currently in its sixth year which addresses the side effects of hormone blocking medications such as anastrozole (Armidex), exemestane (Aromasin), and letrozole (Femara). Approximately 67-80% of breast cancer is estrogen receptor positive, and many times medical oncologists recommend one of these medications to reduce the risk of recurrence.* Staff at the Coalition were listening during weekly Brown Bag Lunches and Evening Networking Groups as survivors routinely shared their experiences with side effects such as joint pain, hot flashes, and fatigue from these prescribed medications. Considering that the course of treatment may last for five, seven, or even ten-years, an intervention seemed important. Surviving and Thriving on Aromatase Inhibitors meets in four weekly classes in which participants learn how this medicine functions in our bodies, gentle exercises and stretches to help alleviate joint pain, mindfulness and meditation strategies to help improve sleep, and nutritional information to improve the diet. In the process, attendees receive support from fellow survivors experiencing similar situations. The program is facilitated by Melissa Clark, MS, OTR/L, CLT; Carol Giffi, NP (retired); Lesley James, MD; and Martha Neubert, LMSW (retired oncology social worker). Those prescribed Tamoxifen are also welcome.

This program and our many others are implemented based on feedback from our survivor participants. We conduct evaluations of all of our programs, and staff pores over the responses, which help direct and shape future programs! Do you have a topic of interest for an Evening Educational Seminar? Would you like to hear from an expert at our annual Gynecologic Cancer Seminar? Did you read an amazing book that our monthly Book Club might enjoy? We encourage YOU, our survivor community, to reach out and let us know! Our programming is supported by funds raised in our region, allowing us to offer programs at no cost to survivors. Make your voice heard and get your questions answered by completing surveys or making suggestions (info@bccr.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 - 4:30 p.m.

MODERATOR: Marcia Krebs, MD, URMC, Wilmot Cancer Institute

Marilyn Ling, MD
URMC, Wilmot Cancer Institute
“Management of Side Effects Of Radiation”

Ajay Dhakal, MD
URMC, Wilmot Cancer Institute
“Medical Updates in Advanced Breast Cancer”

Sabrina Volger, CPC, CEC, CGSS, Heart in the Moment
Mindfulness Coaching
“How Can We Manage Scanxiety?”

Survivor Speakers: Kellie Anderson and Susan Cowdery, MD

REGISTER TODAY!
BCCR.ORG

BreastCancerCoalition.org
Pink Ribbon Walk & Run – A Success!

By Carly Euler

On Saturday, May 7th, we gathered in Genesee Valley Park for the first time in three years to celebrate the 21st Annual Pink Ribbon Walk & Run. It was a chilly day, but that did not deter the warm spirits of our incredible walkers, runners, community members, and volunteers. The day kicked off with our emcee, Deanna Dewberry of News 10 NBC, whose bright smile and pink-and-teal attire (including a tutu!) set the tone for a fabulous day.

It was an honor to have Congressman Joe Morelle stop by to show his support and share the story of his daughter, Lauren, whose spirited two-year walk with breast cancer touched many, and whose memory lives on in our hearts at the Coalition. Other special guests for the day included the Midnight Ramblers, Vault Rochester, and Compass Cycle & Flow.

The event wrapped up with our awards ceremony, where we crowned our big winner and course record holder. Congratulations to Melissa Johnson-White for crossing the finish line with a time of 18:02!

Did you know hundreds of survivors, families, and supporters participated virtually? Here are just a few of their locations near and far: Bluffton, SC; Denver, CO; Morganton, NC; Boston, MA; Cleveland, OH; Las Vegas, NV; and Dansville, NY.

The true heroes of the weekend were our 38 Pink Ribbon Sponsors and 126 Pink and Teal Ribbon Fundraisers. This event would be nothing without your commitment to our mission! You can find a full list of Pink and Teal Ribbon Fundraisers on page 31.

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Alyssa Santana
Ashley Infantino
Carly Euler*
Claire Bopp
Dawn Lee

Deb Bishop*
Holly Anderson*
Jerry Roberts
Michelle Arbore

Michelle Lindsay*
Nicole Murray
Ryan Bopp

* Coalition staff

BreastCancerCoalition.org
HAPPY TO BE TOGETHER AGAIN!

Special Thank you to Lisa Gresens and her daughter Becca for volunteering as our photographers!
An Exciting and Memorable Spring
By Silvia Gambacorta Hoffman

2022 marks a milestone for the Coalition. This is the year our Research Initiative surpassed one million dollars in grant funds awarded to researchers in our region!

A panel of ten members of the Coalition’s Research Advisory Board and eleven survivor-advocates from our Research Committee gathered on April 25, 2022 to review this year’s grant applications, submitted from researchers throughout our region. These proposals came from the University of Rochester, Roswell Park Cancer Institute in Buffalo, Cornell University in Ithaca, and Upstate Medical University in Syracuse.

Each reviewer was assigned two or three proposals to evaluate. In addition, they read the remaining proposals in order to assign an Overall Impact Score to the all the projects being considered for funding. The Coalition adopted the scoring system of the National Institutes of Health (NIH) in 2021, in which proposals are judged by an Overall Impact Score system. The panel met for the whole day to discuss and score thirteen research proposals. They then selected the projects they felt should receive grant awards, and their recommendations were subsequently submitted to the Coalition’s Board of Directors for consideration.

Review Day was educational, productive, and filled with excitement. A survivor-advocate who took part in the process for the first time wrote, “Thank you, this was a wonderful experience. I learned a great deal and look forward to future work.”

The Coalition is grateful to the 2022 Review Panel for their gift of time and for their dedication: Marc Antonyak, Ph.D., from Cornell; Gokul Das, Ph. D., from Roswell Park; Scott Gerber, Ph.D., from the University of Rochester; Chi-Chen Hong, Ph.D., from Roswell Park; Kelly Hume, DVM, DACVIM, from Cornell; Kelley Madden, Ph.D., from Brockport Research Institute; Helene McMurray, Ph.D., from the University of Rochester; M Saeed Sheikh, M.D., Ph.D., from Upstate Medical University; Rachael Turner, M.D., Ph.D., from the University of Rochester; and Robert Weiss, Ph.D., from Cornell. We are also grateful to the survivor-advocates who sat on the panel: Wendy Bachhuber, Gunhilde Buchsbaum, Alison Currie, Stacy Forrett, Wendy Gottorf, Nancy Gramkee-Cuer, Jill Gress, Nancy Johnson, Judi Stewart, Christina Thompson, and Jeanne Verhulst. A special thanks to Alison Currie for being our scribe in addition to reviewing proposals. Holly Anderson, Executive Director served as moderator. Special thanks to Michelle Lindsay who provided technical support.

A second energizing and unforgettable event of spring 2022 was the Coalition’s trip to Washington, D.C., for the National Breast Cancer Coalition (NBCC) Advocate Leadership Summit. Here we attended presentations on topics such as the financial toxicity and complexity of cancer care, the need to bring more affordable drugs with scientifically proven efficacy into the market, the effect of screening on survival, an update on the Artemis Project (the NBCC research project to end breast cancer), and many other informative workshops. On our last day, we went to Capitol Hill to meet our national representatives and advocate for $150 million in research funding through the Department of Defense Breast Cancer Research Program and for the Metastatic Breast Cancer Access to Care Act.

Our Research Committee is open to those who wish to join a dynamic group of informed survivor-advocates working to end breast cancer. Please email info@bccr.org for more information.
someone who can truly understand what you’re feeling. And looking back, I needed to validate some of the emotions I was feeling.

Enter the Breast Cancer Coalition. After a couple of emails and phone calls, I was connected with a mentor and we had great conversations. It was the first time I felt reassured about all that was going on inside me. For some things, it was the first time I shared them with anyone. This was early in 2021, so things were mostly shut down due to the pandemic. I can only imagine how much I would have enjoyed going to the Coalition and meeting other inspiring women in person.

Sometimes you just need to get away. Sometimes you want to see other women surviving, and thriving! Sometimes you just want to go somewhere without a wig and feel normal. The Coalition is all of those and more. I attended some informational virtual seminars to further educate myself on breast cancer, and while I am happy to have this opportunity available, I will admit that keeping the kids quiet in the background while finding a space with a decent Wi-Fi connection is a challenge in our house!

Since my treatment ended, a lot of in-person activities are back in action at the Coalition, and I am grateful that these options are returning to our community. Since returning to work, additional activities have been hard to schedule, but I still have a yoga class on my wish list! If you’re even thinking about connecting with the Coalition as a survivor, please do it. You won’t regret it, and I am certain you will find something there that you didn’t even know you needed.

As I write, it has one year since I finished chemo. There were weeks that felt like they would never end, but they did. Chemo was the hardest part for me. Losing my hair, my eyebrows and lashes, everything that felt feminine to me, was not something I could ever prepare for. We live in a world where ‘the outside’ matters more than it should. Perhaps more than people want to admit. Imagine that you no longer have that exterior that people know. Do people view you the same way? Do you present yourself the same way? Are you still as confident as you once were? If you surround yourself with people who truly know you, love you, and support you, then you are lucky. I am lucky. My support system knows me, loves me, and supports me. I am learning to love and support myself in a whole new way, every day.

My treatment has been over for nine months now. I’m back to work and have resumed my normal life. Except it’s not normal. The challenge for me is accepting that I cannot return to the life I had before cancer. And I’m not meant to. I’m working on being okay with that. I believe there is a positive side to any situation. It might take help from your support system to see it, or might just take time. We can always change our perspective to make the most of our circumstances. I still have residual effects of treatment, and in some ways I will never be like before. But, I don’t have cancer, and so I shift my perspective to being thankful for more time.

"Sometimes you just need to get away.
Sometimes you want to see other women surviving, and thriving! Sometimes you just want to go somewhere without a wig and feel normal. The Coalition is all of those and more."

*Triple negative breast cancer is a subtype of the disease that occurs in about 10-15% of patients. When the cancer cells do not contain three common growth factors often associated with the disease – estrogen receptors, progesterone receptors, or the HER2 protein – it is called “triple negative.” Because it does not respond to therapies that target these three growth factors, chemotherapy is often a consideration for those diagnosed with this form of breast cancer.

BreastCancerCoalition.org
In each congressional meeting were survivor advocates from our group who have been impacted by each of these programs. We were there to convey the importance of these priorities. Two survivors in the room were treated with trastuzumab immunotherapy, a drug which has roots in the DoD-BCRP. Prior to this drug becoming available, those with a diagnosis of HER2 positive breast cancer had a poor prognosis. One survivor recounted her story of being diagnosed with stage II breast cancer without medical insurance despite working full-time. The Medicaid Breast and Cervical Cancer Treatment Program covered the expenses of treatment and alleviated the financial stress that was originally greater than the diagnosis. A third survivor-advocate recounted her metastatic diagnosis and the financial impact of carrying COBRA insurance during treatment, which illustrated the need for HR 3183 to be passed.

The Advocacy Committee of the Breast Cancer Coalition plays a major role in putting faces, voices, and stories behind legislation on local, state, and federal levels. We are currently working at the New York State level on safe cosmetic legislation. We meet monthly as a committee to discuss strategy for furthering our agenda to eradicate breast cancer. If this is something you’d like to be a part of, please email info@bccc.org.

*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 and thus we support NBCC’s public policy agenda.*

CRISPR and its associated enzyme protein (Cas-9) is used to deliberately target small landscapes of damaged DNA and snip it out. CRISPR editing technology has been around for a while, but its potential in cancer research blossomed after two women won the 2020 Nobel Prize in chemistry for the DNA editing “scissors.” DNA can now be custom designed in a laboratory by computer to reflect the base pair sequences a researcher wants to insert into a mutated or damaged section of the gene to repair and restore normal function. His diagrams labeled this akin to a memory chip. T-cells, once activated, can function with a normal immune response and kill cancer cells.

He used the BRCA mutation as one example. In a normal gene, BRCA protects against uncontrolled tumor cell growth, but in its mutated configuration, it applies the “brakes” and silences the killer function of the T-cells. So take the patient’s T-cells out, reprogram the “confused” gene segments, give the cells “new memory,” and send them back in to activate the function they are supposed to perform as healthy killer cells.

Prior technologies in genetic editing were prone to “dilution” of the repaired segment as the cells multiplied. CRISPR is one way to solve that problem, as the inserted segment is more stable in progeny cells. Dr. Knott’s work has become part of the Artemis Project, an initiative of the National Breast Cancer Coalition, where it is complementing the work of fellow scientists with the aim of developing a potential vaccine for breast cancer. Amazing! Will this piece fit in the part of the puzzle where we find a cure? Time will tell and we are watching.

My take on the whole experience: I found great puzzle pieces, plus I have 13 new relationships with other BCCR attendees that will continue to have a special place in my life. Take the time to hear someone’s story and you will be empowered by their courage and blessed by their friendship.
PALS Connections

By Pat Battaglia

PALS connections can be empowering for both mentors and mentees. For those who have recently entered the unfamiliar territory of breast or gynecologic cancer, a mentor’s shared experience can have a significant impact for the better. For our mentors, the simple act of reaching out to a newly diagnosed person speaks to a high degree of healing on their part. When we’ve asked our mentor applicants what drew them to consider taking this step, their responses have been varied and beautiful.

- I was helped through my experiences by an incredible group of women warriors. It’s been a powerful experience. I see this as an opportunity to do the same, to “pay it forward.”
- I feel it is vital to have a relationship with someone who has “been there.” Without the guidance, input, and experiences that other survivors shared with me, I am not sure how I would have made it through.
- I have benefited from the experiences, knowledge, support, and encouragement of others who have traveled this path before me and it would be an honor to help another who faces this devastating diagnosis.
- I think people need to be heard, and I am happy to listen.
- The most powerful support and help has come from meeting other cancer survivors. Hearing their personal experiences and stories, and just seeing that they were able to come out “on the other side” of their surgeries and treatments gave me strength to concentrate on getting through my own.
- There is so much about this process that you don’t understand until you go through it. I’d like to be someone’s mentor through the downs, the ups, the twists, and the turns of this roller coaster ride.

These are just a few of the words shared by our large, diverse, and compassionate group of PALS mentors. If you or someone you know could benefit from a mentor connection – or if you’re interested in becoming a mentor – please email info@bcr.org.

Dawn Lee turned to the Coalition for support and information after her breast cancer diagnosis in 2019. Fortunately, she is doing well and has stayed with us to lend a helping hand in any way she can. After becoming a donor and volunteer for ACTober 2021, she volunteered for the Pink Ribbon Walk & Run in 2022. This was our first live Pink Ribbon event since 2019, and it was one to remember in so many ways. And it was our chance to get to know our volunteers in new ways – including Dawn.

Not only did Dawn create a Pink Ribbon Fundraiser that raised nearly $2000, she said “Yes!” to every volunteering opportunity she could, helping in ways large and small that made her an invaluable contributor to the overall success of the event. She showed up to stuff T-shirts into bags. She came in again to hand out bags during packet pick-up. She assembled and transported the raffle prize - an outdoor furniture set consisting of a couch, two chairs, and a coffee table, complete with a smokeless fire pit – it was no small task! She loaded supplies at the Coalition to transport to the park before the event. Afterward, she was on hand to unload the supplies at our facility afterward. Our Special Events Coordinator, Carly Euler, says, “Overall, it was an insanely large effort from her!”

No one chooses a breast cancer diagnosis. But we are grateful that, in the aftermath of her walk with the disease, Dawn has chosen to assist us in ways that truly matter. We are grateful for her energy, enthusiasm, and willingness to roll up her sleeves and do the hard work that’s needed. Dawn has made a difference for us!
Getting Some **Zzzzz’s** When It's Hard to Sleep

By Pat Battaglia

In the aftermath of a cancer diagnosis, a good night’s sleep can be elusive. This holds true whether you or someone you care about has been diagnosed. Fears and uncertainties can create a continual feedback loop of inner dialogue that often seems to increase in volume during the quiet overnight hours. But getting adequate sleep is essential to our well-being. While you’re asleep, your body releases hormones that regulate many bodily functions and help repair cells. Sleep affects every organ, including the brain, and with the plethora of information to process when cancer enters the picture, getting a good night’s sleep is more vital than ever. And more difficult.

Most adults need between seven and nine hours of sleep every night. Chronic lack of sleep can have a wide range of health consequences and contribute to physical and mental fatigue. It seems unfair that sleep is so hard to come by at a time when it’s needed most!

Fortunately, there are ways to cope. Here are a few strategies that have helped others.

Remember that with time and intention, this will pass. As with all the challenges a cancer diagnosis presents, rely on your support community, including us at the Coalition. We’re here for you!

1. newsinhealth.nih.gov/2013/04/benefits-slumber
2. www.sleepassociation.org/sleep-treatments/essential-oils-for-sleep/

Resources:
- cancer.gov/about-cancer/treatment/side-effects/sleep-problems
- sleepfoundation.org/how-sleep-works/why-do-we-need-sleep
- ninds.nih.gov/health-information/patient-caregiver-education/brain-basics-understanding-sleep
- sleep.org/sleep-environment/scents-for-relaxation/

Try some soothing scents. Scents interact with your olfactory system, the structures related to your sense of smell, and your limbic system, or your “emotional brain.” A few scents associated with relaxation are lavender, rose, chamomile, geranium, sage, and jasmine. If scents are your “thing”, try tucking a fragrant sachet into your pillowcase, or placing a few drops of essential oil in an air diffuser or a warm bath, or using a lotion or skin balm scented with essential oils.
Swiss Chard & Egg Muffins

Preheat the oven to 375 F. Grease a 6 cup muffin tin or line with paper muffin cups.

Put the washed chard with the water still clinging to the leaves in a pot with a tight fitting lid. Wilt the leaves over high heat for 5 minutes (add a tablespoon or 2 of water to the bottom of the pan if needed.). Drain and run the chard under cold water to stop the cooking. Squeeze out the water and coarsely chop. Set aside.

In a small bowl, lightly beat the eggs, 2 tablespoons of cold water, salt, and pepper. Set aside.

Over medium-high heat, heat 1 tablespoon of oil in a frying pan. Add the shallots and sauté until they start to turn golden and caramelize, about 2-3 minutes.

Add the chopped chard, a pinch of salt and pepper to taste, and sauté for 2 to 3 minutes. Add the chopped parsley. Stir in and cook for a few more seconds. Remove from the heat and cool slightly before stirring the chard into the egg mixture.

Spoon the mixture evenly into the muffin cups; they should be about 3/4 full. Sprinkle with crumbled feta if desired. Bake for 15 minutes or until the muffins are well risen and golden on top and a toothpick comes out clean. Place tin on a wire rack. Cool muffins 10 minutes before removing them from the tin. Delicious warm or cold!

*Adapted from cookforyourlife.com.
Friends Remembered

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

Mary Ann Giannoccaro
Manjula Rose Kothuru (Koppera)
Gail Levy
Mary McGowan
Jean Mowry
Denise Munson
Melody Neely
Su Weber
Marjorie Ann Yandow

Hallelujah

VOICES AND VISION GROUP POEM
(Gathered from the writings of our Winter 2022 participants)

Water meeting gray-brown shores. The moment of time, suspended by quiet—a lovely round ball of light shining through bare branches.

I witness it, impelled to share the beauty, the exuberance of the moon, the winter whites when snow falls from the clouds—Mother Earth at her best.

My head is empty. I enjoy the silence. But what about the ceremony? Becoming a wild woman, I am thinking of who I am, who I could be. All I can think about is what I am thinking of: I love letters I envy twins.

The creaks of the house as it converses with the wind, the relationship of the objects, how they reflect off one another the brief moment before the curtain rises.

Wind is a visual noise, there is a luster, a glow inside, a luminous thing that shines. I hear the silence, it moves me to tears.

I love the silence outside—snowflakes dancing through the air crashing into each other. The world comes slowly into focus, I imagine it into existence.

Just outside my gaze so still the green waters. Moments of silence overlooking the water brought me to life.

I wanted to talk about pain, What comes with actual loss. It is like moving through molasses. I might not come up, my brain said dive—and I surfaced.

I see myself sitting in that empty chair contemplating the sky and water, and the water becomes many changing shades of blue.

We still feel it deep in our bones, in the fluid shifts within us. My body relaxes, warmed by the heat of the fire.

Uneasiness is my red cloth, I run straight into it when I see it. A part of me to be kind to, I hope for beauty.

To hope for more energy. To dance to the wee hours. No thank you late winter storms. I am ready for Spring. No thank you to war. Yes to a world that could be.

It is my symbol. My story. I rang the bell. Another victory. I can’t separate things from their stories. I adore what I hold in the palm of my hand.

Constructed by Ren VanMeenen, Facilitator, Voices & Vision
AFTER BREAST IMPLANT RECONSTRUCTION, continued from page 5.

Recalling Kathy’s first experience with her implants, Jen reached out to her and learned of her current dilemma. They have remained in touch, sharing their subsequent experiences with each other and with us at the Coalition.

Jen acted on her OB/GYN’s suggestion. “My plastic surgeon ordered an ultrasound to determine whether it was capsular contracture. When I was going to schedule the ultrasound, I was told a mammogram would need to be completed first.” Like Kathy, Jen was hesitant. But, offered the reassurance she would receive a specific type of mammogram that uses less pressure on the breast area than a typical screening procedure, she agreed. Based on the results of that mammogram, the radiologist recommended an ultrasound, which confirmed capsular contracture. In reviewing the imaging results with Jen, the radiologist let her know the mammogram had not yielded any information that was useful in her case. He suggested that for monitoring her implants in the future, she should schedule a mammogram, then ask to consult with him when she checked in for her appointment. “I will tell them you don’t need a mammogram,” he said, and would order an ultrasound instead.

With capsular contracture confirmed by ultrasound, Jen recently underwent surgery to replace her implants and is now healing.

Screening mammograms after a mastectomy are a matter of medical advisement, and recommendations from different sources can and do vary. However, after implant reconstruction, the criteria of the American College of Radiology state that, “There is no relevant literature to support the use of mammography for screening in this clinical setting.” Individual recommendations are based on individual circumstances. For instance, a diagnostic mammogram may be advised if a symptom such as a lump, thickening, or rash occurs. Those who have undergone nipple-sparing mastectomy may be advised to have yearly screening mammograms due to the amount of breast tissue left behind in some instances. In any scenario, mammography is not regarded as a reliable way to monitor breast implants.

To learn whether insurance coverage might play a role in which imaging procedure(s) might be recommended for monitoring patients with breast implants, I contacted Excellus Blue Cross/Blue Shield, a major health insurer in our area. I was directed to their corporate medical policy for approval of MRI to assess the integrity of breast implants: “To confirm rupture of silicone or saline breast implants, when necessary, in patients whose ultrasound is nondiagnostic of rupture.”

At this writing, this policy is under review. Excellus has no separate policies for mammography or ultrasound of the breast and preauthorization is not required for these procedures. Corporate policies vary among insurance carriers and are subject to revision. Those with implant reconstruction may find it worthwhile to check with their insurance carriers to determine their individual coverage.

Mammography is currently the most reliable method of detecting breast cancer. Digital mammography, in particular, identifies 85% of cancer cases. Mammograms are not, however, the current standard of care for monitoring breast implants. The FDA guidelines state that ultrasound and/or MRI are the preferred modalities depending on patient circumstances.

Kathy, in seeking the procedure(s) to monitor her implants that will yield the most useful information, remains steadfast that a mammogram isn’t needed for her. “I shouldn’t have to fight this hard to get my implants checked,” she maintains.

Those who undergo surgery for breast cancer will live many years with the results, and informed decision-making is vital. The field of medicine is not static, nor do most patients expect it to be. As new information comes to light, new guidelines emerge, and standards of care change and evolve over the course of time. Ideally, those in the aftermath of a breast cancer diagnosis make informed decisions using the best information available to them at the time. However, conflicting advice among different providers can be difficult to sort through. Ultimately, the decision rests with the patient. It’s not an easy place to be. The situations survivors have shared with us at the Coalition regarding long-term follow-up care for their breast implants, illustrated in the stories of Kathy and Jen, speak to a need for clear, consistent messaging among providers whenever possible. And when that isn’t possible, evidence-based, informed decisions are in the hands of those who will live with the results – the survivors.

*A recording of this seminar is available. Contact info@bccr.org.

1. www.fda.gov/medical-devices/implants-and-prosthetics/breast-implants
2. www.ncbi.nlm.nih.gov/pmc/articles/PMC45759163/
3. acsearch.acr.org/docs/3155410/Narrative/
4. www.ncbi.nlm.nih.gov/pmc/articles/PMC4579163/
5. www.excellusbcbs.com/health-wellness/medical-policies
6. www.ncbi.nlm.nih.gov/pmc/articles/PMC3259319/
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 Michelle today by email or call her at (585) 473-8177 for more information.

IT ALL ADDS UP

Krooked Tusker Distillery raised $163.85 during their November fundraiser! Cheers!

DRESS DOWN, FUNDS UP

Our friends at the Courtyard Marriott of Downtown Rochester hosted a “Dress Down Day” which raised $300 to support our PALS Program.

IT TAKES THE CAKE

Friends of the Coalition, Casey and Taylor Capuano, started a business called CAKES Body 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. So far they have raised $234.00 for us!

WIG PARTY

Fun and creativity are always on the menu at Solera Wine Bar. In October, they hosted a Wig Party with a specialty drink, raffle and, of course, WIGS! With proceeds coming to the Coalition, we were thrilled when Evy, the owner, stopped by with a check for $2,200! Cheers!

DISC GOLF TOURNEY

We were thrilled when Sherry Herzog reached out to us to ask if the Coalition could benefit from her annual Share the Love Driven by Innova, Throw Pink and Lucky Disc Golf tournament! We gratefully said, "Yes!" Held on the weekend of October 2nd and 3rd, the event included 3 rounds of disc golf over the two days for both amateur and professionals with various games including an Ace Pool. We were so grateful to receive $1,400.00 from the tournament!

PAM-A-PALOOZA

Our friends and neighbors, Hot Shots, hosted a volleyball tournament on April 9th spearheaded by Tallis Polashenski, daughter of our beloved friend and board member Pam Polashenski, who passed away in December 2021. Pam and Tallis’ shared love of volleyball was memorable for all who knew Pam. We are still mourning the loss of our friend, but this tournament in her memory, gave us reason to smile in so many ways. Congratulations to Tallis and all involved for raising $5,720.00 for the Coalition.

METHOD TO (MARCH) MADNESS

March Madness, the annual NCAA Division I men’s basketball tournament, offered the perfect opportunity for Rob Gentner to elevate his enthusiasm for great basketball to a philanthropic success. Dubbed Method to (March) Madness, and using the bracket format, Rob invited the predictions of friends and family throughout the tournament. Contributions provided for a tournament winner – and a sizeable donation to the Breast Cancer Coalition.

Thanks to all involved for your overwhelming effort and donation of $2,019.00.

RESIDENTS FOR A CAUSE

We were touched when Andrea, the Resident Services Supervisor at The Village at Mill Landing, reached out to us about a fundraiser the residents there had done for us. The amazing residents created and sold 50 Breast Cancer Awareness Easter baskets to friends and family. The baskets included a variety of pink candy, spring treats such as flower seeds and bubbles and breast cancer ribbon pins, bracelets & note cards. Thanks to all involved for raising $550.00!
The COVID-19 pandemic didn’t prevent Chili Fusion Soccer from hosting their 7th Pink the Field Tournament in 2020 and they were back at it this year with the 8th annual Pink the Field event in October 2021, raising an incredible $5,000.00. Thank you to Erin Noll, Amy Wood, all of the soccer players and teams, volunteers and families who made this event successful. And thank you to the Town of Chili for once again painting the field lines pink!

This May, the Greece Storm high school lacrosse team dedicated a game to the Breast Cancer Coalition. Through a combination of t-shirt sales (handmade by Karen Hill) and 50/50 raffle tickets, the team was able to raise over $1,000 for the Coalition! The athletes even took their support one “step” further by adding pink tape to their cleats and sticks.

We were thrilled to receive the news that after a hiatus due to COVID the Pittsford Panthers Hockey team would hold their annual Pink the Rink contest at Bills Grey’s Ice Center on February 2nd. This hardworking group of parents and young athletes has raised $79,354.08 for the Coalition over the years.

This annual event began when former Friends of Pittsford Hockey Board Member, Celeste Frohm, proposed the idea for Pink the Rink after watching her son play in a similar event at the State University of New York at Fredonia. She believed it would be an effective way to bring the Pittsford community together for a worthy cause.

Proceeds from the 2022 game totaling $12,125.00 went once again to the Breast Cancer Coalition. Your hard work will mean the world to the people we serve!

Though older and (presumably) wiser than their student counterparts, the firefighters of the County of Monroe Fire Bureau Hockey are no less enthusiastic about piling on the padding and hitting the cold, hard ice again for charity. They were back in 2022 for a game benefitting the Breast Cancer Coalition. After the event they presented the Coalition with a check for $3,637.00 to be used to provide free programming and services to our communities.

Special Thank You to the Lady Lancers - as they support the Breast Cancer Coalition during home games!
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 October 1, 2021 - December 31, 2021.

IN HONOR OF:
All breast cancer patients and survivors
Mary Reed ♡
All women who have had breast cancer
Carol Loughner ♡
My Niece, Sara
Mary Toole *
Chris P, Debbie, Diane, Julie
Estelle Hitzfield *
The BCCR Staff
Maria Mendicino *
Holly Anderson
Annie Murphy ♡
Helen Antetomaso
Margie Micca *
Jill Ball
Laurie Ball *
Pat Battaglia
Robert Farrell *
Nancy Bricker
Dr. Vito Valenznao *
Sally Brooks & Bud
Higgenbotham
Adele & Michael Campbell
Judy Bryant
Laura Eberstein *
Patti Cataldi
Sandy Kolupski *
Pat & Art Chapin
Adele & Michael Campbell
Karen Battaglia Cleary
Patricia Battaglia ♡
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Fundraiser
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Jeanette & Steve Decker
Adele & Michael Campbell
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Roseanne DiFlorio
Roger Sutphen
Erin Vaseck
Gina DiMonda
National Council of Jewish Women, Greater Rochester Section
Mary Follmer
Diane Van Deventer
Donna Ganfracesco
Deborah Mack
Kathy Guglielm\n\nMarianne Sargent ♡
Therese Wallace
Tani Hubbard
Dotti & Larry Humm *
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# Fundraiser from October 2021. Due to an unfortunate delay by Facebook in providing both the funds and the associated donor contact information, we received notification of gifts in March 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#
- Joann Fabrics gift cards
- Journals for writing
- Warm, fuzzy socks

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- 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.
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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E-Mail: info@BreastCancerCoalition.org
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To keep up to date on all BCCR happenings, follow us on social media:

20th TEE’D OFF
AT BREAST CANCER
GOLF TOURNAMENT

MONDAY, AUGUST 1, 2022
Midvale Country Club

• Staggered tee times • Scramble format
• Breakfast • Lunch • Cocktail Reception
• Online silent auction • Raffle prizes

Contact Carly@bccr.org to learn more about these event and to register!

ACTober

• Celebration •
• Awards • Auction •

Friday, September 30, 2022
at The Highline

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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.