FROM THE DESK OF THE EXECUTIVE DIRECTOR

Twenty years ago, officially on October 1, 2001, I stepped into the role of Executive Director at the Breast Cancer Coalition. My footsteps followed the path forged by our founders just as 1998 was beginning, and a path that began with my own diagnosis of Stage III breast cancer in 1999.

In my earliest weeks and months at the Coalition, I was focused on developing programs and services. There was so much awareness about breast cancer, even back then, but the media and commercial focus was almost entirely on early detection initiatives and screening campaigns. Pink ribbons were everywhere. Those early detection campaigns worked for many of us, but they didn’t always work. We wanted something better.

We wanted better screening methods and we wanted to stop breast cancer from ever initiating in the first place. We were encouraged when computer-aided detection emerged and, later, tomosynthesis. Combined with ultrasound and magnetic resonance imaging (MRI), these have helped. But these did nothing to end breast cancer. Ending breast cancer was, and still is, the overarching goal.

So many of us, shocked in the aftermath, accepted our diagnoses. But then what? This question became the basis for what was to come. Now on the other side of an actual diagnosis, we looked for information about surgical choices, reconstruction options, long term effects of chemotherapy and radiation treatments, wondered about what we were eating and whether supplements or doing anything different would change outcomes. More than anything, we wanted to do everything in our power to not develop recurrences. We were curious about genetics. We grew more and more concerned about environmental exposures, especially for our children and grandchildren. Our government wouldn’t allow a product with dangerous ingredients to be sold to consumers, would it? Now on the path of survivorship, we were looking for information and resources that would help us live our best lives after the devastation of cancer. As we became educated, we uncovered many truths that industry giants hoped to conceal. These discoveries fueled our advocacy work.

Whether you have come to know the Coalition in just weeks or over many years, you know our advocacy focus has been on reducing risk of exposures to toxic chemicals (primarily endocrine-disrupting chemicals), prevention of breast and gynecologic cancers, and increasing funding for research. At the time, it felt like we were asking for the moon. But what we really wanted was to stop breast and, later, gynecologic cancers before they ever started. In our earliest days, this became one of two primary end points for our Breast Cancer Research Initiative: prevention, so you wouldn’t get it to begin with; and halting progression if you did. We have never believed that enough funding was directed towards ending breast cancer and certainly not enough towards halting metastatic breast cancer.

As I turn the page on twenty years, I remain focused on our four pillars: advocacy, education, support, and research. It’s been an honor to walk alongside thousands of women and men as they found their courage and rose from the devastation that comes with a diagnosis of cancer. And they did come. And continue to come. By the thousands. From all walks of life. Survivors and those who love them… everyday people… teachers, scientists, researchers, policy makers, neighbors, coworkers, you. YOU have the power to make real change with us.

Looking back, it’s breathtaking to see all we’ve accomplished together but we are far from ending breast cancer and farther still from ending the range of gynecologic cancers. We need more than awareness months. We need ACTion … every month, every week, every day, every hour. We need you.

Join us.

Holly Anderson
The year 2011 began with joyful news for Heather and her family. With two young daughters to keep her hands busy and heart full, she and her husband, TJ, were overjoyed to learn a third child was on the way. Ten weeks into the pregnancy, she saw her obstetrician for the first prenatal exam. “I remember going into the visit hoping to hear the heartbeat,” Heather reflected when we talked by phone about her experiences during that pregnancy. “I knew it was probably a little too early for that, but I was hoping.”

However, Heather detected a shift in her obstetrician’s manner during her breast exam. “This was my third child and he had been my doctor for a long time. I knew something was wrong.” Concerned about an area he noted during the exam, the doctor referred Heather to an imaging center for an ultrasound. This was followed by a biopsy. By the time these procedures were scheduled and the pathology results became available, a week and a half had gone by. The results confirmed Heather’s worst fears: she was diagnosed with breast cancer. “I’m sure it’s always hard receiving this kind of news,” Heather shared. “But for me it was jarring. It came out of nowhere.”

Heather received a referral to a breast surgeon, who made arrangements to see her the very same day – after hours. This compassionate caregiver reviewed Heather’s pathology report, took into account her young age – she was thirty-three at the time – and reached a conclusion that would be confirmed during a separate consultation with a medical oncologist: chemotherapy would be needed after surgery.

To safeguard her growing baby, Heather’s caregivers recommended waiting until she was out of the first trimester of pregnancy before proceeding with any treatment. It was only a three-week wait until surgery. “It was a long three weeks,” Heather recalled. During the interval, she underwent a series of scans of various areas of her body to be sure the cancer had not spread beyond her breast. This resulted in welcome news: there were no obvious traces of cancer anywhere else.

Heather’s surgeon recommended a lumpectomy – also called a partial mastectomy – to remove her tumor and a margin of healthy tissue surrounding it. “After the surgery is when we found out the cancer was triple negative,” Heather shared. Triple negative breast cancer, a subtype of the disease that represents about ten percent of all cases, does not carry three common biomarkers.

Continued on page 18.
When a recent Brown Bag discussion turned to the topic of life after cancer, attendee Gail H. eloquently described her experience: “I feel like I’m on a bridge between two worlds.” After being diagnosed with breast cancer for the second time in late 2019 (the first time was twenty years prior), she had undergone surgery, chemotherapy, and completed radiation therapy in November of 2020. This signaled the end of Gail’s active treatment, the goal of which is to ensure, to the fullest extent possible, that it doesn’t return.

For most people diagnosed with cancer, the active treatment phase is a time of frequent medical consultations and treatments. Healing from surgery and managing the side effects of treatment also require time and attention. The schedule is often demanding and time-consuming. However, after the initial shock of receiving a diagnosis and making treatment decisions, maintaining this busy schedule can result in feelings of having some control over the disease process; of doing all one can to ensure their survival. And, when evidence-based therapies are employed, these feelings stand on solid ground.

When the goal has been met – when curative treatment has come to an end and no trace of cancer can be detected – it is a time of celebration for many patients and their loved ones. And there truly is much to celebrate. Yet, for many, it is also a time of mixed emotions, some of which can be surprising and even difficult. When the calendar of daily or weekly appointments becomes one of quarterly or semi-annual follow-up visits, a new phase of survivorship has begun, often relatively abruptly. Some Brown Bag participants have wondered aloud, “Now what?”

“...But you should be happy!”

A single cancer diagnosis disrupts many lives. When the afterglow of completing cancer treatment begins to fade, it’s only natural for well-meaning and caring family members and friends to want life to return to normal. Naturally, they want their loved ones to be happy. But for those who have been diagnosed, feeling a sense of relief and returning to a pre-diagnosis level of functioning can be elusive targets. It is possible to feel happy and conflicted at the same time.

After undergoing surgery and chemotherapy, Gail completed several weeks of radiation therapy in November of 2020. A few weeks afterward, she began taking an aromatase inhibitor, an
estrogen-blocking medication, as her cancer was found to be fueled by that hormone. This is a proven and effective strategy to prevent recurrence in these cases. But whether or not a person is a candidate for hormonal therapy, those who have completed active treatment for breast or gynecologic cancer are usually left with reminders of their experiences. Surgery invariably results in scars. For some, it can also result in lymphedema, range-of-motion issues, and pain. Hair regrowth after chemotherapy and the return of cognitive functioning if “chemo-brain” has occurred are slow processes. Skin and tissue healing after radiation also take time. Body image and sexual functioning can be impacted by different forms of treatment. And post-traumatic stress disorder is becoming an increasingly recognized phenomenon in many who have moved beyond active treatment for cancer.¹

Says Gail, “I would tell someone who has just finished treatment that the next stage is still part of your treatment. You might need to talk to other survivors, to slow down and let your body heal. Going through cancer treatments is a kind of trauma to both body and soul, and one doesn’t just bounce back. As my partner reminds me, ‘It hasn’t even been a year since you finished treatment!’ Be good to yourself.”

**Fear of Recurrence**

It is common for those beyond active treatment to fear the return of their cancer. The desire to take positive action to detect cancer as early as possible seems sensible on its surface. However, as counter-intuitive as it may seem at first, blood tests, scans, and x-rays have little, if any role to play in this scenario. More is not necessarily better in this instance. In fact, measuring the levels of circulating tumor markers in the blood² or using advanced imaging techniques such as MRI, CT scans, and PET scans³, have been shown to provide no benefit to survivors of early stage disease. “[A]side from annual mammography, the routine use of advanced imaging to evaluate for recurrence and/or metastatic disease does not result in increased survival or improved quality of life. There is little evidence to justify routine imaging with CT, MRI, radiography, or nuclear medicine studies for the detection of metastasis in asymptomatic women.”³

A trusted oncology provider who is familiar with the particular aspects of your diagnosis is in the best position to advise you about which symptoms to watch for, which ones to report to your medical team, and when it might be advisable to do so. Walking the fine line between healthy body-awareness and stress-inducing hyper-vigilance is an art in which none of us is perfect. It can help to know you aren’t alone in this.

Patty’s self-developed imagery has helped reframe her fears. “I compare it to a famous quarterback who has a shoulder injury at 21. Is it going to come back at age 29? You’ve had this injury that took you out of the game, and you’ve done the rehab and all the things you’re supposed to do. Then it gets fatigued and your coach calls you out of the game – is that not in the back of your mind? These are those moments to take a deep breath and remember the sun’s out, it’s a blue sky, I feel the wind on my face. Sometimes it’s taking a step back before moving forward.”

Gail employs an approach that bears some similarity to Patty’s while being uniquely her own. “Emotionally I feel like I’m still on a bridge between two worlds. I don’t have cancer and I’m not sure I can be cancer free in the other world. Every little ache makes me wonder now. What is helpful is exercise – yoga, walking, riding my bike, and swimming. Drinking lots of fluids. Seeing friends. Giving myself permission to slow down and to get rid of expectations that I must now go full steam ahead. I've been reading a lot and writing with my writing group in the mornings. Slowing down and taking a deep breath. Talking about it, writing about it.”

“What is not helpful is pushing myself, going faster, and feeling like I’m running out of time. Scheduling too much. Saying yes to anything. My partner reminds me that spontaneity is where we are at now. That feels right and good.”

**Crossing the Bridge One Step at a Time**

Each individual cancer diagnosis is unique and the disease affects each life it touches differently. Just as

*Continued on page 15.*

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**Patty B.**

Patty B is uniquely positioned to speak on the topic of survivorship. As the Cancer Survivorship Program Manager at the University of Rochester’s Wilmot Cancer Institute, she works with oncology providers who provide post-treatment follow-up care to their patients. Being a nine-year survivor of breast cancer adds to her expertise, as well as her compassion. She notes, “I remember learning, even before I worked in the oncology world, what the term ‘new normal’ means. But that can be hard to grasp because every day is not the same; every person is not the same. So what is ‘normal?’ Someone once said to me. ‘Normal is a setting on my dryer.’”

BreastCancerCoalition.org
In 2014, I was a patient care technician at a local hospital; ironically, on the very floor that provided post-operative care for breast cancer surgery. Having made a career change to become a nurse a couple years prior, I was hoping to graduate from nursing school and continue on this floor. In June of that year, at the age of 38, I noticed something in my breast self-exam and made an appointment for a mammogram. Although my youngest sister, Lisa, had died of metastatic breast cancer (MBC) in July of 2010, at the age of 31, I wasn’t panicked. Lisa had tested negative for the BRCA gene. Still, I was considered “high risk” due to my family history and had periodic mammograms that were normal. But as I put two and two together, the hair on the back of my neck stood up. I was able to schedule my mammogram for the next day.

I remember parking far from the door in case someone else needed a closer spot. After the mammogram, an area of concern on the right breast was biopsied on-site. By this time, I was in shock. I asked the radiologist whether this could be the same type of breast cancer my sister had. I don’t remember the rest of the conversation except that I was advised to find a surgeon. A nurse led me out a discrete door and I stumbled to my car and called my sister Amy.

Back at work, I called my advisor in a whisper from the break room and asked for help; I had no idea where to begin. Help shortly arrived in the form of staff, who had recommendations based on their own family members’ treatment. Their support meant everything to me. I found a surgeon, scheduled an appointment, and afterward, knew I didn’t need to look any further; it was a good fit. Due to my family history, I chose breast removal and reconstruction on both sides. It was not a hard decision for me. Due to the size of the lesions and some lymph node involvement, I would undergo radiation after IV chemotherapy. Because my cancer was estrogen-receptor positive, my maintenance hormonal therapy was Tamoxifen.

Four years later, now a nurse, I had found a position in a different health system. I was talking to a co-worker, who suddenly noticed that I could no longer respond verbally. I was wheeled down the hall to the emergency room for a possible stroke or any number of concerns. After a battery of imaging and other testing, we learned that my breast cancer had advanced to my brain. I underwent gamma knife radiation in September of 2018 and began taking anti-seizure medication and oral chemotherapy. I tolerated my medications well, and had no further seizures for about a year. But then, as the cells in and around my brain lesions died, swelling resulted and the pressure began to build. My medication regimen continued to change to address this. Then, in November of 2019, I went to the grocery store to pick up some bagels. I woke up four days later in the ICU. Again, my medication regimen was adjusted, but a craniotomy (surgery) to remove the necrotic (dead) cells brought more stability. I continue to be monitored closely.

My challenges have evolved over time, but the biggest challenge for me currently has been the diagnosis of epilepsy coincident with my metastatic diagnosis. To be honest, I’ve only begun to accept it. And by accept I mean it continues to frustrate me on a daily basis. My brain is funny now. A source of comedy and difficult to explain or understand. I stumble with numbers, letters, colors - everything you learned in kindergarten. I know the words, but they spill out of my mouth too fast before I find the right ones. When I try to come up with an alternative on the fly, I feel like I’m back in my Latin class trying to get a better score on my SAT’s!
Humility helps me cope. At a recent Common Ground meeting, I said that I often feel that living with MBC is like taking one forward and two steps back. I believe it was Pat Battaglia that offered it’s more like seven steps forward and three steps back. That helps.

For me, coping is not a static concept. On a good day, I focus on what I can do. I’m optimistic. I exercise to strengthen my heart, my bones, my balance, and my mind. I’m my version of productive or creative. But there are other days when all I can do is nap and/or binge-watch a television dramedy series. I try to take it all in stride.

A focus on my mental health has helped. When I lost Lisa, I enrolled in grief counseling as part of my employer’s Employee Assistance Program. After the dust settled from my diagnosis, I asked for a referral to mental health services. Completing the basic surveys helped me realize that I did need some help and I got it. Engaging in ten minutes of consistent, daily meditation has helped in real ways. I also use medication: antidepressants and medical cannabis. I am fully transparent with my medical team.

I am living proof that my MBC story is not my sister’s and it’s not anyone else’s. It took years, but I’ve learned how to work on my inner dialogue so it’s more in line with what I might tell my sister or a friend, not my worst enemy.

This experience, since I was first diagnosed, has profoundly changed me. But it might be more accurate to say that it has distilled my personality and taught me what matters. When I temporarily lost my voice, I discovered that my voice really matters to me. I am still unpacking what that means: sharing my story, speaking up for those who can’t, and (re)learning what I need to know.

What matters most to me is my family. Having been a family member and primary caregiver during my sister’s illness, I have a fondness for well-meaning family and friends. When Lisa passed, it took six months for me to realize that I wanted to be around my family and know them. That meant moving from New York City back to Rochester.

I have a lot of support from my family (including my in-laws), my friends, my co-workers, and my providers. I can’t begin to explain how much my husband and my sister Amy do for me on a daily basis, so all I will say here is I couldn’t do it without them.

Holly and the Coalition have been there for me too, from the beginning. I was steeped in personal and professional experience and I still had no idea how helpful the Coalition could be. I’ve participated in a number of programs: the Young Survivor Gathering (where no one cares whether you have hair or not); Gentle Yoga classes; the Voices and Vision writing group; and now the Common Ground group for those living with metastatic disease. We are there when you are ready. Better yet, start before you are ready, as one of my favorite instructors reminds me.
How does one live with cancer? It’s a question I never thought I would ask myself. But in August of 2014, I lay in a hospital bed pondering such a question. I had just been in the Adirondacks. As my sister helped me get ready for vacation, I distinctly remember remarking to her that I felt bloated: “Gee I look pregnant!” At age fifty-two, I knew I wasn’t; I had been in menopause for a few years.

During the first few days of vacation, my husband Kris remarked on how little I was eating, but I dismissed his concerns. By Monday, none of my clothes fit, so my daughter and I drove to the outlets and bought some. On Tuesday morning, I asked Kris to take me to urgent care, where the verdict was diverticulitis. This diagnosis made sense to me, and I made an appointment to see my doctor upon my return home. Even though I didn’t feel great, I was having a wonderful time with family and friends. However, as the week progressed, it became harder to hide the fact that I wasn’t feeling well. By Friday evening, Kris didn’t like the way I looked; we left for home early Saturday morning. That evening, he drove me to the Emergency Department.

After undergoing a CAT scan, a Physician Assistant in the ED told me the images revealed metastatic cancer. Kris and I stared in disbelief. Then I very calmly corrected the PA: “It sounded to me like you said ‘cancer’, but I have diverticulitis.” When she left the room, it sunk in that I wasn’t feeling well. By Friday evening, Kris didn’t like the way I looked; we left for home early Saturday morning. That evening, he drove me to the Emergency Department.

After undergoing a CAT scan, a Physician Assistant in the ED told me the images revealed metastatic cancer. Kris and I stared in disbelief. Then I very calmly corrected the PA: “It sounded to me like you said ‘cancer’, but I have diverticulitis.” When she left the room, it sunk in that I was just diagnosed with an unspecified cancer. Kris and I held each other in silence for a long time. I finally told him he had to go home to be there for our daughter in the morning. He also needed let our son know what was happening. I remained awake for the next forty-eight hours; I couldn’t quiet my mind.

My primary care physician was in my room the next morning with encouragement: “We will figure this out, so let’s take one day at a time.” By the afternoon, my husband, children, parents, sisters and brothers-in-law were all with me. When the oncologist walked in, I introduced him to my “big Italian family” and told him he could say anything in front of them. After all, my cancer diagnosis was about to affect all of them, not just me.

That night, I was transferred to another hospital. The next morning, an oncologist told me I had ascites, or fluid buildup in the abdomen - I was not pregnant. I was scheduled for a removal of the fluid and a biopsy on Tuesday, port placement on Wednesday and my first chemo infusion on Thursday. I liked my new oncologist immediately - she had a plan.

My biopsy revealed ovarian cancer. What did I know about ovarian cancer? I knew my Aunt was diagnosed with the disease at the same age as me. I knew how bravely she faced surgery and chemotherapy. She even wrote an article that was published in the newspaper about what cancer couldn’t take from her. I knew what hospice looked like, as I spent many afternoons with her until she passed. And I knew I didn’t want cancer.

My oncologist reassured me we would move ahead with the plan and added that after two cycles of chemo, I would have surgery then continue chemo. She asked if I would be open to talking with her Nurse Practitioner. I agreed. This nurse sat with me and explained that treatments have advanced in recent years. She talked about genetic testing and shared a video of women living with ovarian cancer. I will always remember the time she spent with me as the first
In July of 2020, I reached out to the Coalition. I needed more support and knew gynecologic cancer survivors are welcome. Gentle Yoga classes, a cooking demonstration, and the Common Ground group for those living with metastatic cancer have provided me with wonderful support and peace.

"Deep breaths, Catherine," I thought. "What will you do with this information?"

I shared it with my children, siblings and cousins. I encouraged testing and discussed preventive care. I believe it is important to share any information that may have an impact on others in your family.

Genetic testing is a very personal decision, but for me it was an easy one, as the more information I have, the better I feel. I tested positive for the BRCA2 mutation on my mother’s side of the family. This was unexpected, as my aunt was my father’s sister. Yet, my maternal grandmother had died of an unspecified cancer. A traditional Italian woman, she didn’t speak of “those things.” However, the BRCA2 mutation increases my risk for other cancers, including breast cancer. The thought of dealing with another cancer was a cause of anxiety for me, so after discussion with my husband and children, I elected to have a preventive bilateral mastectomy. I did not go into this surgery lightly and did a lot of information gathering and mental preparation beforehand. Even though I still wake up at night worrying about things not in my control, this decision brought me some calm. I have learned that living with cancer is advocating for what you need.

In the seven years since my diagnosis, I have been on eleven treatment plans. Sometimes I feel I am living the carnival game, Whack-a-Mole! Each progression and each treatment change brings anxiety, which dissipates with support from my family, friends, and my medical team. Since my diagnosis, I returned to work as a physical therapist and have traveled frequently. I retired in the fall of 2019, as I wanted more of my energy to be shared with my family. Kris, our son Kristopher, and daughter Sara have provided me with tremendous love, support, and strength through everything. Kristopher is getting married in December 2021 to a lovely young woman named Stephanie, which gives me something to look forward to!

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In the summer 2021 edition of Voices of the Ribbon, Rebecca Solomon wrote an informative article about H.R. 3183, the Metastatic Breast Cancer Access to Care Act. This bill, if enacted into law, would waive the waiting periods for Social Security Disability (SSDI) benefits and Medicare coverage (five months and twenty-four months respectively) for those living with metastatic breast cancer who are under 65 and have been deemed eligible to receive SSDI. In her article, Rebecca wrote that the current Congress, the 117th, is the third Congress in which the bill has been introduced. One of the things discussed by the Advocacy Committee is WHY this bill has not passed in the previous two Congresses. This question perplexes all of us, but particularly our newer members who haven’t witnessed similar slow action in the past. When I think about it, it comes back to something we all learned in elementary school: what the steps are in enacting legislation. I thought this might be a good time to review those steps and offer a few suggestions on how each of us can help get this bill to the floor.

- A bill is introduced in either the House of Representatives or Senate by its sponsor.
- The bill is assigned a number.
- Additional cosponsors sign onto the bill.

This is where you come in. As an advocate for passage of the bill, you can approach your member of congress or their staff member to express your support and ask them to co-sponsor the bill. Be prepared to answer questions about your support and the bill in general. If you don’t know the answers, contact a Coalition advocate for assistance, then get back to the member with the requested information.

- The bill is referred to the appropriate committee for research and discussion.
- The committee makes any changes, then either accepts or rejects the bill and sends it to the floor for debate or to a subcommittee for further research. You can follow the progress of the bill on multiple websites, including govtrack.us.
- Members of the House or Senate debate the bill, propose any further changes, and then vote. If the bill passes, it goes to the other house for debate and a vote. Both the House and Senate must pass the same version of the final bill.
- Once passed by both Houses, the bill is sent to the President who can either sign it or veto it. If signed by the President, the bill becomes a law. If vetoed, it goes back to Congress, where the veto can be overridden by a 2/3 majority of both the House and Senate.

If the bill passes, contact both your Senator and member of Congress to thank them for their vote. If the bill does not pass, contact them to reiterate your support for the bill, as it will likely be reintroduced in the following Congress.

After seeing what is involved in creating new legislation, it becomes clear why bills may be introduced multiple times before passing. While advocating for passage of a bill, an advocate must possess many qualities, including passion, preparedness, persistence, and patience. If this sounds like you and you’d like to know more about the Advocacy Committee, please contact the Coalition at (585) 473-8177 or email info@bccr.org.
Deb Hennekey

Interested in participating in a fascinating and dynamic committee?

Learn about our Advocacy Committee:
call (585) 473-8177 or email info@bccr.org.

Be a vessel for change in our community!

Correction: on page 11 of our previous issue, alongside the Metastatic Breast Cancer Access to Care article, there is an error in the sidebar under the title "You can be an Advocate!"

- Where it says "NYS Assembly", it should instead be "US House of Representatives."
- Where it says "NYS Senator", it should instead be "US Senate."

The Metastatic Breast Cancer Access to Care Act is a federal bill, and the New York State Legislature is not involved in any discussions regarding its passage.

We regret any confusion this error may have caused.
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**

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 them to be self-advocates as they proceed through treatment, recovery, and survivorship. Our professional facilitators provide a safe, comfortable atmosphere where information can be absorbed and assimilated while the individual formulates a personal strategy for making informed decisions. Also valuable for a gynecologic or breast cancer survivor at any stage of their journey. Contact us for an appointment.

**PALS PROJECT**

In this peer mentoring program, individual breast and gynecologic cancer survivors reach out to those who are more recently diagnosed, providing the reassurance of one-to-one contact with someone who’s “been there,” helping them connect with needed resources, and instilling confidence during a difficult time. Call today to learn how to join the program and be paired with a mentor who has been there, or if you would like to become involved as a mentor.

**HEALING ARTS**

Healing Arts programming is offered in block series of 4 - 6 weeks throughout the year. Call or email us today if you are interested in registering for these beneficial offerings.

**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. Classes are 75 minutes long. Participants benefit most when they are present for the full duration of each class. Offered throughout the year on:
- Monday mornings
- Monday afternoons
- Monday evenings
- Tuesday mornings
- Tuesday afternoons
- Wednesday mornings
- Saturday mornings
- Sunday mornings

**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. Offered throughout the year.

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.
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 links available on our website.](#)
- **Discussion Group:** 2nd and 4th Monday of the month, 5:30-7:00pm
- **Discussion Group:** 2nd and 4th Tuesday of the month, 5:30-7:00pm
- **Discussion Group:** 1st and 3rd Thursday of the month, 5:30-7:00pm

**Newly Diagnosed or In Active Treatment Networking Group**
Join facilitator, Vicki Nugent (retired nurse practitioner) to discuss your experience/questions as a newly diagnosed breast or gynecologic cancer survivor. [Meets virtually; contact Christina@bccr.org](#) for link.
- 1st and 3rd Wednesday of the month, 10:00am

**Brown Bag Discussion Group**
Brown Bag is offered in a hybrid model! **Fridays at 12:00noon**
- **VIRTUAL:** 1st and 3rd Fridays; (link online)
- **IN PERSON:** 2nd and 4th Fridays at 1048 University Avenue. (Those fully vaccinated are welcome.) Bring your lunch; dessert is on us!

**Young Survivor Gatherings**
Young survivors gather four times a year as an informal and fun way to connect with others who have walked a similar path. [Register online.](#)
- Call or email today to be added to our invitation list.

**LGBTQ+ Breast & GYN Cancer Group**
This monthly group offers support to LGBTQ+ breast or gynecologic cancer survivors and their partners. Professionally facilitated. [Meets virtually; links available online.](#)
- **Discussion Group:** 4th Wednesday of the month, 5:00-6:30pm

**Common Ground Partners: Partners of Metastatic Individuals**
Professionally facilitated group for partners/spouses of those living with metastatic cancer. Virtual; contact Christina@bccr.org for link.
- **Discussion Group:** 3rd Tuesday of every month, 5:30-7:00pm

**Common Ground: Living with Metastatic Breast or Gynecologic Cancer**
Join others coping with a diagnosis of metastatic breast or gynecologic cancer. Professionally facilitated. [Register online.](#)
- **IN PERSON Lunch:** 1st and 3rd Thursdays, 12:00-1:30pm at our office
- **VIRTUAL Discussion Group:** 2nd and 4th Thursday, 1:00-2:30pm

**Parent Networking Group**
This discussion-based group supports parents who are coping with the unique challenges they face with their adult child's breast or gynecologic cancer diagnosis. Professionally facilitated. [Virtual links available on our website.](#)
- **Discussion Group:** 1st Tuesday of the month, 5:30-7:00pm

**LEARN**

Studies have shown that patient education and communication have a positive effect on patient health outcomes, including emotional and physical health.

**Evening Seminar**
Evening Educational Seminars bring information and education to our survivors and community friends. [Virtual; register online.](#)

**Book Club**
If a traditional support group isn’t for you join our monthly Book Club. [Virtual links available online.](#)

**Lymphedema Awareness Network (LANROC)**
For anyone living with lymphedema. Caregivers, lymphedema therapists, medical personnel, and those at risk for developing lymphedema are welcome. Professionally facilitated. [Virtual links available online.](#)
- 2nd Wednesday of the month, 5:30-7:00pm

**Surviving & Thriving on Aromatase Inhibitors**
Through increased movement, stretching exercises, and nutrition, this ground-breaking program provides information, support, and empowerment for those prescribed aromatase inhibitors* who are experiencing joint pain or other side effects. (*Estrogen blocking medication prescribed for hormone receptor positive breast cancer.) [Meets virtually; contact Christina@bccr.org](#) to register.
- Wednesdays with series beginning in January, March, May, and September 2022, Registrants must commit to all four sessions in a series.

*The January series is supported with funds from the State of New York Department of Health.*
Healing Arts: Fostering Wholeness, Building Community

by Christina Thompson

“The Healing Arts Initiative is an opportunity for breast or gynecologic cancer survivors to learn a new modality or a complementary healing practice to relax, de-stress, and/or increase range of motion.” (bccr.org, 2021).

Have you experienced one of the many programs that make up the Breast Cancer Coalition’s Healing Arts Initiative? Throughout the year we offer sessions in Gentle Yoga; Fluid Motion; Mindfulness & Meditation; Qi Gong; Tai Chi; and Voices & Vision. Each program is offered free of charge to those touched by a diagnosis of breast or gynecologic cancer.

Evidence-based studies show the benefits of engaging in gentle movement as a holistic addition to those going through treatment for cancer. Advantages include: increased energy, decreased fatigue, improved cognition, and decreased stress or distress. (Danhauer et al, 2019).

There is another element to our Healing Arts Initiative programs: a sense of bonding and community becomes established between those who participate. Some facilitators specifically check in early with participants to see what may be weighing on their mind, and incorporate guided meditation that corresponds.

Participants provide valuable feedback following each four- to six-week session of a program. The comments received remain anonymous and serve as a way for us to continue providing effective tools for our survivors.

I encourage you to try a program or facilitator that is new to you! As our survivors have told me:

“RICK is a wonderful teacher. We learned a lot during each session. He incorporated us as cancer survivors and was open to any discussions. I enjoyed his style and sense of humor.”

“KATHY is outstanding. Her prompts are a wide variety of approaches; they’re fun, introspective, promote creativity. She openly shares from her own heart, and she respects the offerings of others. The best two hours of my week.”

“Too many strengths to mention. Love SUNNI, her teaching style & variety of movements!”

“RAKSHA was great! Calm, encouraging and offered modifications if needed.”

“I always find the yoga with MARGARET very fulfilling. She has awakened a gentleness and calmness that we all need; along with an appreciation for ourselves and others.”

“RAPHAELEA is so knowledgeable about energy and movement. She is a treasure!”

“REN is one of my favorites. She works well with a very diverse group of ages and life experiences. She is very affirming and encouraging to all of us.”

“DEB is wonderful! She helps all and accommodates different methods for individuals when needed. She has a yoga environment that is calm, relaxing, caring, and self-healing.”

“I loved learning from DEBRA she is so wise on this topic and every class I would take a few notes of ways to further my exploration of mindfulness. She took the time to meet with me one-to-one when I had some follow up questions, which I really appreciate!”

“JEAN was friendly, patient, easy to understand, and explained each step thoroughly. I learned so much. Felt very relaxed after each class.”

References:

there is no one-size-fits-all approach to treatment, each person’s approach to long-term survivorship is individual. It is a matter of discussion between patients and their medical providers to develop a plan for the weeks, months, and years that follow the end of active treatment.

Patty hearkens back to her training as a nurse in offering guideposts for caregivers and survivors as they develop survivorship plans. “There are three questions in education: what does someone know? What do they want to know? And what do they need to know? Of course, that could be looked at on so many levels. You meet the person where they’re at and then break it down to those questions.”

Some may want to know every possibility, while others would rather focus exclusively on the information they need to take the next step. Neither way is inherently better than the other; they are simply different approaches to the same goal.

Frank and honest communication is helpful on many levels and in many life situations, especially for those who find themselves on this metaphorical bridge between two worlds. “I’d like more talk with health providers on this subject so it would feel more normal,” says Gail. “There has been some talk about sex post-treatment and sleep issues but that’s all. I do like that they are scheduling appointments every few months so someone sees me. That makes me feel like I’m not out there alone without anyone watching.”

A detour through cancer treatment is not a life path anyone would choose. Yet silver linings do appear on the darkest clouds, and this has been true for Gail. “Time is the gift I’ve received and learning how to use it differently is the healing post-treatment. It takes time to figure this out, to consider your new lease on life. I don’t think one jumps into life in the old way after trauma. And maybe that is the good news. It’s an opportunity, as the saying goes.”

1. ncbi.nlm.nih.gov/pmc/articles/PMC6516338/
2. cancer.gov/about-cancer/diagnosis-staging/diagnosis/tumor-markers-fact-sheet
3. jcancer.org/v05p0281.htm

In May of 2018 I was diagnosed with breast cancer. It was shocking and scary to hear the word “cancer”; I don’t have a family history of cancer in general or of breast cancer. At the time of my diagnosis, I was employed at Bausch and Lomb, where I worked in the Research and Development department for more than thirty years. A few months after my breast cancer diagnosis, I decided to retire. That is when I discovered, in May of 2019, that I had endometrial cancer.

The Coalition has been my rock since the beginning! When I saw my surgeon in 2018 and it became clear that a mastectomy was the best option for me, I asked him to suggest a support group. He recommended the Breast Cancer Coalition. I called and became part of the Coalition that same week.

The very first group I joined was the Evening Networking group. It was the best decision I ever made! Here I found the information and support I needed so much before my surgery. Everyone was supportive, caring and had a welcome sense of humor.

Since that time, I attended many of the Coalition’s programs and have become familiar with the services offered to survivors. I am part of the Research Committee and Advocacy Committee, and I also serve as a PALS Mentor to those who are newly diagnosed.

I am very excited about my new role within the Coalition, as it will allow me to have a first row seat on new breast cancer research and to interact with some of the scientists doing this important work. Ultimately, I will be able to give back and serve this great organization.
Thank you to the golfers, sponsors, volunteers and friends who made the 19th Annual Tee’d Off at Breast Cancer Golf Tournament on August 9 at Locust Hill Country Club a success. With their help, more than $33,000 was raised to support the programs and services offered by the Breast Cancer Coalition.

With 171 golfers, it was a sold out course on a hot August day. The first place men’s team included Joe Bruns, Matt Drummond, Brett Hope and Kristian Hochberg with a 56. The first place women’s team was Carla Edmister, Sheila Hayes, Denise Sawyer, and Raquel Stuewe with a 71 while Marisa King, Lauren Hamburg, Kevin Dinehart and Brandon Hamburg took the honors for the mixed team with a 69.

Kristian Hochberg came closest to the pin on #9 with 6’8” for the men, and Christine Hart got closest to the pin for the women with 6’2” on #15. Brandon Hamburg scored the longest drive for the men on #6 and Cherie Wage scored the longest drive for the women on #10. Bob Baldino had the longest putt of the day at 42’6”.

Congratulations to all of the day’s winners, and thank you to all who participated – as a sponsor, golfer, auction donor or volunteer.
Thank You Sponsors

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Photographer: Lisa Gresens
that represent targets for treatment: estrogen receptors, progesterone receptors, and a cellular growth factor called HER2. However, triple negative disease generally responds well to chemotherapy.²

“I was very, very worried about going through chemo when I was pregnant,” Heather acknowledged. To allay her fears, she consulted with oncologists at MD Anderson in Houston, Texas, who have treated a large number of pregnant women with breast cancer. Those conversations brought reassurance; as counterintuitive as it might seem, many forms of chemotherapy are safe to undergo during pregnancy. With her mind eased in regard to her growing baby – a little girl, as Heather soon learned – she focused on her two older daughters. “The girls were really little. They were four and one-and-a half. My goal for them every day when I was in treatment was just to have life be as normal as possible.”

At the time of her diagnosis, Heather was already familiar with the Coalition. “I had actually run in the Pink Ribbon Walk and Run a couple times previously.” She called the Coalition and scheduled a BC101 session. “I met with Holly [Anderson] and I was like a walking zombie at that point. I was in such a haze – it was all totally overwhelming to me. And [Holly] was so nice, so upbeat. I remember thinking, ‘I don’t even know what to ask for.’” Heather was soon connected with a PALS mentor who had also undergone chemo while pregnant. It helped to know she wasn’t alone in this.

Ultimately, their experience with the Coalition opened new doors for Heather and TJ. “I remember him saying that we’re part of a whole world we never knew existed before. It’s true. I talk to people about the Coalition all the time because it’s a great place to go. It’s a home base, if you will.”

After signing up for a session of Gentle Yoga, Heather felt even more at home. “I looked forward to it all week long. I loved it. I could take my hat off and go bald and I didn’t have to worry about it.” Instead of the pity she often encountered in public, Heather could relax among kindred spirits who understood and supported her. “That was huge,” Heather affirmed.

By the time she finished chemo, which consisted of eight infusions administered every two weeks, Heather’s pregnancy was near term. Three weeks later, after a scheduled induction of labor, she and TJ welcomed their daughter, Molly, into the world. “She was born perfect. There were no complications with her at all,” Heather shared, and continued. “After she was born, I felt like a million bucks. I felt like I was ready to run a marathon – today! The nurses said, ‘Take it easy,’ and I knew they were right. But I felt great.”

One week after Molly’s birth, Heather underwent a PET scan - a form of full-body imaging that could not be done during the pregnancy. “That was hard because I had to stay away from her for a whole day.” But the results were worth the hardship; no trace of cancer was found. A few weeks afterward, she began a six-week course of daily radiation treatments, which ended as the holiday season began. “I went for my first prenatal visit at the end of January and finished radiation at the end of November. “ 2011 had been quite a year for Heather and her family!

“In February of 2021, I celebrated the ten-year anniversary of my surgery – my free-of-cancer day!” Heather exclaimed, then continued. “We did her thoughts on her relationship with TJ. “We were always close but afterward, we became one unit. He was definitely, definitely my rock. I’m thankful for him every day. Looking back, I cannot imagine how hard it must have been for him. But, he was so understanding and so strong for me. I absolutely could not have done it without him.” Heather reflected further, saying, “My mom, too. She and TJ were my pillars of strength. They still are!”

Life has long since returned to normal for Heather and her family. “Right now, my girls are fourteen, twelve, and Molly is ten. They all play travel soccer, travel lacrosse, they swim - they are busy. These days, we travel a lot for them. That’s about it – it’s kind of boring. Honestly, it’s great! It really is.”

2. ascopubs.org/doi/10.1200/JCO.2016.68.4068
Jen Bergstrom was the kind of person who, if given the slightest opportunity, would slip into your life and enrich the world around you. She had a bubbly personality along with a smile and laugh that would brighten a room. Jen was quick with witty sarcasm usually delivered with a switched-on Boston accent fitting for her Worcester, MA hometown. A compassionate individual, Jen had a flair for encouraging and uplifting those around her. She was always happiest to be around her family, many friends, and her Peeps. Exceptionally beautiful inside and out, Jen was the bravest person I have ever met, and I love her dearly.

I met Jen in 2013 and fell in love in a short period of time. We were still dating in 2016 when she received her breast cancer diagnosis. She immediately adopted the motto of “Treat it and beat it,” wasting no time in jumping into treatment. Jen did all she could to bring awareness to metastatic breast cancer and inflammatory breast cancer, and raised funds for these causes, as well as for the Coalition and the Pluta Cancer Center. Never one to let cancer define her or take anything from her, Jen did everything in her power to make the most of every moment. While actively undergoing treatment, she got engaged, married, took two honeymoons, and bought her first house.

Jen’s passion was her yoga practice; she excelled to significantly higher levels while in treatment than she had achieved before her diagnosis. Jen loved to travel and to be in nature. Her favorite place was anywhere near or on the water. She would have turned 40 in August. Jen leaves behind beloved family members, friends, cherished memories, and lives touched. Jen’s instructions for me on how to go on living is a powerful remembrance and embodies her spirit:

Remember to smile, laugh, be happy,
Spend time with friends and family,
Take pictures, just have a good time,
Live your life, try new things,
Go on new adventures, just have fun!
I love you so much!

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

Diane Alley  Mary Jane Elliot  Roger "Buzz" Van Horn
Susan Copenhagen  James Edward Herman  Helen Wilkinson
Marjorie Cseplo  Lane Holding  Devin Williams
Joseph Dioguardi  Evelyn Kane

Jen Bergstrom
By Andy Hicks
As most people have heard, the FDA recently announced expanded emergency use authorization (EUA) for a third dose of the mRNA COVID vaccines (Pfizer and Moderna) for individuals with compromised immune systems. This has since been endorsed by the CDC’s Advisory Committee on Immunization Practices (ACIP). Approximately three percent of Americans, or ten million people, qualify for a third dose based on these guidelines. Although there is some debate as to the specific health conditions that cause immune compromise, patients on chemotherapy for all cancers qualify for a third dose of a COVID vaccine under these guidelines. This most recent recommendation has raised many questions, some of which will be addressed below.

**Why get a third dose of either the Pfizer or Moderna COVID vaccine?**

Early studies are showing that patients with certain conditions, including those with breast and gynecologic cancers who are being treated with chemotherapy, make lower levels of antibodies from COVID vaccines as compared to people without these conditions. Studies have shown that a third dose of a COVID vaccine in patients with organ transplant increases the immune response and leads to higher levels of antibodies against COVID. This information likely applies to patients being treated with chemotherapy for other cancers as well. Even in patients who did not make an adequate antibody response to the first two doses of the COVID vaccine, the third dose may lead to higher antibody levels and increased protection against COVID.

**Is a third dose safe for patients with breast or gynecologic cancer?**

In general, additional doses of vaccines do not pose significant health concerns or an increased risk of side effects. This appears to be true for COVID vaccines as well, and a third dose has been shown to be well tolerated in patients with compromised immune systems. Those with breast or gynecologic cancer on chemotherapy who receive a third vaccination should expect to experience side effects similar to doses one and two; most commonly pain at the injection site, fatigue, and muscle aches that last twenty-four hours.
Quick Black Bean and Sweet Potato Chili

With the addition of sweet potatoes, this easy chili is invigorating yet comforting. Black bean and sweet potato chili has become a classic combo.

1 1/2 tablespoons olive oil
1 large or 2 medium onions, minced
2 to 3 cloves garlic
1 medium red bell pepper, diced
2 medium-large sweet potatoes, peeled and cut into approximately 3/4-inch dice
Two 15-ounce cans black beans (drained and rinsed) or 3 to 3 1/2 cups cooked black beans
14.5-ounce can diced tomatoes (pref. fire roasted)
1 cup salsa
1 cup water
2 teaspoons chili powder
2 teaspoons ground cumin
1/2 teaspoon dried oregano
1/4 to 1/2 cup cilantro leaves
Salt and freshly ground pepper to taste

Heat the oil in a large soup pot. Add the onion and sauté over medium heat until golden, 5 to 7 minutes. Add the garlic and bell pepper and sauté for 2 minutes longer.

Add the remaining ingredients except the salt and cilantro. Bring to a rapid simmer, then lower the heat and cook gently, covered, for 15 to 20 minutes, or until the sweet potato is tender.

Season gently with salt. If time allows, let stand off the heat for an hour or two, then heat through as needed. Garnish each serving with extra cilantro, if using.

Recipe adapted from The Vegetarian Family Cookbook by Nava Atlas. Visit Nava at TheVeganAtlas.com for lots more easy, tasty vegan recipes for everyday meals and special occasions.

Does a booster imply patients will need additional doses every year, or even sooner?

The term “booster” implies the need to boost the immune response at specific intervals, for example, every eight to twelve months. Our immune system has memory, and antibodies tend to last far beyond that time frame, with most antibodies lasting for many years. Therefore, the term “booster” is a bit misleading, since frequent doses (such as annually) are unlikely to be necessary. It is more likely this third dose represents a three-dose series of vaccination, which we hope will provide long lasting immune protection. This is similar to what is already done with certain childhood vaccinations, such as hepatitis B.

Who is most likely to get a good response from a third dose of a COVID vaccine?

Many factors go into determining a patient’s immune response to vaccination, including the stage of the underlying disease. Patients with early or localized breast or gynecologic cancer are likely to respond better to vaccination as compared to patients with advanced disease on aggressive chemotherapy. Given the difficulty in predicting a person’s immune response, all cancer patients on chemotherapy are advised to receive a third dose of a COVID vaccine, since the risk of significant side effects is very low. The upside is increased protection from significant COVID-19 infection.

Should I get my antibody levels tested to determine if I responded to the vaccine?

Although antibody levels are routinely checked by immunologists to evaluate a patient’s immune system, there are a lot of unknowns on how to best interpret antibody testing for COVID. A test showing no antibodies is suggestive of a poor immune response. However, a test showing the presence for antibodies against COVID does not necessarily prove protection, since the optimal level of antibodies remains unknown. Additionally, antibody levels can fluctuate over time and do not necessarily assure protection in the future. For these reasons, even though antibody testing is not recommended for routine use, people with breast or gynecologic cancer on chemotherapy may wish to discuss the utility of testing on a case by case basis with their oncologist or immunologist.

How should I proceed if I get a third dose of a COVID vaccine and still do not mount an immune response?

Patients with immune compromising conditions would likely benefit from additional risk mitigation techniques, such as wearing a mask in indoor public spaces, avoiding large crowds, maximizing hand hygiene, etc. Additional therapies to provide protection to those who cannot respond to the vaccine are also being studied, with early but promising results. For individuals with immune compromise who have been vaccinated but still get COVID, early treatment with monoclonal antibodies can decrease the risk of severe disease and hospitalization. All patients should discuss these options with their oncologist.

Dr. Mustafa is a member of the Coalition’s Professional Advisory Board. We thank him for sharing his expertise on this timely topic.
I became a breast cancer survivor in January of 2021. Surgery was behind me, I was taking an aromatase inhibitor (AI), and I had my final radiation treatment. I was full of joy when I rang the bell to signal the end of my active treatment! Finally, I could breathe again, after months of tremendous mental strength and courage. Though I was physically fatigued from radiation, I was ready to focus on building my stamina and my overall health – body, mind, and spirit.

I was experiencing some slight joint pain in my hands, which I assumed was from the AI. I thought, “I've handled everything else; I can handle this too.” However, what I didn't expect was the downward spiral of my mental and emotional health. I felt sad. I couldn't concentrate. I wasn't sleeping. I felt lost. This was not at all how I thought a breast cancer survivor was supposed to feel. This post-treatment “low” was surprising and troubling. I thought, “I survived breast cancer. Shouldn’t I feel elated? What is wrong with me?”

When I shared my concerns with my oncologist, she reassured me that my feelings were normal and quite common among cancer survivors. She explained that trauma from a cancer journey is very real. Then she suggested I contact the Breast Cancer Coalition for support.

That one suggestion was a game-changer for me in many ways. At my BC101 session, Holly validated my concerns and I was soon connected to a supportive PALS mentor. I was encouraged to participate in the Surviving & Thriving on Aromatase Inhibitors series of four classes. The facilitators of this program are amazing. I learned the importance of movement, mindfulness, and nutrition to offset the joint pain and other potential AI side effects in a supportive “sisterhood” environment. It was inspiring to meet other survivors and draw strength from their journeys, advice, and support. I felt validated and empowered. I learned that my AI side effects were manageable, that my emotions were real and okay, and that mental health is just as important as physical health for survivorship. Throughout the program, I began to reflect and consider how I want to live life as a survivor.

Months after finishing the program, I am happy to say that my healthy habits are still going strong. I’m exercising regularly, eating better, monitoring my side effects of the AI, and choosing happiness as I “shed the negative” in my life. I am in a much better place physically, mentally and emotionally.
Breast cancer isn’t a single disease, and gynecologic cancers occupy equally complex territory. These diseases can and do occur at all stages, from small in situ growths to advanced disease that has spread to distant sites within the body—and all phases between. And they often carry certain biomarkers that can influence treatment decisions. Genetic factors play into the picture for some as well. In addition to wide range of variables in these diseases, the individuals affected come from all walks of life and represent all ages, races, and genders. Making strong peer connections through our PALS program has become possible because of the depth and breadth of the survivor community we serve at the Coalition. And that community continues despite the pandemic.

Those who turn to the Coalition for support and information after a recent diagnosis of breast or gynecologic cancer, and who then choose to participate in our PALS program, take advantage of this opportunity to speak one-to-one with someone who has faced a similar situation. COVID has not slowed the pace of PALS connections that have been made in the past year-and-a-half. We have adapted, while our savvy mentors have grown ever more creative in finding ways to connect with their mentees. Phone calls, text messages, facetime, Zoom meetings, Facebook messaging, and remote communication of all types have ensured that these helpful survivor-to-survivor conversations happen at a time when they are truly needed.

I look forward to the time when we can safely gather in person again. When that time arrives, long awaited hugs will abound! And we’ll carry forward an important lesson: we can communicate effectively and meaningfully even when we’re not able to be together physically. The possibilities are endless!

Learn more about our PALS program on page 12, by calling 473-8177, or email info@bccr.org.

When Nancy was diagnosed with breast cancer in 2015, she turned to the Coalition for information and support. During the months of her treatment, Nancy became a kind, caring presence in our survivor community. As a full-time administrative nurse, nursing educator, and respected member of the local health care community, Nancy’s time was divided, and she attended our groups and educational events as she was able. And while at the Coalition, she was with us one hundred percent.

Two years after her original diagnosis, Nancy’s cancer was found to have metastasized. She soon made the decision to retire, and since that time, we at the Coalition have been beneficiaries of her brilliant mind and compassionate heart. As a member of our Research Committee, Nancy has been a survivor-advocate on our Research Advisory Panel. This has meant poring through the dense scientific language of grant proposals to assist in scoring these proposals according to the goals of our Research Initiative; it requires close familiarity and alignment with the Coalition’s mission.

Alongside her fellow members of the Advocacy Committee, Nancy has spoken with legislators, seeking their support for laws beneficial to those touched by a cancer diagnosis. This includes advocating at the national level for the Metastatic Breast Cancer Access to Care Act. Her eloquence shines on these occasions, just as it has when she spoke about her experience to our Professional Advisory Panel, and again when she shared her story at our Advanced Breast Cancer Seminar. As a PALS Mentor, Nancy’s peaceful yet purposeful presence combined with just the right amount of humor offer the reassurance that living well with this diagnosis is, indeed, possible.

Whether she is speaking with her fellow survivors, with lawmakers, or with members of the healthcare and research communities, Nancy’s steady manner, intelligence, and understated but rock-solid resolve shine through. Hers is a voice to be heard.

Learn more about our PALS program on page 12, by calling 473-8177, or email info@bccr.org.
It’s the fall of 2021, and while many of us believed we would be looking at the Covid-19 pandemic in the rearview mirror by now, it remains a part of our lives. As I’m writing this article in late summer, mask mandates are going back into place (or are already reinstated) for certain activities, and the top story in the news is the need for vaccine booster shots. Our annual fall fundraising event remains virtual. We have all adjusted to a new ‘normal’ way of life.

Throughout this time, the Coalition’s programs and services have continued via online platforms. Our fundraising work has also continued. Many of you participated in our virtual walk/run in 2020 and 2021, played in our golf tournament, made a gift through the United Way, or made a gift in response to our annual campaign mailing. You, our donors, have continued to be vital and generous members of the Coalition community – even in the strangest and most uncertain times. We really cannot do what we do without your support. For that, we say: thank you.

Thank YOU for ‘sticking’ with us.
Thank YOU for completing a ‘virtual’ walk or run – twice.
Thank YOU for asking your friends and family to support the Coalition.
Thank YOU for donating auction items. For purchasing auction items.
Thank YOU for mailing in a gift.
Thank YOU for all the ways that you have contributed during this time.

With your help, the Coalition continues to provide education and support programs at no charge to all who need them. Your gifts also support our advocacy efforts and research initiative. We cannot say it enough: THANK YOU.

Like many donors to the Coalition, Darnell and Gail Garland have not been personally touched by breast or gynecologic cancer. But they have family members and friends who have received a cancer diagnosis, and they understand how important the Coalition can be for those who have heard the words, “You have cancer.” They have been loyal donors for almost a decade – making personal contributions as well as making a yearly gift with their church, Restoration Church of God in Rochester.

Why do you give to the Breast Cancer Coalition?
DARNELL: It’s a great organization and a very important cause. The Coalition has helped so many people in our community. I can’t think of any negatives or reasons not to support the Coalition.

Is it important to you that donations to the Coalition stay local?
GAIL: It’s very important that our gifts to the Coalition stay local. We have given to organizations that are out of the state, but it’s better for us knowing that the money we give to the Coalition helps people in our area, people we know, our friends and neighbors. We live and work here. This is our community, and we are proud to support it.

DARNELL: The Coalition does good work. You want to help anyone you can, but when we give to the Coalition, we can see how they use the funds, see the results of the gift and know that we have helped someone in our community.

Tell readers about the gifts to the Coalition through the Restoration Church of God:
DARNELL: We met with staff at the Coalition, and one of them offered to come by and do a presentation for our congregation. She came and discussed all of the programs and services offered to survivors through the Coalition. Our church has been donating ever since. We take a special offering once every year for the Coalition. So many people have been touched by breast cancer. Most of our members have insurance and are able to get screenings, but they recognize the importance of the services provided by the Coalition for those who are diagnosed. We are proud to make an annual gift to the Coalition to fund these much-needed programs.
OUTREACH UPDATE

Since January of 2013, I have enjoyed, savored, celebrated, relished, appreciated (and occasionally rued) my work here at the Coalition. What a place! And what a worthwhile endeavor to create this safe haven for those facing such frightening diagnoses.

I have had FUN above all else. I’ve loved working out in our community, with diverse people of all ages and situations - and in all weather! I’ve enjoyed interacting with the incredible community of cancer treatment providers and professionals; with festival-goers and health fair attendees. I have been awed and inspired by the work being done at area nonprofits to make our community welcoming, safe, and helpful.

I have been privileged to celebrate the generosity of individuals and businesses who support us though sponsorships, donations, grants and community-based fundraisers. I have taken the gratitude of our appreciative survivor community back to these folks, and let them know the meaning their gifts have to our survivors.

“Goodbyes make you think. They make you realize what you’ve had, what you’ve lost, and what you’ve taken for granted.”
– Ritu Ghatourey

I have made amazing friends. Volunteers have made me look good, and saved my skin, and become some of my closest companions. Survivors who come to the Coalition have let me into their souls, and I am better for it in every way.

I have worked with some of the most talented and dedicated team players I could imagine. These are people who give their energy, their creativity, their evenings and weekends and above all, their hearts to their work.

What I’ve lost: People I have come to love, to a disease I have come to despise. Some days this mountain seems so big, and the ways we are able to help seem so small. Losing these treasured friends is heart-wrenching, and the one and only “bad” part of working here. Let us never forget that eradicating this terrible disease IS our Mission!

What I took for granted: the sheer, pure JOY of seeing people come in and out of this building every single day. The camaraderie of working with some of my best friends each day. Lunches, meetings, seminars, groups, parties, check presentations, and visitors. Oh my, how I have missed you all!

And so I say farewell, for now. I take to North Carolina all I have experienced here, and I am thankful.

Lori Meath

“Lori has been an integral part of the Coalition for many of our volunteers; members of our survivor community, our medical community, and the community at large; and, of course, our staff. She has left a lasting impression on our organization and in our hearts. As she begins a new chapter of her life, we cherish our memories of her time with us. Au revoir, dear friend!”

BreastCancerCoalition.org

FUNDRAISING FRIENDS

A LONG, LONG WALK

Teacher Jim Arrigenna’s Contemporary Issues health class got in many thousand “steps” on a cloudy June Friday recently. The class is offered at Honeoye-Falls Lima High School, and is open to Juniors and Seniors. The class is a service-learning based offering, and each year the students explore and then support a health concern and raise money to help a local organization.

In a relay-style event, the group took turns walking a course over a long day. Games and food trucks kept spirits high, and the students raised $1000 for the Coalition!

WINE-A-BIT

Some of our wonderful friends from the region have once again celebrated their Wine-a-Bit event at the SunValley Campground in Arkport on June 26, 2021.

This merry group of campers started an annual fundraiser for the Breast Cancer Coalition after two of their core group were diagnosed with breast cancer in 2012. Missy Aikin is one of the early organizers, and was inspired by her sister in law’s diagnosis, as well as that of fellow early organizer Michele List. The event involves much revelry and features an incredible array of donated baskets and auction items. Camp participation is always growing, with new campers joining in the effort each year.

Missy says they honor and celebrate the memory of Michele, who sadly died from her disease in 2019, as well as the many other campers dealing with breast cancer; “Unfortunately too many to name them all.”

We are grateful for this dedicated group and for this year’s donation of $2788.
The dynamic women of Penfield Country Club are dedicated not only to their golf game, but to service in the community, and the Coalition has been the fortunate recipient of the club’s generosity once again.

The club held their Pink Ribbon Rally on June 9 - a truly perfect weather day! 112 golfers savored the sunshine and moderate temps and sported pink bandanas to mark the occasion.

During the dinner that followed, club friend Mel Callan spoke to the group sharing her personal story of dealing with breast cancer and also spoke of the invaluable support the Breast Cancer Coalition is able to provide. Organizer Sue VanStrydonck shared that hearing the personal journey of such a dear friend to many brought home the value of the club’s donation to the work we do.

Thanks to Sue and all who work so hard to raise a much-appreciated gift of $4500.

The ROC City Mustangz car club reports a truly “banner” year for two of their big events, both of which support of the Coalition!

After 2020’s more restricted gatherings, the Club set records for participation at both events. The 9th annual Cancer Awareness Car Show took place at the Big M Game club on May 22. And on Sunday August 8th, they gathered at VanBortel Ford on Marsh Rd. for the 5th Annual Perfect Pony All-Mustang Car Show. This day featured “great food, live DJ, an auction, Top 35 awards, and much more.”

The incredible Kitty Van Bortel attended the Perfect Pony event, where she was honored with the Club Appreciation Award for her support of this event as well as the Rochester community in general. Kitty, of course, is also dedicated Breast Cancer Coalition supporter through her Subaru dealerships’ participation in the Share the Love national Subaru event!

We offer big thanks to all involved in these efforts, especially to tireless organizer Chris Washington Sr.

The Mustangz Club raised a terrific donation of $2500 for the Coalition this year!

Stormy weather postponed the first attempt at a home-business vendor fair planned for the infield at Batavia Downs on June 13. In spite of the day’s cancellation, a few diehard vendors set up inside the club and were gratified to raise $392 for the Coalition.

The second date of June 26 was extremely successful with much more cooperative weather and full roster of enthusiastic vendors offering everything from make up to Tupperware to clothing! Vendor fees, generous raffle prizes donated by the vendors, and other offerings resulted in a total gift of $2413 to the Coalition!

Thanks to Batavia Downs organizer Donna Beane, to our longtime Board member Mel Bianchi, and to the kind and generous efforts of the many vendors and customers who made this event so successful.
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 April 1 - June 30, 2021.

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- Burt’s Bees Lip Balm (sealed, no mint)
- Ear plugs (individually wrapped)
- Journals for writing
- Note cards, notepads (bound at top)
- Sleeping masks, lavender or unscented only
- Tea: black pekoe, green, herbal, and flavored, in unopened boxes or tins (unopened packages of 20 or fewer)
- Thank-you cards (unopened packs)
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Coalition GEMs are a special group of dedicated supporters who help the Coalition throughout the year by making a monthly gift. Monthly gifts offer a steady and cost-effective source of income.

Coalition Loyal

Coalition Loyal Giving Society

Coalition Loyal Giving Society

Coalition Loyal 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.

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- Donna Wescott
- Joelle West Donahoe
- Joanne Wheatley
- Arlene Wiesenber
- Anita Wilburn
- Amy Wilkin
- Angela Wilkin
- Lisa Wille
- Rachel Williamson-Naga
- Kathleen Willison
- Dawn Wilson
- Maureen Wing
- Jennifer Wiss
- Fred Woelk
- Womens Association of Penfield Country Club
- Jen Wozniak
- Jaime Wrobel
- Cynthia Wyman
- Dr. Wende Young
- Nina Zarate
- Hope & Bruce Zicari
- Marcha Zimmerman

BreastCancerCoalition.org

Autumn 2021 • 31
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 and 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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Online at www.BreastCancerCoalition.org

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

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**Bid High, Bid Often!**
Don't miss out on our 2021 ACTober Silent Auction that runs through **October 20, 2021**.
Gift baskets, restaurant gift cards, artwork, jewelry and more are available at BreastCancerCoalition.org.

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**21ST ANNUAL**

**Lives Touched, Lives Celebrated**

**October 27, 2021 • 7:00PM**
Held virtually. **Register in advance online:**
BreastCancerCoalition.org/lives-celebrated/

This virtual program honors and pays tribute to the lives of those who have been touched by a diagnosis of breast or gynecologic cancer.

The evening will include:
- Inspirational speaker, Johanna Rehbaum
- Breast and gynecologic cancer survivor reflections
- Poetry
- Uplifting musical performances

Call us at (585) 473-8177 for more information.