FROM THE DESK OF THE EXECUTIVE DIRECTOR

Research Matters

In 1997, our Coalition foremothers envisioned a full-scope nonprofit organization that would stand on four pillars: Advocacy, Research, Education and Support*. While each pillar shares equal importance, spring is the time when we actively work toward an objective that is central to our mission: to advance research in our region with the goal of ending breast cancer. And it’s spring!

Our Research Initiative, which is unusual for a nonprofit grassroots organization, is an integral part of our continuing efforts to eradicate this disease. Since 2003, we have provided seed grants to researchers right here in our own region whose work has the potential to yield significant medical breakthroughs in the cause and prevention of breast cancer, halting progression of metastasis and, ultimately, cure of the disease. In fact, several Coalition-funded projects have gone on to receive funding at the national level.

Why is our Breast Cancer Research Initiative so important to us? First and foremost, we grew tired of seeing millions of dollars raised in our region for “breast cancer research” — dollars that literally left our region. Where did they go? How much was returned to scientists where these funds were raised? Why did the funds leave at all? We had no idea. And this made no sense to us. Though these funds were raised by us and our friends, family, coworkers, and others living in our very own community, there was no way of knowing how much, if anything, was returned to support breast cancer research right here where we live, work, and receive our medical care. We longed for transparency.

And why were we so focused on the endpoints of breast cancer? Those endpoints are, specifically, cause and cure. What do these mean? Plain and simple, we didn’t want our children, siblings, parents, friends, and others to experience a breast cancer diagnosis at all. And if they did, we certainly didn’t want them to die of it. We stood by as plenty of research dollars were directed toward screening, early detection, and primary treatment of the disease. Yes, these are important. But little funding was directed toward understanding what causes breast cancer in the first place and even less was directed toward metastatic disease. We were determined to change this. Today, the majority of Coalition research dollars have been directed to halting progression of metastatic disease, achieving regression, and ending breast cancer altogether. Read about the projects we have funded at bccr.org/research.

Our Research Advisory Board, comprised of breast cancer survivor-advocates and scientists, does the intricate, complex work of determining which projects will receive funding. Together they will complete a comprehensive review of proposals in April with a funding decision made in May. A public announcement will be forthcoming in early summer. Amazing research is happening right here in our region and we are proud to have played a part in it.

In the summer of 2022, the total amount awarded to regional researchers will exceed $1,000,000, a huge milestone worth celebrating! And we won’t rest until the day when breast cancer is no longer a threat to those we love. Our Breast Cancer Research Initiative is YOUR Breast Cancer Research Initiative. Thank you for all you do to support our efforts!

*N*Descriptions of each pillar can be found on our website at bccr.org/about.

In the issue:

- Personal Journey .......... 3
- Feature Story: Hormone Receptor Positive Breast Cancer .......... 4
- Living with Advanced Breast Cancer .......... 6
- Advanced Breast Cancer Seminar .......... 7
- Ovarian Cancer with a Genetic Connection .......... 8
- Gynecologic Cancer Seminar .......... 9
- Advocacy in Action .......... 10
- Coalition Programming .......... 12
- Program Director Update .......... 14
- Research Update .......... 15
- Development Update .......... 16
- Pink Ribbon Walk & Run .......... 17
- Volunteer Spotlight .......... 19
- PALS Update .......... 19
- Healthy You .......... 20
- Friends Remembered .......... 22
- Judy Braiman: Fifty Years of Advocacy .......... 23
- Fundraising Friends .......... 24
- Thank You Donors .......... 27
- Board of Directors & Staff .......... 31
A PERSONAL JOURNEY: MIMI Y.
By Mimi Y.

Cancer, COVID & Connection

On a chilly fall day, October 30, 2020, I had my annual mammogram; something I have been doing for the last thirty-five years. The difference this time was that 2020 was a year of COVID, so I waited in the car alone until my appointment time. My walk into the center was a lonely one; the seats in the waiting room were empty, the warm, cozy blankets gone. It felt ominous. Since it was the season of COVID, there was no waiting to learn the outcome after my mammogram was done. I was sent home to receive the results either by phone or, as had happened in years past, to await the arrival of a letter in the mail saying, in effect, “you are clear, we’ll see you next year.”

But half an hour later, I received a call: “Mimi, your mammogram showed some changes since your last one. We need you to come back November 5th for another mammogram and possibly an ultrasound and biopsy.” I could feel my whole body getting hot and my heart pounding. What could that mean? My husband encouraged me to stay positive and reminded me it could be nothing to worry about.

My mother was diagnosed with breast cancer at 64 years old. She had a mastectomy in 1986 and at that time, chemo and radiation weren’t available to her. That memory was heavy on my mind. Still, I tried to stay positive and hopeful, deciding not to say anything to my three children and their spouses; I would wait. I had my second appointment on November 5th and underwent a mammogram, then an ultrasound, and finally a biopsy. I was told I would get a call with the results the next day, which was a Friday.

I spent that day caring for my grandchildren, keeping myself occupied by games and crafts. I was overwhelmed and fearful, and worked hard all day to keep it together. The call finally came; I was diagnosed with Invasive Ductal Carcinoma, or IDC. At that point, it became reality: I had breast cancer. I jumped on the rollercoaster of multiple appointments, surgery, radiation and the challenge of sharing my diagnosis with my family and friends. IDC with lymph node involvement, estrogen and progesterone receptor positive, and HER2 negative* was the final diagnosis. My life would turn upside down, and COVID added to the stress. My kids were being very cautious, so I could no longer care for my grandchildren for fear I might get COVID, which in turn, might interrupt testing or treatment.

One of the first calls I made was to the Breast Cancer Coalition. I was so grateful for the support, the wisdom, and the compassion I received. Ali Dennison was my first contact, and soon I started taking classes, all virtual: Mindfulness & Meditation, Yoga, and QiGong, as well as educational programs and seminars. These became my saving grace; a road map to surviving my breast cancer. The staff at the Coalition truly helped me to move forward with hope!

Family and friends came into our lives and blessed us with loving kindness. They filled our sadness with joy, our fear with courage, our loneliness with friendship. Their cards filled us with inspiration. Delicious meals kept us fed when we had no energy for simple daily tasks. Their friendly visits filled our lonely anxious moments with hope. Their prayers draped us in comfort, helping us to remember how loved we were.

Simply said, it all helped me to remember to be grateful and hopeful. I knew that even while facing cancer at Christmas time during COVID, I was never alone.

*The presence or absence of these three common indicators – estrogen receptors, progesterone receptors, and HER2 (human epidermal growth factor 2) – can help patients and their health care providers understand an individual breast cancer diagnosis and guide treatment decisions.

Mimi Y.

BreastCancerCoalition.org

Spring 2022 • 3
Rochester-born Alissa Huston, MD, is a hematology/oncology specialist associated with the University of Rochester whose focus is on breast cancer. A familiar presence to many at the Coalition as a caring oncology provider, an occasional presenter at our educational seminars, and a past recipient of the Hearts and Hands Award, Dr. Huston kindly agreed to share her abundant knowledge regarding hormone receptor positive breast cancer.

Some breast cancer cells have receptors that bind to the hormones estrogen and/or progesterone. These cells need one or both of these hormones to grow. About eighty percent of breast cancer cases are estrogen and/or progesterone receptor positive. While this form of the disease affects many, approaches to treatment vary widely according to individual needs. We thank Dr. Huston for helping to clarify the intricacies of this all-too-common breast cancer subtype.

Dr. Huston: They can. In terms of hormone receptor positive breast cancers, there are some that more strongly express estrogen and there are some that express it more weakly or behave less like your typical estrogen positive cancer. We know there are some that have some hormone expression but that may not be the big driver of what’s causing that cancer to grow and develop. When I’m talking with patients, I like to think about it in terms of what options we have available for treatment.

When you think about the most common breast cancer subtypes — hormone positive, triple negative, and HER2 positive — this is directing what tools I can use to treat the cancer. In triple negative breast cancer, all our treatments are chemotherapy, although for some patients now, immunotherapy can come into play. In HER2 positive cancers, there are targeted medicines for those receptors. Not every cancer is going to behave the same way and that’s true in every subtype. Everyone is an individual and everyone’s cancer behaves in its own unique way.

Dr. Huston: There are many elements that can be involved in a breast cancer growing, and when we think of one that’s driven by hormones, having that information helps us in tailoring what treatments an individual may receive. Medicines we use to block hormones will be an important part of their treatment plan. Sometimes I use the analogy of a cupcake. It sounds funny, but if you think of a hormone blocking medication as the cake portion, then what else will add benefit on top of it? It’s that icing — how much additional benefit you are going to get from adding chemotherapy.

We can have two estrogen-positive cancers and approach each of them differently. Some people have very little benefit from chemotherapy, and some of the new molecular tests help us in determining that specifically for hormone receptor positive cancers. Estrogen expression is one of the big drivers of breast cancer, and there is a group of medicines that will block those hormones and help provide that benefit to patients.

For the person recently diagnosed who may be learning for the first time that their breast cancer is hormone-receptor positive, it can be a confusing time. What do they need to know about their diagnosis?

Dr. Huston: There are many elements that can be involved in a breast cancer growing, and when we think of one that’s driven by hormones, having that information helps us in tailoring what treatments an individual may receive. Medicines we use to block hormones will be an important part of their treatment plan. Sometimes I use the analogy of a cupcake. It sounds funny, but if you think of a hormone blocking medication as the cake portion, then what else will add benefit on top of it? It’s that icing — how much additional benefit you are going to get from adding chemotherapy.

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Do hormone positive breast cancers differ significantly from those in which the growth is not driven by estrogen or progesterone?
one of those characteristics. There are other factors such as the growth rate, the grade – a whole number of things – that affect how a cancer responds to treatment. I look at the hormone receptors and think, okay, I have certain options as part of my overall plan.

Are there any new treatment possibilities on the horizon for hormone positive breast cancer?

Dr. Huston: Yes. There have been a few clinical trials looking at a class of medications called CDK4/6 inhibitors. Many patients with metastatic breast cancer are familiar with them. There are three of these medicines, and they’ve been studied for quite a number of years in the metastatic setting, showing improvement in responsiveness over time in patients who take them along with the typical anti-estrogen medications like aromatase inhibitors. There have been a few studies looking at patients with early stage disease and whether these medicines can help to further reduce the rate of recurrence. One of the studies is still ongoing. One was mixed in its results, but the third showed a benefit. So there is a subset of patients that are considered higher risk – meaning a higher growth rate of their cancer above a certain threshold with positive nodes and a higher grade – that may benefit from the inclusion of this medicine for two years. It’s called abenaciclib or Verzenio. That’s been a new tool that we can talk about for patients with early stage disease and how to manage them from our setting, showing improvement in their risk and improve that outcome.

It’s not without side effects but we have a good sense of what those are and how to manage them from our advanced breast cancer patients. It’s not for everybody and it’s approved in a very select subset of patients. We’re certainly waiting on data from some of the other trials.

For molecular tests such as OncotpeDX, we have more and stronger data, and ongoing studies showing that even in node positive patients that are estrogen positive, it can help us more precisely tailor treatment to the individual. All hormone positive cancers aren’t the same. While some may get some benefit from chemotherapy, others will not. Molecular testing may not always be appropriate in every circumstance, but that would be something else for us to talk about with patients.

Considering the hormone-blocking agents that have been in use for a long time, we know they often come with a set of side effects. We’ve developed a program at the Coalition that helps people manage one of the most common side effects of aromatase inhibitors – joint pain – if they experience that.

Dr. Huston: Your program is wonderful. I spend a lot of time talking about aromatase inhibitor side effects with postmenopausal women, as that is the preferred anti-estrogen for them. Joint aches are one of the most debilitating side effects, and fatigue and hot flashes can also be debilitating. But your program has been wonderful and I continually receive great feedback from patients about how it’s helped them. While we have medicines that can also help, the thought of layering medicine after medicine can be overwhelming for many patients who are committing to, at minimum, five years of treatment and probably a little longer.

Looking at the total duration of treatment with aromatase inhibitors, we began treating people for five years, then ten years was better for some, and there was a study released last summer that said seven years seems on par with ten in terms of effectiveness and maybe less in terms of some of the side effects. There are still patients that may benefit from longer treatment but we’re trying to narrow down that timeline. So it’s a matter of having those conversations and figuring out what’s best for an individual.

We recently piloted through the Pluta Integrative Oncology and Wellness Center a small program based on large study that came out a few years ago looking at acupuncture to help reduce joint pain from aromatase inhibitors, and that showed a reduction in pain. Those are ways we can support patients for that duration of time they need to be on treatment.

Tamoxifen can also carry different side effects, but certainly it’s something to talk about with your provider. If you’ve struggled with all three aromatase inhibitors, Tamoxifen may still offer benefit for some patients.

At the Coalition, we often see premenopausal survivors whose oncologists have recommended ovarian suppression in combination with aromatase inhibitors as superior to Tamoxifen, which has typically been used in that age group to block estrogen.

Dr. Huston: There is data to support this, and the strongest data is in the very young patients where chemotherapy was recommended for node positive cancer, although those are the ones that we also have to support too. Because if you’re in your early 30’s and now you’re in menopause, it’s hard to be in that place. But there is a benefit of that combined suppression. We start with what we think is going to offer the best benefit, do all we can to support the patient, and then look at things like Tamoxifen if we need to. It still offers benefit. But it’s hard, especially in our younger patients, where it brings in the conversations about fertility. Those are really important conversations to have when you’re talking about the timeline of treatment.

There is a study that closed a couple years ago that was looking at treating young patients for eighteen months to three years with anti-estrogen therapy and then, if they met certain criteria, coming off treatment to have a family then resuming treatment. We’re waiting on the data from that
I was born “Unnamed Baby Girl Britt,” and my mother never used the word “adopted.” I was the “Chosen Child” to my parents, and became Elaine Caroline. When I was a teen, I dreamed of becoming a nurse to make a positive difference in the lives of others. However, life led me in a somewhat different direction: that of being a life-long family caregiver. But the most valued position I hold is the gift of being a mother. My daughter Krystle, the true love of my life, was born in 1985. I don’t know how I found the energy to hold a full-time job (or two) supporting my daughter and home while caregiving for family and friends, but hope has always kept me going. It has become part of my character; it recharges, regenerates, and strengthens me.

In 2003, my journey veered off course when I was diagnosed with Multiple Sclerosis (MS). Though it was shocking, especially to a single mom, I moved forward into a world of sometimes awkward imbalance, learning about and developing my new normal. I never let MS define who I was and that belief still resides in me today. In fact, many people are unaware that I have MS.

2008 “was the best of times, it was the worst of times” as Charles Dickens wrote in A Tale of Two Cities. In the month following Valentine’s Day, I experienced the whirlwind excitement of falling in love again at age 50. A few months later, my mother fell, requiring an unexpected move to a skilled nursing facility. Happiness and sadness took their places sitting on my shoulders and in my heart. Summertime brought a fantasy trip to the Napa wine country with my newfound love.

My cancer story began after that trip while performing one of my most beloved, relaxing hobbies: I’m passionate about gardening. I love working in the dirt and watching new life (including weeds) develop. I took on the challenge of creating a lakeside garden for my love. Three weeks later, one sore over my left breast remained quite noticeable. September brought the diagnosis of breast cancer that was HER2 positive and estrogen receptor positive. I proceeded to have two lumpectomies, yet the margins were still not clean. I entered 2009 having a left breast mastectomy and elected not to have reconstructive surgery, as my medical professionals felt it could activate my MS.

Unveiling myself to myself after the surgery and looking in the mirror, I felt alone and in disbelief – perhaps even shock – at seeing the scars. It was a moment when my life began to change; body, mind and spirit. I asked myself one important question: “Was my life easy before cancer? Did I overcome difficulties and hard times then too?” The honest answer was that I’ve never had an easy life and yet I am still smiling today. I still look at myself each day but with a different view: I am still here. I am a voice and warrior for this life-changing disease that can affect my outside appearance but not my spirit.

In March 2009, my mother miraculously recovered from an illness to celebrate her 90th birthday. However, her health continued to decline and she died in June, with me alongside her, holding her hand. Through all of this, my love faced the loss of one beloved family member and a serious health crisis in another. I lost my job, causing me financial chaos and a downward spiral. But through it all, my faith and hope, along with the determination by my oncologist that there was no evidence of my cancer, gave me strength to move on. This was huge for me.

As can happen in life, my romance faded, I sold my Rochester home in 2018, moving to Canandaigua to be near Krystle. After celebrating an enormous milestone in January 2019 – ten years cancer free – the wind was taken out of my sails the following March. I had trouble breathing and thought at first it was related to the cottage I lived in. But after returning to my oncologist, a lung
biopsy indicated that my cancer had returned. It was HER2 negative, a different cancer than before. This was metastatic breast cancer residing in my lungs.

But yes, I am still here and, remarkably enough, still finding humor, beauty, and gratitude in every day I’m given. The gift of seeing my beautiful daughter grow into adulthood and become the talented, professional woman she’s become is priceless to me. My positive personality along with my faith, hope, and the support of friends continue to be my strongholds.

One trait I encourage in others is to swim daily in humor and hope. I often find myself laughing at myself! If I didn’t believe my middle name was HOPE, I’d think it was Lucy, as in Lucille Ball. For example, I once fractured seventeen bones in my face after falling onto my leaf blower. Two days later, looking swollen and black and blue, I attended a Halloween party as a bumble bee that hit a windshield. Sharing hope and humor have become part of who I am and who I remain.

Also important to me has been the impact of the Breast Cancer Coalition; namely, the Common Ground Group, not to mention all the other supportive programs they offer. Here, I’ve made newfound friends that feel like family: I am fortunate to have many well-meaning friends with wonderful intentions, and the Common Ground “Peeps” group has fostered in me a new understanding of my disease, since we’re all in this together. Pat Battaglia, Holly Anderson, and my oncologist in Clifton Springs became my angels, and the Coalition has brought me personal empowerment and education through their four pillars of Research, Support, Education and Advocacy.

For those recently diagnosed with any stage of breast or gynecologic cancer, I encourage you to call the Coalition. This group will inspire you more than you can imagine with coping skills they’ve learned. They will, most assuredly, make you smile. Your fellow survivors have a deep desire to walk alongside you, to listen to your story, to share their own, to laugh and cry with you, to celebrate the good news and be there with you if the news isn’t always so good. They will definitely encourage you.

Together, we are warriors, worriers, welcomers. We’re walking forward, all different yet we share something life-changing together. We may never know the impact that our stories have on others. My hope in sharing mine is that it will impact someone positively, as I have learned to look for beauty everywhere including in MYSELF.

I wish you hope and humor in each of your days ahead!
I was diagnosed with ovarian cancer in April of 2017 at the age of 58. During the six months preceding my diagnosis, my “normal” seasonal allergies had begun to worsen and I suddenly found myself allergic to medications and foods I had never reacted to before. My primary care physician referred me to a new allergist who prescribed a treatment plan to help “calm everything down” and get me back to normal.

After several months of worsening allergies and no improvement with my new plan, I returned to the allergist. She proposed that sometimes an allergy ISN’T an allergy but another condition causing a reactive response. She asked if I would mind taking a CRP (C reactive protein) test to look for systemic inflammation. It wouldn’t diagnose the problem, but it could help us see if perhaps something else was going on. I took the test in early April 2017 and my results showed a high level of inflammation.

Upon receiving the CRP results, I reflected on my increasing fatigue, lack of appetite, backache, and occasional abdominal discomfort, and made an appointment with my gynecologist. After an exam and ultrasound, as well as a Cancer Antigen125 (or CA125*) blood test that yielded a reading of 2500 (normal range is 0-34), I was immediately referred to a gynecologic oncologist.

Ten days later, I had a total hysterectomy with midline incision. The pathology revealed a Stage 2 grade 3 serous ovarian cancer. My allergist had saved my life.

Physically, the surgery was rough. It was a major surgery with a lengthy recovery. The biggest challenge for me was having patience with the amount of time it would take to heal. I was an active, strong, and “healthy” person up to this point. It was hard to feel “weak.”

One month following my surgery, I began six rounds (eighteen infusions) of dose dense Taxol and Carboplatin chemotherapy, administered weekly, finishing chemo in late October of that year. Chemo was no party. It started out not too badly and when it ended, I was physically and emotionally drained. As a result of chemotherapy, I have neuropathy in my feet and tinnitus in my ears. These are things I can live with, and a fair trade for the good the chemo accomplished.

A FAMILY CONNECTION

After being diagnosed with ovarian cancer, current protocol is to have genetic testing. I received my testing results in June 2017 and was found to carry the BRCA1 mutation**. This was not surprising to me, as my mother was a sixteen-year breast cancer survivor and died of esophageal cancer in 2003 at the age of 66. Her first cousin is an eighteen-year ovarian cancer survivor, my maternal

Continued on next page.
grandmother died from multiple myeloma, my maternal grandfather died from pancreatic/liver cancer and my mother’s grandmother died of breast cancer at the age of 50. Cancer maintained a very real presence in our family.

At this point, I was very fortunate to be referred to a local Hereditary Cancer and Risk Reduction Clinic. After meeting with the director of the clinic, I learned that with my particular BRCA1 mutation, my lifetime risk for developing ovarian cancer was 63 percent and my lifetime risk for developing breast cancer was 87 percent. I elected to have a prophylactic bilateral mastectomy with reconstruction before I turned 60. This surgery lowered my lifetime risk of developing breast cancer to five percent. If I had a chance to help myself avoid developing another cancer, I was going to take it. I’d already lost the ovarian cancer risk lottery and wasn’t willing to try my luck again. I underwent my double mastectomy in April 2018 and completed reconstruction in September 2018. Somehow, this surgery felt easier than my cancer surgery. I believe it being my choice had a lot to do with that.

Once we found I carried the BRCA1 mutation, it was important to find out if anyone else in my immediate family also carried this mutation. Since all of the cancer in my family appeared amongst my maternal relatives, it was easy to narrow down who needed to be tested. I have two younger brothers, one of whom has three daughters. Fortunately, all three of my nieces tested negative for the mutation. My youngest brother, who also tested positive for BRCA1, has no children. And, in one of those odd quirks of fate, my husband and I decided to grow our family through adoption, after we had dealt with infertility for many years. Our daughters, who are of Asian descent, are much less likely to carry a BRCA mutation. Thankfully, my brother and I mark the end of this particularly destructive and sad strain of BRCA1 in our family.

MY ONLY REAL CHOICE

At the time of my diagnosis, I was a thirty-plus-year public school music teacher and orchestra director as well as a “Teacher on Special Assignment,” coordinating the elementary music program offered in the eleven elementary schools in our large school district. My husband also was a full time school orchestra director. Our youngest daughter was sixteen and an active high school junior, while our older daughter was twenty and in her second year at Rochester Institute of Technology. We were a stressed and busy household and my world had come to a screeching halt. I was devastated. How could this be? We had plans!

That was the first lesson I learned from cancer: it just is. My only real choice was how I reacted to it. Like many people, I had lived my life thinking I was in charge of the direction my life took, when in reality we are all just a diagnosis (or accident, or natural disaster…) away from finding we have no real control at all.

HELP ALONG THE WAY

How did I get through this difficult time? One step at a time, one chemo appointment at a time and with the unwavering support of my husband, daughters, father, brother, friends and many coworkers. And, of course, with a gifted medical team that was always willing to listen, answer my questions and help me negotiate this difficult path.

Learning to accept help when I was used to helping and directing everyone else was humbling. I know

Continued on page 15.
It’s Spring; change and growth are in the air.

We at the Coalition extend a warm welcome to the new Chair of our Advocacy Committee, Christina Thompson. We are grateful to Kathy Guglielmi, our previous Advocacy Chair, who has recently moved into the role of Chair of the Board for the Coalition. We’re excited by these new developments in our organization and congratulate both Christina and Kathy as strong leaders at the Coalition and in our community.

Coalition Advocates: Building on Strong Roots

By Christina Thompson

Shortly after joining the Breast Cancer Coalition as the Program Director, I became a member of the Advocacy Committee. I found myself surrounded by such powerhouse committee members as Phyllis Connelly, the first Chair of the committee and former Chair of the Board of Directors for the Coalition; a woman affectionately known as the ‘Queen Mum.’ Marianne Sargent, whose solid leadership carved guidelines we continue to refer to, has paved the way as another former Advocacy Chair. Miriam Steinberg served as committee Chair and enjoyed learning and forging connections in Albany and Washington, D.C. Jean Lazeroff and Melisande Bianchi steered the committee through often turbulent winters during the Coalition’s efforts to see the 48-Hour Notification Law passed in Monroe County; efforts that ultimately succeeded. Rebecca Solomon is hands-down the authority on all things related to the National Breast Cancer Coalition. I’ve learned much from the knowledge and passion of Kathy Guglielmi, who served as the Advocacy Committee Chair for the past four years. These strong leaders have headed a committee that has made huge strides for our survivor community.

Advocacy seemed like an easy fit for me – isn’t that something we do once we’re faced with a breast or gynecologic cancer diagnosis? We advocate for our health by seeking providers to counsel us on treatment protocols and by speaking up about our concerns or side effects. Advocacy continues after treatment while navigating survivorship.

In addition, those who surround the survivor are advocates. When accompanying a loved one to an appointment, asking questions, researching providers, or exploring treatment options, you are acting as a health advocate to help someone you care about better understand their illness.

The Advocacy Committee is a dynamic collection of people who are passionate about seeking out legislation that impacts all who are affected by breast or gynecologic cancers. These concerns can range from types of treatment to positions on environmental bills before local, state, or national legislatures; to funding for various programs in support of the Coalition’s mission – and more. Once pertinent legislation has been identified, we reach out to our representatives and explain why their support is important. Committee members write letters and emails, make phone calls, and even hold Zoom meetings with representatives and their staff members. The Committee works hard to establish and maintain relationships with local, state and federal delegates and actively pursues bipartisan support for bills that are important to the cancer community.

We collaborate with universities, grassroots organizations, and others to increase awareness about environmental and other public health issues. We work together with state and national organizations to further our goal to end breast and gynecologic cancers; groups such as Breast Cancer Action, Breast Cancer Prevention Partners, Clean and Healthy New York, and the National Breast Cancer Coalition.*

We have just begun looking at New York State legislation S3331 and A143, which involve regulating personal care products sold in our state. These are identical bills that require the personal care product industry to identify all ingredients and disclose whether any ingredients are chemicals of concern. The bill would also ban the sale of any product containing thirteen known chemicals of concern within a three-year period. We are also looking to pursue legislation on the federal level with bipartisan support regarding safe cosmetics and personal care products.

If this legislation seems important to you and those you love, I encourage you to contact the Breast Cancer Coalition for more information on how to get involved – (585) 473-8177 or info@bccr.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. We also send many of our advocates to their annual leadership summit.
TAKE ACTION
We are stronger together!

These Are the Elected Representatives that Serve Our Region of Upstate New York

U.S. Senators
Kirsten E. Gillibrand
Charles E. Schumer

U.S. House of Representatives
Elise Stefanik, 21st District
Claudia Tenney, 22nd District
Tom Reed, 23rd District
John Katko, 24th District
Joseph D. Morelle, 25th District
Brian Higgins, 26th District
Christopher L. Jacobs, 27th District

NYS Senators
Pamela Helming, District 54
Samra Brouk, District 55
Jeremy Cooney, District 56
George Borrello, District 57
Thomas O’Mara, District 58
Patrick Gallivan, District 59
Sean Ryan, District 60
Edward Rath, District 61
Robert Ortt, District 62

NYS Assemblymembers
Brian Manktelow, District 130
Jeff Gallahan, District 131
Philip Palmesano, District 132
Marjorie Byrnes, District 133
Joshua Jensen, District 134
Jennifer Lunsford, District 135
Sarah Clark, District 136
Demond Meeks, District 137
Harry Bronson, District 138
Stephen Hawley, District 139
David DiPietro, District 147

Your voice matters!

CALL • EMAIL • WRITE

Your Congressional Representatives in the House and Senate to express your support for:

House Bill H.R. 3183 • SENATE BILL S. 1312

This act would waive the five-month waiting period for SSDI and the subsequent 24-month waiting period for Medicare for those under 65 disabled due to MBC. Introduced in Congress for the third time, it is crucial that we, as citizen advocates, raise the profile of this Bill with our legislators and help move it to the floor for a vote.

Use the contact information to the right.

If you’re unsure who your representatives are, find out at congress.gov or call us at the Coalition!
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.

**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. 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

**Mindfulness & Meditation**

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

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

**Qi Gong**

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

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

**Tai Chi**

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

Offered throughout the year on:
- Saturday mornings

**Voices & Vision**

An engaging writing class for those interested in thinking creatively while recording personal experiences, memories, feelings, and thoughts. Each week you will respond to prompts that challenge you to reflect on the broader aspects of life’s journey. For those interested, there will be opportunities to share your writing with the group. Classes are 1 hour and 30 minutes.

- 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.
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
Virtual links online.

IN PERSON Discussion Group:
- 1st and 3rd Thursdays at 5:30

Newly Diagnosed or In Active Treatment Networking Group
A professionally facilitated group to discuss your experience/questions.

VIRTUAL Discussion Group:
- 1st and 3rd Wednesdays at 10:00am
Virtual links online.

Partners/Spouses, Family & Friends Networking Group
Find camaraderie with others supporting a loved one diagnosed with breast or gynecologic cancer. Professionally facilitated.

• IN PERSON:
  - 1st Tuesdays at 5:30pm

• VIRTUAL:
  - 3rd Tuesdays at 5:30pm
Virtual links online.

Brown Bag Discussion Group
A weekly discussion group over lunch!

VIRTUAL Discussion Group:
- 1st and 3rd Fridays at 12:00noon
Virtual links online.

IN PERSON Lunch Group:
- 2nd and 4th Fridays at 12:00noon.
  Bring your lunch; dessert is on us!

We are grateful to our Brown Bag sponsors!

Common Ground: Living with Metastatic Breast or Gynecologic Cancer
Join others coping with a diagnosis of metastatic breast or gynecologic cancer. Professionally facilitated. Register with Christina@bccr.org.

IN PERSON Lunch:
- 1st and 3rd Thursdays at 12:00noon

VIRTUAL Discussion Group:
- 2nd and 4th Thursdays at 1:00pm
We are grateful to our Common Ground sponsors!

Common Ground Partners: Partners of Metastatic Individuals
Professionally facilitated group. Register with Christina@bccr.org.

VIRTUAL Discussion Group:
- 3rd Tuesdays at 5:30pm

Young Survivor Gatherings
An informal and fun way to connect with others who walk a similar path.
- Call or email to be added to our invitation list.

LEARN

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

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.
- April 27, 2022: “Updates in Breast Cancer Subtypes,” presented by Alissa Huston, MD and Carla Falkson, MD
- May 25, 2022: “Updates in Surgical Management of Breast Cancer,” presented by Rachel Farkas, MD
- June 22, 2022: Topic to be announced

Book Club
Join our monthly Book Club every 4th Thursday of the month at 6:00pm. VIRTUAL links online.
- April 28: The Silent Patient, by Alex Michaelides
- May 26: Lilian Boxfish Takes a Walk, by Kathleen Rooney
  June 23: Hamnet, by Maggie O’Farrell

Lymphedema Networking Group
For those living with lymphedema and caregivers, therapists, medical personnel, and those at risk for developing lymphedema. Professionally facilitated. VIRTUAL links online.
- 2nd Wednesday of the month, 6:00pm

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 series beginning in May and 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.
I was recently asked to participate in a survey for breast cancer patients. This survey was designed to research the correlation between breast cancer survivors who had or had not joined support groups and their body image.

I answered questions like: “When you were first going through breast cancer treatment, what were you feeling?” “Describe a time when you felt helpless when you were going through treatment.” “Was there ever a time when you felt like nobody around you really understood what you were going through?”

As I answered the questions, I reflected on my treatments in 2018 and 2019. There were many times when I felt helpless and overwhelmed, or that I didn’t want to burden those around me with how I was feeling... again.

I am so thankful that I was connected with the Breast Cancer Coalition. While I didn’t know what to expect the first time I attended the Breast and GYN Cancer Group on Thursday evenings, what I discovered was the caring voices of others who knew that same helpless, overwhelmed feeling. They encouraged me by recounting their experiences and empowered me with suggestions on mitigating side effects of treatment. They provided support and hope.

Perhaps the movements of Tai Chi with Jean, or Gentle Yoga with Raksha or Susan, can help provide a new frame of mind when you feel vulnerable from treatment. Why not try Mindfulness & Meditation with Rick or Debra? “Research provides evidence that mindfulness meditation increases positive affect and lowers anxiety and negative affect.” (Davis & Hayes, 2012). Does putting pen to paper help verbalize what you’re experiencing? We offer Voices & Vision writing workshops as a safe place to help process emotions. Do you prefer to escape with a good book? Take part in our monthly Book Club discussions with guest facilitators! The Coalition has networking/discussion groups at different times throughout the week, and educational Evening Seminars on topics survivors want to learn more about.

What do all the programs at the Coalition have in common? They are provided free-of-charge to those with a breast or gynecologic cancer diagnosis. Each program is professionally facilitated and populated by fellow survivors. All programs are evaluated by participants, and those evaluations are carefully assessed by Coalition staff to ensure our offerings are meaningful and relevant to those at any stage following their diagnosis.

A dear friend shared his acronym for HOPE: Having Other People’s Encouragement. That is exactly what Coalition programs provide.


Conversation with Alissa Huston, MD, continued from page 4.

At the end of the day, what gives you hope?

Dr. Huston: I always look at what I do as a partnership with myself and my patient, and trying to look at everyone as an individual, and to do what’s right for them. And there’s hope in the midst of everything. Hope can take many different faces. At times it can be very hard and challenging and conversations can be very difficult. I feel that I get so much from what I do; from those that allow me to care for them.
Preparations for Research Review Day are in High Gear

By Silvia Gambacorta-Hoffman

Members of the Research Committee are getting ready to review the 2022 grant proposals submitted by researchers in our region. This year, we have a new timeline: the submission deadline for all proposals was March 15, with Review Day planned for the last week in April. During Review Day, survivor/advocates from our committee gather with experts from throughout our region (including some of our past grant recipients) to review and score the proposals that have been submitted. The resulting recommendations of studies to receive Coalition grant funds is then reviewed by the Board of Directors and ultimately either approved or sent back to the Committee for further discussion. Every year, the Coalition offers a training session for Research Committee members who are new to the process of reviewing grant proposals, as well as experienced reviewers who wish a refresher course.

The 2022 application process is similar to the previous year. Proposals can be uploaded by applicants into a secure online folder. Paper copies are also submitted to the Coalition and distributed to those assigned to review the proposal. Reviewers have the option to read their assigned proposals electronically, work with paper copies if they prefer, or both. This system worked well last year.

In 2021, the Coalition adopted the National Institutes of Health (NIH) scoring system, in which proposals are judged by an Overall Impact score system. The NIH uses a 9-point rating scale system wherein 1 is considered exceptional, 9 poor and 5 is a good medium-impact proposal. Generally, proposals with an Overall Impact score of 1 to 3 are most likely to receive consideration for Coalition funding. The reviewer evaluates each assigned proposal using seven different criteria to derive their individual overall impact score. An applicant does not need to be strong in all the categories to receive a high score and be judged to have a major scientific impact. The final overall impact score of each proposal will be determined by calculating the average score from all the reviewers. It’s a complex, collaborative process that is rewarding to all involved, and we provide support and assistance to our reviewers at every step of the way.

If you are interested in learning more about the Coalition’s Research Initiative and joining the Research Committee, contact silvia@bccr.org.

Ovarian Cancer With a Genetic Connection, continued from page 9.

that as strong as I thought I was, I could not have made it through without the caring people in my life and their many kindnesses.

In January of 2018, I came to the Coalition for my “Cancer 101” session. I had learned about the organization from my breast surgeon and also learned the Coalition was reaching out to gynecologic cancer survivors. I was amazed and moved by the generosity of all the staff members I met that day. After getting to know the Coalition and its many offerings, and completing my breast reconstruction, I found the weekday Gentle Yoga class with Susan Wood. This class was the perfect fit for me. In Gentle Yoga, I have met many other cancer survivors. These strong women have generously shared their individual journeys and experiences in the safe space of our class. The stretching and strengthening has helped me reconnect with my body after so much surgery. And, most importantly for me, the class has helped me to better focus and stay in the moment. Not the past, not the future. This class is a lifeline.

EVEry Day Is a Gift

April 2022 marked the fifth anniversary of my ovarian cancer diagnosis. It amazes me that I have the privilege of being here to say this. Every day since April 2017 has been a precious gift. I am thankful for my family, friends and the miraculous medical treatments that got me here.

* CA-125 is a protein that is often found in high amounts in the blood of patients with ovarian cancer. Used in conjunction with other types of testing, it can be a helpful tool in diagnosing the disease and monitoring the response to treatment. However, it is not an effective screening tool in the general population.

** A person who inherits certain mutations (changes) in a BRCA1 gene has a higher risk of developing breast, ovarian, and other types of cancer.
The Secret to Fundraising Success: “Just do it!”

By Carly Euler, Special Events Coordinator

The Pink Ribbon Walk and Run is right around the corner! Many know the event is the largest annual fundraiser at the Coalition, but did you know that our event participants are the foundation of our fundraising success? It’s true! Last year alone, Pink Ribbon walkers and runners raised over $120,000 to support the Coalition.

Referred to as “Peer-to-Peer Fundraising,” this strategy empowers our network of existing supporters to raise money on behalf of the Coalition by providing them with the tools, knowledge, and encouragement they need to raise funds. Time and time again, this strategy has proven to be a wildly successful way to support our mission – just ask a seasoned fundraiser: Ashley Zicari-Infantino.

Ashley has been an integral part of the Pink Ribbon Walk & Run since its inception – even serving as the Youth Race Ambassador in 2004 – as a way to carry on the legacy of her mother. The late Nancy Zicari-Infantino was one of the founding members of the Breast Cancer Coalition, who sadly passed from the disease in 2002 at the age of 32.

Ashley admits, “I have BIG shoes to fill!,” but the event is essential because “It is organizations like the Coalition that support those who receive the news of a diagnosis. They are helping fund the research to make sure the diagnosis is found earlier... Put simply, I don’t want another family to lose their loved one to this disease.”

“My ‘Mom on Earth’ (Step Mom) also gave me the extra encouragement to ‘raise the bar’ in regard to my fundraising goals.” Ashley’s stepmother, Delaina, as well as two of her aunts, all experienced their own breast cancer diagnoses in the late 2010s. They each found essential knowledge and lasting support from the Coalition during this time. “To see the Coalition that my Mom co-founded go on to help my Step Mom and my aunts through their diagnoses was just amazing.”

To Ashley, this was even greater proof that the proceeds from the event are vital and she was compelled to start fundraising. Initially, Ashley was hesitant to ask people to donate, fearing she would be seen by others as an annoyance. But she was quickly and enthusiastically met with the opposite reaction.

“People were inspired that I have such a passion for philanthropy. I have even inspired others to raise money for causes special to them. To hear that I’ve had that impact really encourages me to keep going.” Now, when asked her secret to peer-to-peer fundraising, Ashley states: “JUST DO IT!”

“I have found social media and direct outreach to be the most effective. Also, tell your story! Why does the cause mean so much to you? The people who connect with your story are eager to support causes that have a meaningful impact in their community.” Through these methods, in 2021 Ashley hit our Power Player Fundraising Level (over $2,500), and coordinated 25 additional people to walk, run and raise funds of their own!

This year, she has brought her dedication to a whole new level by serving on the Pink Ribbon Committee. Ashley is thrilled to participate in person, but loves that other options are available. “When I was living abroad, I participated virtually from across the pond. I love that people can still support from a distance.”

Ashley’s story is proof of what we have always known here at the Coalition: our supporters are our greatest asset.

If you would like to make a difference like Ashley, register for the Pink Ribbon Walk & Run today, and click the “Become a Fundraiser” button. Once you create your page, you have the ability to add your personal photos and story. Then the Coalition will provide you with a Fundraising Toolkit to assist with your success. Please contact me at carly@bccr.org with any questions or for help getting started. We hope to see you May 7th!
Join Us in the fight against breast and gyn cancer!
Mother’s Day Weekend • SATURDAY, MAY 7 • Genesee Valley Park!

We’re excited to announce the Pink Ribbon Walk & Run is back in person – on SATURDAY, MAY 7, 2022. You can help provide vital services to those in our community touched by breast or gynecologic cancer at this two-in-one event. Join us for event day raffles, music, and fun!

PINK RIBBON WALK
Everybody Welcome!
9:00am start

PINK RIBBON 5K RUN
Women Only!
8:30am start

All proceeds from this event benefit the Breast Cancer Coalition. Register and fundraise online at www.BreastCancerCoalition.org. Contact Carly@bccr.org with questions.

Register by Friday, April 1, 2022 to guarantee your event shirt!

EVENT REGISTRATION:
[ ] Pink Ribbon Walk Registration ($25)
[ ] Pink Ribbon Run Registration ($30)

VIRTUAL REGISTRATION:
[ ] Pink Ribbon Walk Registration ($25)
[ ] Pink Ribbon Run Registration ($30)
[ ] Additional Donation of _______

TOTAL AMOUNT ENCLOSED: $ _______

Thank you for supporting our mission!

BreastCancerCoalition.org
OTHER WAYS TO JOIN THE FUN!

Honor your loved one

Warrior Walkway signs

Honor your loved one on the event course! For a $100 donation, we will produce a Warrior Walkway sign featuring a photo of your loved one. Signs are weatherproof and approximately 18 x 24 inches. After the event, it’s all yours!

This is a stunning way to honor a survivor or the memory of a loved one – A visual reminder for all WHY we walk and run.

The 5K Run Is for Women only

Here’s Your Chance to be One Lucky Runner!

It’s true: The Pink Ribbon 5k Run is a women-only event. But, did you know there will be "One Lucky Runner" who joins them?

This event invites our male and non-binary friends to enter for a chance to run alongside our inspiring group of women survivors and supporters. $10 = 1 Entry.

Make a greater impact:

Pink Ribbon Fundraisers get awesome gifts!

Want to make a greater impact? It’s easy to do! Just click the “Become a Fundraiser” button when you register.

As you raise funds, we will reward you with a gift for all your hard work (like these custom YETI products, pictured). We have even created a Fundraising Toolkit to give you all the tools you need to raise funds successfully.
PALS UPDATE

Mentor Training

Since the PALS program began in 2008, well over a thousand newly diagnosed individuals have been connected with peer mentors. That’s a lot of support! The program works because of our trained, compassionate peer mentors who represent diverse experiences. In fact, some of our mentors have been on board with the program since its beginning! We hold PALS mentor training sessions annually to empower breast and gynecologic cancer survivors with the tools they need to offer the most meaningful support for those more recently diagnosed. After all, adding fresh faces and new perspectives to PALS helps keep the program dynamic and relevant. Mentors who are long-term survivors offer a unique form of hope while those more recently diagnosed have personal experiences with new developments in treatment. It’s a win-win!

2021 was an exceptional year in many ways, including the fact that we did not hold our annual mentor training due to pandemic concerns. As the year drew on, scheduling this training seminar became an increasing priority. But with new COVID variants circulating through the population, the prospect of holding our usual in-person training seminar was clearly out of reach. So we adapted. We divided the full day of presentations into two half-day workshops that were held via Zoom on consecutive Saturday mornings last winter. I am grateful to the entire training team – Ali Dennison, Christina Thompson, Holly Anderson, and our professional expert, Vicki Nugent, NP – for their roles in ensuring our nineteen new mentors had the best possible training experience.

In another new development, we will be holding our first-ever mentor training for gynecologic cancer survivors later this year. It has become clear that members of this group, who have been included in past trainings for breast cancer survivors, have concerns and experiences that can best be addressed this way. If you are interested in learning more about this, please email pat@bcr.org.

Volunteer Spotlight

Alison Currie

By Pat Battaglia

While many cancer survivors can relate to the feeling of having scaled a mountain once the experience is behind them, Alison Currie has literally climbed the highest mountain. Yes, she has been to Mount Everest. And Mount Kilimanjaro. And others. All in the wake of her breast cancer diagnosis in 2016 and subsequent treatment. She is unstoppable.

An ardent triathlete, Alison first came to the Coalition to run in support of her mother-in-law during our Pink Ribbon Walk and Run. Soon afterward, Alison faced her own diagnosis and returned to us as a program participant. She has since served the Coalition in many capacities. As a member of our Programs Committee (a role now carried out by designated Coalition staff members), Alison co-chaired an initiative called Eat Well Live Well in which she used her technical know-how to lead survivor/participants as they tracked the number of daily steps taken and amounts of fruits and vegetables consumed. As a PALS mentor since the inception of the program, Alison has shared the walk with others more recently diagnosed. She has also volunteered for the Pink Ribbon Walk and Run in many ways through the years, including leading the clean-up crew along with her husband John. An environmentally-conscious couple, the Curries helped ensure we left not a trace behind.

A steadfast presence on our Research Committee, Alison has lent her survivor/advocate’s voice to help discern which projects would receive Coalition funding. She joined the Coalition staff as Research Administrator for a couple of years, steering the committee as the initiative gained ground in our community. Although she stepped aside from her administrative role to attend to family matters, Alison has remained an active committee member.

In her spare time (where does she find it?), Alison plays the french horn in a local ensemble and is a woodcarver who specializes in detailed renderings of birds. Her work is stunning. Her kindness is even more so. She has presented members of our community with specially made birds, carved so they are smooth and comforting to hold in the hand during difficult times. Members of the Polashenski family (see the tribute on page 22) are among those who have been deeply touched by the receipt of these thoughtfully carved treasures.

Alison herself is a treasure and we at the Coalition are grateful for her long-standing commitment to our organization.
It seems that everywhere you turn, you’ll hear advice to watch your carbs, cut carbs, or go low-carb. But in truth, we all need carbohydrates. They provide the body’s primary energy source – glucose – which fuels everything we do, from breathing to walking to thinking to reading this article. In fact, glucose is the main source of energy for the human brain.\(^1\)

Carbohydrates are one of three macronutrients, meaning that our bodies use them in the largest amounts for energy, growth, healing, and maintenance of bodily systems. The other two macronutrients are protein and fat. Depending on individual needs, about forty-five to sixty-five percent of a person’s daily calorie intake should be carbohydrates.\(^2\) But all carbs are not created equal.

Grains, vegetables, fruits, milk, and milk products are the major food sources of carbohydrates, which are subdivided into three categories.

- **SUGARS**, or simple carbohydrates, contain short-chain molecules. Found in foods such as fruits, dairy products, and refined sweeteners, simple carbs are digested quickly.

- **STARCHES**, or complex carbohydrates, are long chains of glucose molecules that take longer to break down into the smaller molecules our bodies use for energy.

- **FIBER** is also made up of long-chain molecules, but they are indigestible and pass through the digestive system while nourishing gut bacteria along the way.

Because complex carbs digest more slowly, they help lead to greater feelings of satiety. Whole grains, vegetables, fruits, beans, and legumes are all high in complex carbs and contain an array of other essential nutrients. Whole grains are a marvelous example of this. Each kernel is a nutrient-dense gift package made up of three parts: the bran, germ, and endosperm. The bran – the “wrapping” – is the fiber-rich outer layer that also supplies B vitamins, iron, copper, zinc, magnesium, antioxidants, and phytochemicals. The endosperm – the “packing” – is the interior layer that holds carbohydrates, protein, and small amounts of some B vitamins and minerals. The germ – the “gift” – is the core of the seed where growth occurs; it is rich in healthy fats, vitamin E, B vitamins, phytochemicals, and antioxidants.

Incorporating whole grain into your diet doesn’t need to be hard. Small changes can make a big difference over time. To get you started, here are five simple ways to incorporate whole grain foods into your daily routine:

- Start your day with a bowl of oatmeal. Whole grain cereals and bagels are also quick and easy.
- Choose whole grain breads and pasta.
- Substitute whole wheat flour for all or part of the white flour in your regular recipes.
- Eat popcorn when you need to nosh.
- Use brown rice instead of white rice. Or be bold and try wild rice, quinoa, or bulgur.

A cancer diagnosis is highly stressful to the mind and body. Nourishing both is a challenge to survivors and caregivers alike. Regarding your food intake, remember that carbohydrates – both simple and complex – are part of a healthy diet. Emphasizing whole grains, fruits, and veggies while minimizing processed foods that contain added sugars will help your body get the energy it needs in a healthy way.

1. ncbi.nlm.nih.gov/pmc/articles/PMC6331362/
2. mdanderson.org/publications/focused-on-health/what-are-macronutrients-.h15-1593780.html
3. www.ncbi.nlm.nih.gov/pmc/articles/PMC4224210
4. www.hsph.harvard.edu/nutritionsource/what-should-you-eat/whole-grains/
Spring Orzo with Asparagus, Lemon, and Dill

INGREDIENTS:
• 6 - 7 ounces orzo (whole grain options are available)
• 2 tablespoons olive oil
• 1 shallot, diced
• 3 garlic cloves, rough chopped
• 1 extra large bunch asparagus, tough ends removed, cut into 1 inch pieces.
• 1 cup snap peas
• ½ - ¾ teaspoon salt and pepper
• 2 lemons
• ½ cup fresh dill
• crumbled feta (optional)

DIRECTIONS:
Set salted water to boil and cook orzo according to directions.

In a large skillet, heat oil over medium heat.

Add chopped shallot and garlic, and stir frequently, sauté until golden and fragrant.

Add asparagus and snap peas. Sauté 5-7 minutes stirring often, scooping up the shallot from the bottom of the pan. Add salt and pepper. Cook until asparagus it is bright green and cooked al dente. Watch carefully; the thinner the asparagus, the faster it will cook. Turn heat off. Add the zest of one lemon.

Drain pasta and if serving warm, save a little of the hot pasta water.

If serving warm, add the warm orzo pasta to the skillet with the asparagus and stir in just a little pasta water to loosen it up. Add a generous squeeze of lemon juice. Taste for salt and lemon, adding more if necessary. Fold in the fresh dill and sprinkle with optional feta (keep in mind that feta will add salt too). Serve immediately.

If serving chilled, place the cooked asparagus mixture in a bowl and let it cool. Rinse the cooked orzo with very cold water until cold. Drain it, then add to the bowl with the vegetables. Drizzle with a little olive oil and generous squeeze of lemon juice. Mix and adjust seasoning. Refrigerate – then taste once more before serving, again adjusting if needed. Fold in the fresh dill and top with crumbled feta, then serve.

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

Donatella Capurso
Jeannette Harrison

Gail Levy
Virginia Mueller

Cynthia Schneider
Tanya Schutt

Pamela Delp Polashenski, MD “Pam”
By Pat Battaglia

A brilliant, compassionate physician. A fiercely competitive volleyball player who brought joy and laughter to her teammates and competitors alike. An outspoken breast cancer advocate. An ally for the LGBTQ+ community. A steadfast, adventurous friend. An active member of the Coalition’s Board of Directors, Research Committee, and Advocacy Committee. A charismatic presenter at our educational seminars. A cherished Common Ground “Peep” (our group for those with metastatic disease). The coolest mom ever – just ask her three daughters Maya, Tallis, and Anastasia. A loving partner to her husband Walter. There are more words to describe Pam Polashenski than there are pages in this newsletter to contain them.

Pam’s diagnosis of breast cancer in 2016 led her to the Coalition and she began showing up whenever and wherever she could. When she became a last-minute addition to the speaker panel at our Advanced Breast Cancer Seminar after a sudden cancellation, she delved into a topic outside her realm of experience and became an expert as she prepared for her talk. This seminar was where I first met Pam, and her dynamic presentation cemented her in the hearts of many of us at the Coalition. Clearly, she was more than equal to any challenge.

Her determination was put to the test in 2018 when, shortly after stepping aside from her role as Chief Medical Officer of Newark Wayne and Clifton Springs Hospitals to return to clinical practice, Pam’s cancer was found to have metastasized. Pam adjusted her work schedule to accommodate her treatments, even as her commitment to advocacy for others and herself, as well as to her beloved family and vast circle of friends, continued unabated. Last summer, Pam prevailed against all odds in a heroic effort to gain access to an experimental drug used to treat a specific gene mutation she was found to carry, and began her chosen therapy in autumn of 2021. This led to a remarkable recovery from some overwhelming symptoms of her disease. Sadly, that recovery did not last, and cancer took her from our midst in December.

I will always hold tightly to Pam’s repeated message for her Common Ground Peeps, which was encapsulated at the very end of a talk she delivered at our 2021 Advanced Breast Cancer Seminar during which she spoke as a survivor:

“‘We have two lives. And the second one begins when we realize we only have one.’ I am living that second life and making the most of it. I wish you all the same.”
Fifty years ago, Judy Braiman was a young mother of five children when she began to volunteer her time as a consumer advocate. In 1971, she founded the Empire State Consumer Project, a registered 501c3 nonprofit organization dedicated to reducing the use of unsafe products and chemicals that are toxic to humans and the environment in which we live.

New York State Attorney General Letitia James recently honored Judy with a Lifetime Achievement Award for fifty years of tireless advocacy. Judy’s efforts have resulted in national regulations to reduce toxins in consumer products and the environment. A trailblazer in gathering accurate, reliable information, testing consumer products, and educating the public on the harms of toxins in the products we use and in our environment, Judy’s focus has been largely on products marketed to women and children, and toxic exposures among these groups. Her efforts have included advising the US Product Safety Commission and the FDA; co-authoring reports for the likes of Consumer Reports and the Associated Press; and being featured on CNN and PBS. Yet Judy stands for the most vulnerable among us.

In 2005, a group of Coalition advocates collaborated with Judy and other members of our community – from scientists to farmers to cancer survivors to environmentalists and many more – in a coordinated effort to persuade the Monroe County Legislature to sign on to the New York State 48-Hour Neighborhood Notification Program. Despite vocal and sometimes vehement opposition, our advocates joined forces with Judy and others to speak with knowledge and conviction, and the effort was ultimately successful. Monroe County Legislature opted into the program in 2006. It requires commercial lawn care and landscaping businesses to provide written notification to the owners of surrounding properties before spraying a property with pesticides. Working side-by-side with Judy in this effort, our advocates found her to be a thoughtful, knowledgeable collaborator while she maintained a powerful advocate’s stance. She was – and is – an inspiration to us.

Judy continues to be a force of nature and has targeted such products such as certain toys, cribs, playground equipment, tampons, contraceptive sponges (which are no longer being produced), and artificial turf, which is used on some sports fields. She is a voice for change on behalf of those whose voices are too often unheard. We at the Coalition offer our heartfelt congratulations to this tireless advocate.

Thank you, friend!
EXTRAORDINARY CARE

No one likes taking their car in for maintenance, but those who did so at Schoen Auto in the month of October were also supporting the Breast Cancer Coalition. As they have done for the past several years, Ben Lee and Emili Gibson donated 10% of all preventive maintenance bills to the Breast Cancer Coalition through their “Regular Maintenance, Extraordinary Care Campaign” in October. Thanks to Ben, Emili, and the entire staff at Schoen Auto for their friendly, high quality service that raised $981.39!

VAULTING TO NEW HEIGHTS OF SUPPORT

For the second year in a row, Vault Rochester completed a fundraiser for the Coalition in the month of October, donating 100% of the proceeds from one day of their classes. Vault is a boutique fitness studio offering class-based cycling, boxing and fitness experiences. Thank you Vault Rochester for your gift of $1,025.00.

GENETASKA CLUB

Our 2021 Fundraising Friends have been an inspiration to all of us. We are so grateful to The Genetaska Club of Rochester, Inc. for collecting $2,000 in donations for the Coalition this October. Support like yours is invaluable.

SCHOOLS PINK OUT!

Greece Olympia Soccer hosted a “Pink Out Week” to raise funds and awareness for the Coalition. They raised $257.20!

Victor Girls Soccer collected funds during October at their snack stand and raised $267.00!

ACCELERATE THE GOOD

We are so grateful to the team at Matthew’s Kia for choosing the Coalition to receive the funds from their "Kia Accelerate the Good Campaign!" Patrick from Matthews stopped by recently to present the Coalition with the funds totaling $1,962.00. Thank you!

TRULY CARING COWORKERS

Our friend, Faizulis Vides, let us know that their coworkers at TruCare Connections were going to hold an employee fundraiser for us during the month of October. We couldn’t be more pleased to be their charity of choice. Congratulations on raising $408!

HOCKEY TIME

A big thank you to Monroe County Fire Hockey – in January, they braved the frozen tundra at Dick’s House of Sports in Victor to have a mini tournament and a “Skate With A Firefighter” night in support of the Coalition. Over the years, their support has raised over $9,500!

BUCKIT BRAND

We are so grateful to our friends at BUCKITBRAND.COM and all of their partners who presented us with a check in November for $3,000 from their fundraising efforts in October! Thank you!

A SPOOKY GOOD TIME

In October, Dave Lippa embraced the Halloween spirit and honored his mother when he curated his annual skeleton display in his yard, with proceeds coming to us. Featured on some local news stations Dave raised $2,530! Fa-boo-lous!

KIND AND GENEROUS NEIGHBORS

Our friends and neighbors at Fp Wellness held a raffle during the month of October for their specialty t-shirt, with the proceeds coming to the Coalition. They raised $965.00! Thank you!
PUTTING THEIR SKILLS TO THE TEST

We were thrilled when three of the student leaders from Rochester’s chapter of SkillsUSA stopped by to present us with a check from their October fundraiser. SkillsUSA is a “partnership of students, teachers and industry working together to ensure America has a skilled workforce.” The students raised a total of $1,000!

CHEERS!

We love all the support from small businesses in our area. When Rob Shaffer reached out to let us know that he was doing a fundraiser at his craft brewery – Stumbling Monkey Brewery in Victor – to honor his wife, Shelly, we were grateful! Sales of a special brew during the month of October brought in a total of $500! Cheers!

NY Kitchen in Canandaigua continues to offer their toasts to survivors in our region. Their bartenders created a pink drink and donated $1 from the sale of each to us during the month of October. All in all, they raised a total of $405! Cheers!

FOR ONE OF THEIR OWN

As a neighborhood family-run enterprise, Triano’s Meat Market is carrying on a fine tradition. The Market has raised funds for our Coalition several times in previous years. This year’s effort was more personal, as one of their beloved family members faced a breast cancer diagnosis. In a community show of support, the customers of Triano’s helped the store to raise $429 in October for our benefit. Thanks to all, and best wishes for a long, healthy life to the family survivor!

HEADSHOTS FOR A CAUSE

The gifted photographer, Natalie Sinisgalli, chose the Coalition to be the benefactor of her annual Headshots For A Cause fundraiser! Local professionals signed up for a timeslot to get a professional headshot AND give back! We were blown away by the support – Natalie was able to raise $2,200!

INSURANCE QUOTES MAKE A DIFFERENCE

VanScoter Insurance donated $10 for each person that called for a quote in the month of October. Congrats on completing 96 quotes and raising $960!

WEAR PINK DAY

Local law firm Martin, Harding & Mazzotti held a Wear Pink Day in October, in which their staff could deck themselves out in pink if they made a donation. We were thrilled to be the recipients of the funds they raised, totaling $1,850!

GET IT STRAIGHT

The long months of braces are followed by the diligent wearing of a specially fitted retainer to maintain the newly perfect smile. Unfortunately, retainers are incredibly appealing to family pets when left on nightstands, easily disposed of in a folded napkin after a meal, and will be squashed in a pocket or purse!

Each October, this is good news for the Breast Cancer Coalition, thanks to the generosity of Dr. Terry Giangreco and his staff at Get It Straight Orthodontics. 100% of the fees from lost or broken retainers benefit the Coalition. This year, thanks to the family pups, we are so fortunate to receive Get It Straight’s donation of $5,210. A big thank-you to all of the parents who so generously supported this effort!

CHEER-FILLED CHARITY

Driven by the unbridled energy and enthusiasm of their students, the Rochester and Fairport locations of NY Icons Cheer combined their efforts once again to raise money for the Breast Cancer Coalition.

The real “winners” are the many, many families who benefit from the services and programs offered at the Coalition. Icons, your gift of $1,187.75 helps make these programs and services – and all we do – possible.
COOKIE AND COFFEE AND SHOPPING, OH MY!

Long time supporter Deb DiShaw Smith of Deborah Jean & Co. partnered up with Carousel Cookies for a Cookie and Coffee Tasting and Shopping Event in December, just in time for the holidays! We were thrilled to receive $180 from the event!

IN MEMORY OF A FRIEND

Friends Elaine Vanatta, Nancy Gramkee-Cuer, Anne Wells and Tracie VanEpps partnered up to remember beloved friend and member of the Coalition’s metastatic community, Diane Mason, with a day of raffles and good times. They raised a total of $1,005 for the Coalition in Diane’s memory.

HEAD, HEART, HANDS, HEALTH... AND GENEROITY!

We were thrilled to receive funds totaling $900.00 from The Wild Turkey 4H Club in December from their Shopping Bag Fundraiser! What a great idea for the holidays! Congratulations and thank you!

IT ALL ADDS UP

• Mary Bassett, owner of MAE Beads on Park Avenue, once again supported the Coalition through an October Fundraiser. Proceeds from the sales of face masks (still a needed commodity) throughout the month were donated to the Coalition to support our programs and services. Thank you for the gift of $20.00

• And thank you to Salon ROC on Pattonwood Drive for donating 20% of all of their sales in the month of October to the Coalition. Your gift of $218.00 is greatly appreciated.

• The employees at the Highlands at Pittsford held a bracelet sale with the proceeds coming to the Coalition! Their gift of $105.00 is treasured!

• ErbaQuest held a cannabis event with proceeds of $400.00 coming to the Coalition. Thank you!

• The team at Peko Products held an internal employee giving campaign during October for the Coalition, raising $540.00!

• Hedonist Chocolate sold special boxes of salted caramel chocolates with proceeds coming to the Coalition during October. We’re grateful for their donation of $240!

• Gleason Orthodontics donated a portion of their fees whenever a patient chose to have pink rubber bands put on their braces. Thank you for raising $257.65!

• Hope Hall School held a Day of Giving for the Coalition. Their gift of $45 is deeply appreciated!

• The local Morgan Stanley office held a jeans day in October, raising $250!

• The City of Rochester IT Department held their annual fundraiser, totaling $335!

• The Fairport Crew Club sold socks to their rowers to raise money for the Coalition in October, donating a total of $250!

The Marilyn Lichtman Foundation: Making a Difference

After a five-decade career as a change-maker, Marilyn Lichtman created the Marilyn Lichtman Foundation. This philanthropic organization supports initiatives that impact human health and wellbeing (among other great causes), and now continues in her memory. The Foundation’s circle of generosity includes the Coalition, and we are truly grateful for the continuing support we’ve received from this remarkable group.

We recently welcomed Rich Yarmel and Patty Yarmel from the Lichtman Foundation, who presented the Coalition with a grant to support our BC101 and GYN101 offerings, as well as our PALS program.

Mary Ritter Beard, the great American historian and suffragist, once said “The results of philanthropy are always beyond calculation.” Also beyond calculation is our gratitude to the Lichtman Foundation for helping us make a difference for those diagnosed with breast or gynecologic cancer in our community.

Thank you!
We are truly amazed at the many ways our generous donors support our work at the Coalition. Some host fundraisers among their peers on social media or in person; others donate directly through their payroll with the help of an employer and/or the United Way. And there are those who respond to our annual fund campaigns, honor a loved one with an honorary or memorial gift, or simply return the donation envelope enclosed in this newsletter.

We are grateful to all donors for their valuable contributions and their commitment to our mission. Every effort has been made to ensure the accuracy of this list. We apologize for any errors. Please join us in thanking the following individuals, companies, and organizations for their contributions between October 1, 2021 - December 31, 2021.

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To all survivors of breast cancer – keep fighting!
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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
Individuals who make an annual fund or United Way gift – of any amount – for two or more consecutive years are part of our Coalition Loyal Giving Society.

Wish List
• Breast cancer stamps
• Burt’s Bees Lip Balm (sealed, no mint)
• Coloring books (pocket or travel size preferred)
• Ear plugs (individually wrapped)
• Sleeping masks, lavender or unscented only
• Thank-you cards/note cards (unopened packs)
• Computer paper, white, 20#
• Joann Fabrics gift cards
• Ear plugs (individually wrapped pairs)
• Journals for writing
• Warm, fuzzy socks

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Breast Cancer Coalition.org
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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Join us for our 20th Golf Tournament

TEE’D OFF AT BREAST CANCER GOLF TOURNAMENT

Monday
August 1, 2022
Midvale Country Club

We are planning our 20th annual golf tournament this year! Join us for a great day of golf, raffle prizes, silent auction, breakfast and lunch, followed by a cocktail reception.

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

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ACTober

- Celebration
- Awards
- Auction

Friday, September 30, 2022
at The Highline

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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.