I knew right away who it was whenever I picked up the phone and heard, “Hey, it’s me!” My niece Terri Schmitt and I would immediately begin talking and laughing about something—anything—everything. I am the mother of five wonderful sons, and Terri was the daughter I never had. We loved having a cup of tea together! When she was nine months pregnant with her youngest child, Chelsea, Terri loaned me her little car. She said she was too fat to get behind the wheel, and since my car was being fixed, I could use hers. After I drove off in her car, she went into labor and Chelsea was born—oh, what a night, but that’s another story!

Terri had a laugh that was infectious. That is, until one morning when she called to tell me she had been diagnosed with breast cancer. In the weeks and months of treatment that followed, I never saw her cry or heard her complain. With her positive attitude, she bounced back and went on living her life with her beautiful family in Rush.

For some reason, Terri became involved in the politics of her town; she probably wanted to help make real change in the way things were done. When she ran for Rush Town Supervisor, she was backed by every woman who wanted a voice. Terri became not only the first Democrat Town Supervisor in Rush, but the

“She (Terri) taught me how to ask questions, advocate for myself, and not to be afraid to get second opinions”
As we watch the seemingly gentle transition from summer to autumn, we are also winding down in the aftermath of a very busy month! Have you heard? October was Breast Cancer Awareness Month, that time of year when everywhere you look or listen, someone is talking about breast cancer. Almost everywhere you look, you’ll see a sea of pink. It sometimes seems that everyone wants to help with a (fill in the blank)-for-a-cure action, or is operating an awareness campaign. Make no mistake; it is important to keep breast cancer at the forefront of minds when you understand the impact this disease has on families everywhere. Yet, those of us living with a history of breast cancer or who have otherwise been touched by the disease in any way know that breast cancer awareness cannot be confined to one particular month.

With all the awareness about breast cancer, the most common cancer in women of any race or ethnicity, it’s easy to forget that the statistics can be broken down further in a variety of ways. Breast cancer is the second most common cause of cancer death among white, black, Asian/Pacific Islander, and American Indian/Alaska Native women. It is the number one cause of death among Hispanic women. Though a slightly higher percentage of white women are diagnosed with breast cancer, black women are disproportionately likely to die of it.

In our country alone, 236,968 women and 2,141 men were diagnosed with invasive breast cancer in 2014, the latest year for which we have finalized data. And the losses that year - they matter. 41,211 women and 465 men died of breast cancer in these United States.1

In New York, over 15,000 women (and men) are diagnosed with breast cancer each year. 25% of these women are under the age of fifty and 11% of these women are under the age of forty-five. More than 2,600 New Yorkers die of this disease. Each year.2 Staggering, isn’t it? This. Is. Not. Okay.

It is important to periodically revisit these facts and figures because these statistics represent real people with names and faces and, to those of us in the trenches of this war, people we have come to know and love. We’ve had some particularly devastating losses this quarter and we are all feeling these losses greatly.

One of the most frustrating aspects of this disease, when trying to sift through what’s known about breast cancer, is that there isn’t consensus on its root cause. But we can agree its origins are likely multifactorial, including inherited gene mutations (see story on page 8) in a subset of people. However, when it comes to cancer in general, most scientists recognize that people can get the disease through repeated long-term contact with carcinogens including tobacco, sunlight and indoor tanning.
Andrea Reynolds
A Young Mother Faces Breast Cancer

Andrea Reynolds is a busy mother of two young children. She is also a breast cancer survivor. We chatted by phone about the events that led to her diagnosis and continued to unfold as she went through her treatment and recovery. It’s an exhausting ordeal for anyone; add a young, growing family to the mix and the challenges multiply immeasurably.

Andrea Reynolds was 29 years old and eight months pregnant with her second child when she discovered a tiny-pea-sized lump in her breast. Considering her young age, and advised that it would be difficult to obtain an accurate picture through imaging while pregnant and nursing, she and her doctors decided to wait until her baby was weaned before undergoing any diagnostic procedures. The possibility of breast cancer seemed remote.

By the time her infant son had stopped nursing, the lump seemed to disappear at times, only to reappear. Around the same time, her family moved from Memphis, Tennessee, to their home town of Rochester. Newly settled in her home, Andrea discovered that the lump had grown a little larger. The time of watchful waiting was over; it was time to schedule a mammogram. So it was that in July of 2013, eighteen months after she first discovered the lump, Andrea heard the words no one wants to hear: “You have breast cancer.”

“I consider that it was the universe, or God, or whatever you want to call it, that put me back home [in Rochester] before I was diagnosed,” Andrea shared. She was surrounded by her family and friends, who recovered quickly from their initial shock and rallied around her, providing support and assistance through the days, weeks, and months of treatment that followed. Still, in the immediacy of the moment as a newly diagnosed woman, Andrea couldn’t help wondering, “Where do we go from here?”

But the train had left the station and was gaining speed. Friends and family members recommended a number of surgeons and oncologists, and Andrea’s calendar began to fill with medical consultations. “It was quite a flurry of appointments,” she remembered. Andrea selected the doctors with whom she felt “comfortable and at ease”, and formed her medical team. Her surgeon recommended a mastectomy as the best option in Andrea’s case, and the procedure was scheduled. Reconstructive surgery would take place at the same time.

“I remember waking up in the recovery room,” Andrea recalled. “My eyes weren’t open yet, but I heard them say ‘radical’…and I knew there were lymph nodes involved, so then it was kind of a battle of the wills for my mind to not go to the worst spot.” The procedure she had just undergone, a modified radical mastectomy, is far less extensive than the radical mastectomies of past decades, and involves removing breast tissue while sparing surrounding muscle. Andrea had thirteen lymph nodes removed during her surgery, and soon learned that cancer had been found in eight of them.

Every cancer is unique, every patient is unique, and each person responds in their own way to treatment. For Andrea, recovery from surgery was a longer road than she anticipated. “I had no idea how involved it was going to be,” she observed, as it took months of physical therapy to regain her former strength and range of motion. But she got there. “Overall, I can’t complain because I had such great support and help with the kids. My son was still in a crib at that point. I couldn’t even lift him out of his crib. That was hard. But you do what you have to do.” Family members took over the lifting duties and much of the care of her children, ages four and eighteen months, while Andrea healed.

Due to the lymph node involvement, Andrea’s oncologist recommended chemotherapy. When the day of her first chemo treatment rolled around, “I was terrified,” she confessed. But to her surprise and gratitude, Andrea’s worst fears were not realized. “It wasn’t as scary as I

“the little things don’t matter. Your mind is more powerful than anything you could ever imagine. And the world is full of kind, generous people.”

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Advocacy Updates

National Breast Cancer Coalition 2017
Summit Leadership Legislative Report

The National Breast Cancer Coalition Leadership Summit in May, which ended with a full day of meeting with our elected representatives on Capitol Hill, focused on two issues. But our work does not end there; it is ongoing.

The Department of Defense Breast Cancer Research Program (BCRP) is a funding appropriation, one of many Congressionally Directed Medical Research Programs that must be re-appropriated every year in the federal budget. A model program that has yielded extremely important results, it has been funded by the DoD since 1992.

The House Appropriations Committee passed the Defense Appropriations bill that includes $120 million for the BCRP; the bill now moves to the full House of Representatives, then to the Senate. This appropriation has, in general, received popular support from both chambers. However, it now faces an uncertain future. Sen. John McCain introduced an amendment in the last Congress containing provisions that would have redirected research monies back into the military budget. The problematic language was countered by an amendment drafted by Sen. Richard Durbin (D-IL). Advocates waged a successful effort to gain Senators’ support for the amendment, which passed and the language repealed. In the current Congress, Sen. McCain introduced S. 1519, the National Defense Authorization Act for fiscal year 2018, which again includes several provisions that are problematic for the BCRP. In response, Sens. Richard Durbin (D-IL) and Roy Blunt (R-MO), have introduced the Durbin-Blunt NDAA Medical Research Amendment #592 to repeal the problematic language. Again, advocates are working to gain Senate cosponsors when the Senate reconvenes in August.

What you can do: Contact our Senators, Charles Schumer and Kirsten Gillibrand, who have staunchly supported the BCRP. Thank them for their support and ask them to encourage colleagues to support Amendment #592.*

Guaranteed Access to Quality Care for All:
Preserving access to affordable and quality healthcare for women and men with, and at risk of, breast cancer has long been one of NBCC’s top priorities. NBCC advocates worked to stop Congress from repealing the Affordable Care Act (ACA, aka “Obamacare”) with the message that the organization opposes any bill that will increase the number of uninsured, decrease protections for people with pre-existing conditions, and cut Medicaid.

A complex program, the ACA was first voted in as a program designed to be developed over time. Focusing on fiscal and structural shortfalls, the Republican-majority House passed the Affordable Health Care Act (AHCA, aka “Trumpcare’) in May. Headed now to the Senate, where Democratic members and a small number of Republican senators have rejected it and signaled they would draft new version of the bill, the AHCA faces what may be a long road to reconcile language and coverage options.

What you can do: If you have personal experience of being helped by the ACA, or having your health care threatened by a change in coverage, communicate with your elected representatives and tell them your story.

Breast cancer is a non-partisan issue. This is an incredibly important time for all of us to step up and work together to further our mission to end breast cancer.

* For Senate contact information, go to www.senate.gov/senators/contact.
first woman in that position as well. People still talk about how caring she was, and her constituents miss her.

It was during that time that I was diagnosed with breast cancer and boy, Terri took me under that wing of hers and trotted me right to her surgeon. She taught me how to ask questions, advocate for myself, and not be afraid to get second opinions. She was and is my “angel.”

Terri became the Chair of the Board at the Coalition in June 2000. Her husband, Rob (also known as Bix) took over the role of Race Director for the Pink Ribbon Walk & Run in its fourth year. I have walked in each one until this last Mother’s Day. After Terri’s passing, I began attending Brown Bag Fridays, something Terri would have loved to participate in had it been around during the course of her disease. At Brown Bag, we learned to “pay it forward” by reaching out and listening to others who often needed answers to their many questions and were scared following their own diagnoses.

When Terri’s cancer came back, it came back with a vengeance, and eventually took her life. Rob (Bix) and their kids were robbed of this fun-loving woman who loved her family above all else. Although she never got to see any of her beautiful grandchildren in person, she is surely doing something “up there.” Her son Dan and daughter-in-law Laura have three daughters, including a set of twins; her daughter Mary Beth and husband Tim also have three children, also including a set of twins; and now Terri’s son Tim and his wife Jessica are expecting their second and third children - you guessed it, a set of twins!

Chelsea, beware! Your mother’s up to something!

Terri Schmitt was – and still is - a role model for other women in the community, not only in politics, but in the battle against breast cancer. When I was diagnosed a second time in the other breast, I knew she was by my side, guiding me through it. She left us with so much, especially hope that a cure will be found.

I’m proud to be a member of “Team Terri!”

Miriam Steinberg, Advocacy Committee Chair, presents Rebecca Solomon with a certificate of recognition.

Ralph Van Houten with the Hon. David Seeley

Sylvia Ryndock and Lisa Franclemont

Below: Marianne Sargent, Patti Cataldi, and our youngest advocate, Oscar

Taryn Windheim, Trisha Turner, and Annie Chwiecko
A Talk with Musa Mayer - By Pat Battaglia

A writer and advocate who has spent over two decades working on behalf of those diagnosed with metastatic breast cancer, Musa Mayer has amassed a wealth of knowledge, skillfully transmitting information to those who need it through her writing and in online forums. As she prepares to retire from her long path of forging connections between patients and the most current, relevant research, she agreed to sit down and share her thoughts for our readers.

Pat: What drew you to this work of advocating for those with metastatic breast cancer?

Musa: I was diagnosed with stage II disease in 1989. I’m a writer and part of what got me through it was setting down my own experience. I published a memoir not long before I was diagnosed. I ended up publishing another memoir about my breast cancer experience in ‘94, called Examining Myself, One Woman’s Story of Breast Cancer Treatment and Recovery. This happened to coincide with the very beginnings of online communities. The web wasn’t really functioning at that point, but I discovered that there was a large, active group that was started by a microbiologist in Newfoundland. He had an interest in distance medicine; it’s an issue for the Atlantic provinces of Canada. So, as a way of giving and getting support, he started one of the first online cancer communities – the Breast Cancer Mailing List.

At one point, this online community consisted of some 2,000 people. It was a widely active group. I had come there with the idea of letting people know about my newly published memoir, which I did. But I got much more interested and engaged with how people were making use of this online community - the way they were writing about their experiences. I had been a therapist in a former lifetime, so I have a real interest in how people work through traumatic events.

As time went on in this group, people started having recurrences. There became a dialogue within the group about how inhibited they felt sharing their experiences. A woman who had just been diagnosed with brain mets, along with her husband who was a web developer, offered the possibility of starting a new mailing list. And the online group BCmets was born.

At the same time, I was encouraged by more newly diagnosed people in the online community to do a book on breast cancer for a publisher in California. There was a lot of literature on early
breast cancer, but nothing on metastatic disease. I said, “I’ll do it if you let me do it on metastatic disease,” and she agreed. The book that eventually became *Advanced Breast Cancer: A Guide to Living with Metastatic Disease* was first published in ’96 under the title, *Holding Tight, Letting Go*.

When the book was published, people started reaching out to me as some kind of an authority, which I wasn’t. As an advocate, I’d had some training at the National Breast Cancer Coalition; I took Project LEAD [their science training course for advocates]. I was very interested in the medicine and the research, but I didn’t know a lot, so I was put in a position that was uncomfortable for me. I decided, “I’m going to learn.” I threw myself into attending the major research conferences. I took it upon myself to learn everything I could about the treatment of metastatic breast cancer. In that process, I got to know many of the top researchers. I would give them my book, and they would give it to their patients. I formed these long-term bonds with some really wonderful researchers over the years.

And then I got involved with the FDA. Drug development is a really crucial issue – it’s preventive strategy for patients. I applied to and was accepted in 2001 to be a patient representative. I served for a number of years and got very interested in the issues having to do with how much evidence there needs to be for new treatments.

Then I was approached by Kay Dickerson, an epidemiologist from Johns Hopkins who was one of the mothers of Project LEAD, to work with her to write an online course. It’s called *Understanding Evidence-based Health Care: A Foundation for Action* and it went live in 2007. The course has been taken by thousands and thousands of people around the world. There’s a version of it for physicians in training and it’s something that we’re very proud of. We developed it for advocates, but many of the people who take the course are health workers in low resource countries that are trying to understand the medical literature and make sense of available treatments.

With all of this background, I ended up working on the BCmets list and on the BClisit for many years, sort of as an information translator. I spent hours every day writing responses to people who were looking for advice or for understanding about available treatments. I’ve developed two websites and in 2007, I started working as a researcher. One of the largest projects I worked with was with scientists from the NCI who had a grant to study brain metastasis in breast cancer. There were two of us advocates involved and, as our part of the project, we developed a website called brainmetsbc.org. We are still keeping it up to date in terms of recent trials and published research even though the grant is long gone at this point.

**Pat:** It’s wonderful you’ve kept it going.

**Musa:** Yes, Helen Schiff does the work with me and puts more energy into it now. I have a dream of replacing myself, but that won’t happen in the next couple of years.

**Pat:** Women in our metastatic community sometimes express the fear of running out of treatment options. How would you address that fear?

**Musa:** I’ve been working in recent years with the Metastatic Breast Cancer Alliance and one of our recently published projects is work I did with statisticians from the National Cancer Institute who are documenting length of survival in metastatic disease. In fact, survival is improving. Women are living longer as more treatments are being developed and as protocols are being developed to help doctors sequence treatments to get the most out of each treatment.

There are lots of reasons for optimism. It’s not uncommon for women to only go through two or three treatments over the course of a decade. On the other hand, what I always try to stress is the variability of the disease. It’s a case of uncertainty, and levels of uncertainty. But uncertainty is almost the friend of the woman with metastatic disease because she has reasons to hope that a treatment will be found for her that does work for a long time. I always encourage people to think of themselves as quite unique, because every cancer is unique.

**Pat:** As you said, it’s widely variable. No one can predict their situation based on someone else’s experience.

**Musa:** I find that women who stay with groups and communities like yours gain a sort of existential strength from their exposure to the disease process of other women, which is very powerful. It’s not that you ever get to the point where it doesn’t affect you. But I think a lot of fears get allayed in these women. I look at this very philosophically in the sense that coming to terms with our own death is a human enterprise. We all

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“Cancer is not one disease but many diseases,” says author Siddhartha Mukherjee in the introduction to his book, *The Emperor of All Maladies.* “We call them all ‘cancer’ because they share one fundamental feature: the abnormal growth of cells.” Whether cancer affects breast tissue, the reproductive organs, or any other part of the body, its characteristic unchecked cell growth is the result of a series of genetic mutations.

When mutations passed through generations in families are involved in the series of genetic changes that result in cancer, it is known as hereditary cancer. About five to ten percent of breast cancer diagnoses fall into this category.1 The vast majority of cases are sporadic cancers in which acquired gene damage results from such diverse causes as environmental exposures, hormones, normal aging, and many other factors both known and unknown.2

Abnormal inherited genes can cause cells to be one step closer to cancer, but they do not cause the disease by themselves. Additional sporadic mutations must also occur.3

The most well-known and well-studied inherited mutations that increase the risk of breast and ovarian cancer occur on genes known as BRCA (BReast CAncer)1 and BRCA2. These genes provide instructions for making tumor-suppressor proteins that regulate cell division and repair damaged DNA. If either gene is mutated, cells are more susceptible to random genetic changes that can lead to cancer.4 Another gene called PALB2 works in conjunction with BRCA2, among other genes, and when mutated, can increase the risk for certain cancers, including breast cancer.5 Mutations on other genes, known by such names as such as ATM, BARD1, CHEK2, PTEN, RAD51C, RAD51D, and TP53, are less common than BRCA mutations, are less well studied, and the breast cancer risks associated with them are not always clear.

85% of women diagnosed with breast cancer have no family history of the disease.6 Those who do have a family history may be referred for genetic counseling and/or genetic testing to assess their risk of recurrence and guide treatment decisions. Other considerations can also affect this recommendation; for example, those diagnosed at a young age or are of Ashkenazi Jewish heritage might be asked to consider genetic testing as well.

But the decision whether or not to follow through on this recommendation can be complicated. While genetic testing can reveal crucial information or offer reassurance, there are many factors that come into play when considering this option. Genetic counselors are health professionals knowledgeable about cancer genetics and the issues people can encounter when information on their genetic status is revealed. They can discuss the pros and cons of testing based on individual situations, including the medical implications of a positive or

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She could tell something wasn’t right. “I knew for quite a while that I was having medical issues,” Diane Mason shared when we met recently to talk about her journey. “I was having problems that were gynecological. I was having pain. I was extremely tired and very bloated. I thought I had a UTI.” Diane has always been faithful about her yearly medical checkups, including visits with her gynecologist, with whom she discussed her symptoms. But no cause was found. It wasn’t until the autumn of 2016, when she and her husband were getting ready to travel to their Florida home for the winter, that he suggested she consult with her primary care doctor before leaving. Diane agreed.

“As soon as [the doctor] touched my belly in one spot, I almost jumped off the table,” Diane recalled. He immediately ordered the progression of tests that would reveal the true cause of her ongoing discomfort: Diane was diagnosed with ovarian cancer, stage III, with metastases to the omentum.

Putting her Florida plans on hold, Diane underwent a complete hysterectomy. Also removed during her surgery was part of her omentum, the sheath of tissue that surrounds the abdominal organs. Chemotherapy began shortly afterward. As the months of treatment passed, Diane found herself dealing with intense fatigue, among other side effects, but she forged on. May 18, 2017, was her last day of chemo. Since then, “I’ve been feeling stronger all the time,” she observed.

Shortly after her diagnosis, Diane had seen a Coalition brochure at her doctor’s office “…and it listed some of the great free programs for women. And I thought, how wonderful.” But, considering her particular diagnosis, Diane didn’t feel as though the information applied to her.

With her treatment behind her and once more in her doctor’s office, Diane noticed the brochure was still there. “I picked it up and looked at it, and read that [the Coalition] was open to women with all gynecological cancers,” she explained. “So I called, made an appointment to come down, and I actually was quite overwhelmed with the gifts I was given [in my Peer Advocates Lending Support (PALS) Pak] that were so meaningful and so helpful and so generous. It was the day of a Brown Bag so I got to stay for that and I listened to other people with similar things in their lives. It was just amazing to me.”

In addition to being a “frequent flyer” at Brown Bag, Diane attends our Common Ground group for those living with metastatic disease. She has also enrolled in healing arts classes that “…have helped me physically,” as she continues to heal and gain strength. And the human connections she has formed along the way continue to sustain her. “The people I’ve met, both the staff and the women in the groups have been very supportive. And it works the other way, because I feel good being supportive to them. I really want to know those things they talk about. I’m not listening to be polite. I’m listening because I care. And maybe I have something to share that’s going to help somebody.”

In an interesting twist of fate, family connections have taken on new meaning for Diane. An adoptee, she was able to reconnect with her birth family many years ago. She maintains close connections with both families and, through her walk with cancer, has deepened some bonds with certain members of her birth family who are also facing cancer. “We are able to laugh at our ‘chemo fog’ moments and we can talk about life with cancer – I mean really talk about it.”

Similar conversations occur at the Coalition daily, and Diane is often a part of these important, sometimes
Voices & Vision: A Writing Workshop
This well-loved group gives people with breast or gynecologic cancer an opportunity to explore and express their feelings through writing. Led by professional instructors, Elizabeth Johnston, Pamela Emigh Murphy, Kathy Simpson, Nancy Steinkamp, Angelique Stevens, and Karen VanMeenen, these workshops run in five week cycles on Tuesday evenings. Seating is limited, and advance registration is required.

The Healing Arts Initiative
This initiative is an opportunity to learn a new modality or practice a complimentary healing course to relax, de-stress, and exercise.

For more information, please contact Coalition Program Director Jennifer Gaylord at jennifer@bccr.org or by calling 585-473-8177.

Surviving & Thriving on Aromatase Inhibitors
This ground-breaking program provides information, support, and empowerment for those taking aromatase inhibitors who are experiencing the side effect of joint pain.

Our third session is underway and is proving to be a great success! Please look for a registration email for our next 4 sessions, which will be held throughout 2018.

Note: registrants must be able to commit to all sessions.

Weekday Healing Arts Programs
Gentle Yoga
A popular program facilitated by Susan Wood, is offered in six-week sessions on Monday evenings and Tuesday mornings and afternoons.

Qi Gong
Offered on Wednesday afternoons in six-week sessions throughout the year, and is facilitated by Raphaela McCormack.

Mindfulness & Meditation
Offered in four-week sessions with Estalyn Walcoff or Siobhan LeGros on Thursday afternoons.

Weekend Healing Arts Programs 4-week sessions
Gentle Yoga
Saturday Yoga is offered with instructor Raksha Elmer.

Sunday Yoga is offered with instructor Sunni Ingalls.

Nia Movement
Saturday Nia Movement with Jane Pagano is a mind/body movement that embraces elements of Tai Chi and dance.

Fluid Motion
Saturday Fluid Motion with Tracey Boccia is a movement-based class helpful for those managing lymphedema and others.

Tai Chi
Saturday Tai Chi with Jean Frances Sica is a martial art using small flowing movements.

Expansion of the Healing Arts Initiative has been made possible by a grant from Excellus Blue Cross Blue Shield

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Young Survivor Soiree
A young survivor may identify with those who have faced breast or gynecologic cancer in the midst of a career climb, or while raising children, or perhaps those whose family plans have been derailed by treatment.

Four times a year, we hold these soirees as an informal way to connect with others who have walked a similar path.

The next soiree will be Friday, March 9, 2018. Please call to be added to the invitation list.
BC 101 & GYN 101

These one-to-one sessions assist the newly diagnosed in managing the complex tasks and emotions of a breast or gynecologic cancer diagnosis, empowering 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 each individual formulates a personal strategy for making informed decisions.

Peer Advocates Lending Support: PALS

In this peer mentoring program, individual breast cancer survivors reach out to those who are new to the disease, 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. Please call to learn how to enroll in the program after your own diagnosis, or if you would like to become involved as a mentor.

See page 12 for PALS Program updates.

Tuesday Night Breast Cancer Support Group

This discussion-based group, led by Joan Mitchell, meets on the 2nd and 4th Tuesday evening of each month from 5:30-7:00pm. Join others coping with breast or gynecologic cancer, share your experiences, and lend your support. No registration is required.

Thursday Night Breast Cancer Support Group

This discussion-based group, led by Peg DeBaise, LMFT, meets on the 1st and 3rd Thursday of the month from 5:30-7:00pm. Gather support, network and discuss your journey with others diagnosed with breast or gynecologic cancer. No registration is required.

Brown Bag Fridays

Any given Friday at noon finds a group of survivors of breast or gynecologic cancer conversing over anything from making treatment decisions to hair loss and funky re-growth…from the latest clinical trials to our own locally-funded research initiative…from prosthetics to bathing suits…and on and on. Feel free to drop in for this non-traditional support group. Bring your lunch and we will provide delectable desserts.

The Lymphedema Awareness Network

LANROC provides awareness, education, and peer support for anyone living with lymphedema. Caregivers, lymphedema therapists, medical personnel, and those at risk for developing lymphedema are also welcome. This group, facilitated by Karen Miltner, meets from 5:30 to 7:00pm on the second Wednesday of each month.

Common Ground: Living with Metastatic Cancer Discussion Group

For those living with metastatic breast or gynecologic cancers, we offer a discussion group on the 1st and 3rd Thursday of the month at noon. Led by Peg DeBaise, LMFT, the discussion is topic-based, although all concerns of those present will be addressed. Lunch and beverages are provided, so an RSVP is needed.
The PALS program revolves around the wealth of experience represented in our trained peer mentors, who serve those recently diagnosed with breast cancer. In addition, our group of mentors for those facing gynecologic cancers is growing. Once a year, we hold an intensive, day-long training session for a new group of PALS Mentors.

As survivors, PALS Mentors offer the voice of experience to women and men who have been diagnosed with breast or gynecologic cancer. They’re also helpful to those struggling with treatment decisions, are in the midst of their walk with the disease, or may be dealing with survivorship issues after active treatment has ended. In short, a PALS mentor can play a role at any point along the way for those facing a cancer diagnosis.

Our peer advocates are knowledgeable. In the ever-changing landscape of cancer treatment, many mentors take it upon themselves to keep updated on the latest advances by attending our monthly evening seminars, by reading and researching, and by interacting at various Coalition gatherings with those more recently diagnosed.

PALS Mentors are good communicators. Most have participated in one or more of our support programs, where compassionate listening is not only spelled out in group guidelines, it is modeled in the behavior of other attendees. With their skills reinforced through training, our mentors are able to truly listen to the concerns of their mentees, acknowledging their strengths while brainstorming solutions to problems.

Our mentors also serve as resources for the newly diagnosed, referring them to appropriate programs and services within the Coalition or in the community at large. A peer advocate doesn’t “do it all,” but empowers others to move forward in the best way possible for them.

The next PALS Mentor Training Session is scheduled for Saturday, February 3, 2018 at the Coalition. For more information, please email me at pat@bcr.org.

Associate Program Director’s Update

PALS - Peer Advocates Lending Support

Kim Toombs
-By Pat Battaglia

In 2014, when Kim Toombs learned she had breast cancer, she walked into her garage and took a sledge hammer to an old door that was stored there. Afterward, with the door in pieces and her pent-up energy released, Kim moved forward; she sought information, put her medical team together, and called the Coalition. And while we were sorry about her diagnosis, we’re glad she called!

Kim soon became a regular at the Brown Bag table, receiving support and offering her characteristic blend of compassion and wit. When her treatment was finished, she was eager to give back to the Coalition. In the years that have followed, Kim has given back and then some.

Whether sitting on committees for our major fundraisers or representing the Coalition at community events, Kim is a joy to work with. “She is able to connect with anyone who comes to our tables and booths,” says Lori Meath, our Outreach Coordinator. Kim interacts easily and naturally with her fellow volunteers, and often enlists the help of her daughter Kelly as well.

“Kim is one of those delightful people who lights up the room around her,” adds Holly Anderson. “We have come to depend on her honest appraisal of whatever she is involved with. She is always ready to delight us with stories about her experiences or join in for a celebration in the afterglow of a successful event. She is a dream come true!”

A middle-school Family and Consumer Science teacher, Kim has guided her students through the process of making surgical pillows for post-mastectomy patients. The students then donate their handmade pillows to the Coalition for distribution in our PALS Paks. The class also makes fleece ponchos to keep patients comfortable during radiation treatments at the Pluta Cancer Center.

Kim has taken a sledge hammer to preconceived notions of survivorship, adding human dimension to a devastating disease while making meaningful contributions to our survivor community. We’re grateful for her caring, spirited presence!

“A mentor is someone who allows you to see the hope inside yourself.”
~Oprah Winfrey
I vividly recall the Brown Bag Friday discussion that focused on the experiences of those in our breast cancer survivor community taking an aromatase inhibitor. Aromatase inhibitors (AIs) are powerful and effective estrogen-blocking drugs prescribed for postmenopausal breast cancer survivors with hormone sensitive tumors. Brand names of these drugs include Letrozole, Exemestane and Aromasin.

About 80% of breast cancers are fueled by estrogen.* Aromatase inhibitors have been proven to measurably reduce the rates of recurrence and disease progression in estrogen positive breast cancer.

A few of the women at that Brown Bag described manageable or non-existent side effects. Many more women reported hot flashes, weight gain, sleep interruption and hair thinning. Overwhelmingly, arthralgia-like joint pain was the most common and debilitating side effect discussed; one that sometimes led to discontinuing the treatment. Luckily, not all women who take an AI experience significant side effects. But many do.

One participant in the discussion shared how the quality of her life had been severely impacted by AI side effects. Simply crossing the room to her seat caused visible difficulty and pain. For ninety minutes, we listened to story after story describing the extent of the joint pain, the variety of joints affected, and the impact of AI-induced arthralgia on women’s lives.

With the assistance of Candice Lucas, a recent PhD from St. John Fisher College who selected the Coalition as the site for her required field work, we hosted focus group discussions to hear more from our breast cancer survivor community about their experiences while taking AIs. These discussions confirmed that arthralgia is a significant problem for many taking an AI, which are typically prescribed for five to ten years.

In the absence of a commonly-agreed-upon way to address this problem, the Coalition set out to develop its own program to alleviate aromatase inhibitor induced arthralgia. In late 2016, thanks in large part to the data-gathering skill of our summer intern, Sarah Rollinson, we were awarded a grant from the New York Department of Health to develop and implement such a program. Our first four-session series of “Surviving & Thriving on Aromatase Inhibitors” debuted in March of this year. The program is facilitated by an occupational therapist, a social worker, a nurse practitioner and an integrative medical doctor. Participants learn simple movement exercises, strength and stretching techniques, dietary interventions and nutritional supplements, and other strategies to alleviate their joint pain - all in the supportive company of others experiencing similar side effects. The survey results are in, and the program is proving to be a great success!

For more information about future sessions of “Surviving & Thriving on Aromatase Inhibitors”, please call or email Jennifer Gaylord at 585-473-8177 or jennifer@bccr.org.

Welcome to Ali Dennison, Program Assistant

As our survivor programs continue to grow and evolve, Jennifer Gaylord, our Program Director, has juggled her many responsibilities skillfully and cheerfully. And now Ali Dennison has come on board to help ensure all the balls remain in the air. As our Program Assistant, Ali brings a wealth of experience to her new position. Furthermore, she is a survivor who has faced her own breast cancer diagnosis head-on. Having Ali’s gentle, sure hand in guiding our programs is a gratifying development for us, and her warm presence makes her a great addition to our caring staff. Welcome, Ali!

Are you on our mailing list? Learn more about how the Coalition can support YOU.

Contact Jennifer at 585-473-8177 or jennifer@bccr.org
Sifting Through Nutritional Guidelines:

Americans have a long and complex history with food, and with dietary recommendations. The United States Department of Agriculture first entered the discussion in 1893 when W.O. Atwater, an agency chemist who focused on nutrition, established the first federally funded studies of human nutrition. But it wasn’t until 1943 when the USDA issued its first visual guideline: the Basic Seven. With food groups organized into seven equal wedges in a pie chart, the guideline quickly came under criticism for not offering information on portion sizes.

The USDA went back to the drawing board and, in 1956, produced the Basic Four, consolidating the original seven groups and offering recommended serving sizes. This information guided the food choices of many Americans through the 1970’s.

After links between diet, obesity, and heart disease came to light, the Food Wheel was created in 1980 as a guide to not only get the right nutrients, but avoid those considered to be detrimental. This guideline, which emphasized a low-fat, high-carbohydrate approach, was re-organized in 1992 into the Food Pyramid. Breads, cereal, rice, and pasta occupied the wide base of the triangle, while the upper tip represented fats, which were to be consumed sparingly. Other foods were arranged in the middle layers of the pyramid.

America’s obesity epidemic progressed, and the emphasis began to shift from carbs to fruits and vegetables. This was reflected in the 2005 My Pyramid, which featured vertical wedges of varying widths, as well as a color-coded system to identify different food groups. In 2011, the USDA simplified the message by creating My Plate. A circle represents a plate of food eaten at a typical meal; vegetables and fruit occupy half the plate, grains and protein make up the other half, and a smaller circle representing a glass of milk sits on the side to indicate dairy products.

It’s been an interesting evolution, and few will say the current guidelines are perfect. New studies on nutrition are continually being released and popular media is crowded with nutritional advice of all sorts. Each person has their own opinions as well. When it comes to making healthy food choices, one thing is certain: many people are confused.

This confusion was confirmed by the International Food Information Council Foundation, which conducts an annual Food and Health Survey.

Sources:
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In the latest survey results, released in May of 2017, seventy-eight percent of respondents reported that they had encountered conflicting nutritional information. For about half of them, contradictory advice caused them to question the food choices they had been making.

A cancer diagnosis can introduce further questioning and self-doubt. But, although obesity and alcohol consumption are risk factors for breast cancer, diet is not known to be the cause or the cure for the disease. However, some foods can help nourish and sustain patients through treatment, while others are less helpful or may even interfere with the process. Many cancer treatment centers have a registered dietician on staff that can help each patient develop an individualized nutrition plan.

The International Food Council survey also noted that one third of respondents selected a dietary plan based on advice from family and friends, while only one in seven relied on health care professionals. This speaks to the influence of loved ones in decision-making. The Cancer Resource Center of the Finger Lakes has released their new Caregiver’s Guide that begins with the words, “The best advocates are the quiet forces who support mostly by their steadfast presence. One patient referred to his advocate as his “designated listener.” Whether making nutritional choices or any other decisions regarding cancer care, listening opens the door to honest communication. This helps keep patients, families, caregivers, and health care professionals on the same page in considering the best interests of the newly diagnosed person. That “designated listener” can make a world of difference.

When you’re facing a recent cancer diagnosis, it’s not the time to make major changes to your diet or any other aspect of your lifestyle. If (after careful consideration, some heart-to-heart talks with your “designated listener[s]”, and a little professional guidance) you find room for improvement, be kind to yourself and begin small. Your walk through cancer may seem like the proverbial journey of a thousand miles, but it will be taken one step at a time.

Helpful Recipe

**Constipation is a serious problem many people encounter while undergoing treatment. This easy, natural recipe came to us from Norma and Gordon Steele as a remedy for treatment induced constipation.**

Mix together:
- 1/2 cup applesauce
- 2 tablespoons bran
- 1 - 6 ounces of prune juice

Store mixture in refrigerator. Eat 2 tablespoons each day while going through treatment. Gordon suggests putting it into hot cereal in the morning.

Baked Spaghetti

1-1/2 cups spaghetti sauce
2 cups blended Italian cheeses
1 box spaghetti noodles

Heat oven to 350 degrees. Cook noodles until not quite al dente. Drain and mix with the spaghetti sauce and 1 cup of cheese. Place into an oiled 9x13 baking dish and top with remaining cheese. Bake 20 minutes.

Get creative!
Add veggies and/or meat as desired.

Serves 4 - 6
In a scenario that brought back memories of last year, the 15th annual Tee’d Off at Breast Cancer Golf Tournament, which took place at Brook-Lea Country Club on July 24th, got off to a rainy start. Morning showers made the course too soggy for carts, and only one of the teams scheduled to tee off early managed to complete nine holes before switching to a cart to finish with the other golfers in the afternoon. Most of the afternoon was dry with some sunshine and only a few brief showers. The scattered rain did not dampen the spirits of our golfers, who made the most of their outing with smiles on their faces.

The high spirits on the course continued inside the clubhouse as the golfers returned to enjoy dinner and prizes after purchasing raffle tickets for a wide array of donated items. We wish to express our gratitude to the many golfers, sponsors, and donors whose generosity make this event possible. A big shout-out goes to our returning Presenting Sponsor, Signet Management, whose combined support resulted in another successful tournament that raised over $33,000 in net profit for the Coalition.

We’re sincerely grateful for the outstanding efforts of the planning committee, led by co-chairs Sean Patton and Lee Cordero, and joined by Holly Anderson, Sylvia Cappellino, Cindy Dykes, and Susie Smith. Of course, we could not host a successful event like this without the help of our volunteers and staff who cheerfully lent their helping hands: Lauren Henry, Marcy Lazio, Michelle Lindsay, Lori Meath, Margie Micca, Maja Miličević-Klugh, Jan Salzer, Brenda Tartaglia, Marty Tessoni, and Kim Toombs. We hope you will join us next year for the 16th Annual ‘Tee’d Off at Breast Cancer’ Golf Tournament. Stay tuned for an announcement about the date and location!

Please visit our website, www.bccr.org for 2017 Tournament results.
15th Annual
Tee'd-Off at Breast Cancer Golf Tournament

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- Wild Wood Country Club
- Windsor Cottage
- Carolyn Yaekel

Left, the dynamic golfing duo, Rick Harris Jr. and Sr!

Joe Buss from Brook-Lea keeps everything running smoothly!

Event photos included here taken by Ria Tafani.

Feeling lucky!

Birds of a feather
Valerie Wahl and Patti Cataldi.
negative result; potential impacts on family members; the possibility that the results might not be informative or raise more questions than they answer; psychological repercussions; and financial considerations. It is also possible that mutations exist that are not detectable by current methods. A genetic counselor can help people sort through the complexities involved before making a determination to either undergo the testing or forego the option.

Genetic testing results can impact treatment decisions and have a ripple effect in families, so informed decision-making is crucial. However, a recent survey found that only about half of those who received genetic testing had discussed their results with a genetic counselor.7 Access to this type of professional guidance is limited in some regions of the country. Fortunately, that is not the case in the Rochester area. Wherever you live, the National Society of Genetic Counselors offers a searchable directory of providers throughout the United States and Canada: nsgc.org/p/cm/ld/fid=164.

Financial questions surrounding genetic testing are a concern for many, and confirming your health insurance coverage before consenting to the test is a good idea. The Genetic Information Nondiscrimination Act (GINA), which passed in 2008, prohibits health insurance companies from denying coverage to those with a gene mutation, so genetic testing will not affect your health insurance coverage. But the law does not apply to life insurance, long-term care, or disability insurance.8 If you are considering purchasing one or more of these forms of coverage, a recommendation for genetic testing can affect the rates you will be charged.

The results of genetic testing can be empowering and allow for proactive decision-making, but each situation is different. As with all significant medical decisions, the choice to accept or decline this option depends on a number of individual factors that vary widely from person to person. If the testing is suggested for you, a genetic counselor can help you weigh the implications of positive and negative results for yourself and your family. When all the information is in place and your questions answered, make your best decision and move forward. These are your genes, this is your life, and the decision is yours.

*The Emperor of All Maladies, Siddhartha Mukherjee, 2010, Scribner

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**Book Review**


-By Pat Battaglia

Raychel Kubby Adler, a Certified Wellness Coach from Davis, California who holds an advanced degree in Public Health, has written a memoir about her life experiences as a breast cancer “previvor”. A poignant and honest book, the full title offers the first clue about what lies ahead in its pages. *Life in Asymmetry: A Hopeful Journey Over the Peaks and Valleys of Genetic Breast Cancer* is warmly human and often irreverently funny as Raychel recounts the many dilemmas she and her family faced – and continue to face – as carriers of the BRCA2 genetic mutation. When this gene is mutated, it results in a substantially...
have to do it. That’s why I have never felt burdened – I can’t say I’ve never felt terribly sad and at times devastated, but I never felt burdened, as though this is something I don’t need to be exposed to. Quite the opposite; this is part of my life’s path.

**Pat:** I agree.

**Musa:** I remember my father-in-law, who remarried at 85. After a few years of wedded bliss, his wife developed lung cancer. She was, I think, 88 and was like “I don’t understand why this is happening to me, it’s out of the blue, I never smoked…” I had to bite my tongue and just hold her hand and be with her. But I was thinking “You’ve gotten to 88 years. That’s an accomplishment! I hope I make it that long.”

**Pat:** What I’ve witnessed among women in our metastatic community is they’re so present in their lives in powerful ways.

**Musa:** I’ve corresponded with people on brainmetsbc.org and I’ve always been struck by how grateful they are for information that they can hold on to delivered in a calm way. They often find that no one wants to talk about it. I alluded to that in my book on how important it is to keep communication open, especially at the end of life.

**Pat:** It can be hard to talk about, especially in October when we’re awash in pink and the media messages don’t resonate with those who have metastatic disease.

**Musa:** Nothing has changed in that way, although working with the Metastatic Breast Cancer Alliance, I think there’s more awareness. Even the term metastatic breast cancer is more widely known. If you read the first chapter of my book, you’ll see how it was back in 1995 when there were no resources and there was no one in the breast cancer support community who was offering anything for MBC patients. I’ve seen a world of difference between what’s happening now and twenty-five years ago.

I’ll tell you a little anecdote. I’ve been on the faculty of the ABC Consensus Conferences on MBC, which are held by the European School of Oncology in Lisbon every two years. It’s a guidelines-developing conference. I was asked last time to be on the selection committee for the honorees of the conference. I said it’s got to be the researcher who was most responsible for bisphosphonates and bone modifying agents. This researcher has not received that much attention, but when I was first working with metastatic patients, one of the women in my original support group rolled over in bed and broke her arm. You never see this now – never. Certain things don’t receive a lot of attention and make a huge difference in terms of quality of life. And this is just one example.

**Pat:** Is there a message you’d like to give to women in our metastatic survivor community?

**Musa:** We’re not treating breast cancer like one disease anymore; we’re entering the age of individualized medicine where each patient’s cancer will be genomically analyzed and treated. We’re not there yet, but we’re on the way. It won’t change everything for everybody, but I think we’re going to start making much quicker progress. So “hang in there” is what I’d say.

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**Executive Director’s Column, continued**

As we approach our twentieth year as a grassroots, independent, community-based breast cancer organization, we find a most reliable source of scientific peer-reviewed information about breast cancer and environmental relationships is Breast Cancer Prevention Partners (formerly Breast Cancer Fund). In an easy-to-understand format, BCPP describes current peer-reviewed science and the methodology used to conduct reviews, outlining critical concepts that frame and sort the data into seven major areas:

1. Hormones: Pharmaceutical agents and personal care products
2. Endocrine disrupting compounds (EDCs)
3. Hormones in food: Natural and additives
4. Non-EDC industrial chemicals
5. Tobacco smoking: Active and passive
6. Shift work, light-at-night, and melatonin
7. Radiation

While studies exist that suggest that breast cancer most often happens simply due to “bad luck,” that is a passive explanation we cannot (and won’t) live with. It lets cancer-causing industries off the hook entirely. We prefer an empowered approach. Not a day goes by when we don’t count our blessings that we have collaborators that won’t rest until we understand the questions and, like us, insist upon the answers. Our lives depend on it.

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Welcome to our staff, Helene!

As the new Research Administrator for the Breast Cancer Coalition, I’m excited to be joining and serving an organization that was invaluable to me during my own journey with breast cancer. The opportunity to work with such a dedicated group of people - staff members and an impressive network of volunteers - is inspiring. I hope to continue the outstanding job done by our previous administrators.

Scientific and medical research increases our knowledge of the causes, prevention and treatment of breast cancer and, ultimately, will help find ways to eradicate it. But on a personal level, hearing about the latest research discoveries offers new hope to the patients, families and friends who are affected by this disease.

This past year, the Coalition expanded its Research Initiative to include a grant for a Pre-Doctoral Trainee or Post-Doctoral Fellow in addition to the annual grant presented to a Faculty Researcher. The process to solicit proposals and award grants in spring 2018 is already underway. I’m grateful to the staff members and volunteers who have done the preliminaries and look forward to building on their work.

Please call (585) 473-8177 or e-mail research@bccr.org for more information.

Welcome Special Event Director, Kim Smith

Attendees at our ARTrageous Affair may have had the chance to meet our recently hired Special Events Director, Kim Smith. It was a trial-by-fire for this accomplished, hard-working woman who joined our staff just before the gala - one of our major events. She handled the evening with aplomb, pitching in while learning from one of the best: our soon-to-be-retired Development Associate, Cindy Dykes. Kim, with good-natured flexibility, did her part to ensure the gala went seemingly flawlessly for our guests while connecting easily with the small army of volunteers who were on hand to assist. We’ll be sad to lose Cindy, yet we realize what a gem we have in Kim. Welcome, Kim!

Our Gratitude to Dominique Boller, former Research Administrator

Until recently, the efforts of our Research Initiative were coordinated by the astute and talented Dominique Boller. The Research Initiative, which began in 2003, awards grants to regional researchers seeking to address primary prevention of breast cancer or to understand the process by which the disease metastasizes. Under Dominique’s direction, we have provided two consecutive years of funding for work that’s being done throughout the Western New York/Finger Lakes region. Dominique carried out her detailed and labor-intensive work with equanimity. Her calm demeanor and gentle wit made her a welcome addition to our staff, and we look forward to her continued volunteer efforts on behalf of the Coalition. A gifted photographer, Dominique’s photos have appeared in our newsletter on many occasions. As she moves forward on her life’s path, we’ll always be grateful for the presence of this remarkable woman.

We wish her well as she returns to her academic studies toward a Masters degree at SUNY Brockport.
Outreach Coordinator’s Update

Hints for Helping – I am a naturally outgoing person. As a teacher and performer by nature, crowds and an audience thrill me. But that is not the case for everyone. Sometimes a volunteer (you?) may feel intimidated or nervous about being “the face of the Coalition” at events.

First of all – SMILE. Your presence is most welcome and vital since we cover a wide variety of events throughout the region. Your commitment to this organization, your desire to share information about our great resources, and your listening ear are your best qualifications!

Realize that you are never on your own. Volunteers always work with a staff member or other seasoned volunteer. Often volunteers discover there is someone they particularly enjoy working with, and I am happy to schedule you with the partner of your choice.

If you are working at a festival or fundraiser, take a look ahead of time at that event’s Facebook or Webpage. There is generally a map of the event site, and you can familiarize yourself with restroom facilities, event layout, music venues, ATMs, and shuttle stops. People quite often ask our volunteers for general information, and I believe our “pink” booth tends to look friendly!

You are not expected to have medical knowledge; your task is to be familiar with the programs of the Coalition. There are written materials in the booth - open up that newsletter to the center spread and put it in the visitor’s hands.

YOU are appreciated and valued. Remember, your kindness and smiles are the Coalition’s very best publicity!

For more information on how you can help, or to request to be added to the Coalition’s regional programs notification list call:

LOCAL OUTREACH (585) 473-8177 x304 or e-mail lori@bccr.org
REGIONAL OUTREACH (585) 473-8177 x310 or e-mail tracy@bccr.org

Share the wealth, spread the word, become part of an effort that cannot be done without YOU!

Regional Programs & Outreach Director’s Update

Most of us spend a good part of our lives wondering (and worrying), “what is going to happen next?” We’re not often content to live in the present, or focus on where we are right now. No, usually we’re looking ahead to that “distant day.” Of course, planning can be a good idea, and working toward an important goal can enrich our lives.

And yet, as the year winds down and we settle into harvest season, I find myself reflecting on Rainer Maria Rilke’s words: Live everything. Live the questions now.

I won’t pretend to know exactly how to do just that, but I have begun to purposely ease my stride, slowing my tendency to rush. I’m starting to let go of wanting to know all the answers, solutions, and outcomes right now – because I cannot predict the future. The questions will remain – How do I do this? How will I accomplish that? What if this happens? What if this does not turn out like I hope it will? What next?

My new practice is to live with the questions when I don’t have the answers. They are here. I am here. We might as well sit together.

Maybe in the future the answers will be waiting. Maybe they won’t. Rilke doesn’t offer a guarantee in his words.

Uncertainty about the future can be difficult, so let me offer this idea. For now, let’s just be in the space that we know in this one, singular moment. Let’s be present in what we have today, placing our feet on this solid ground. In this harvest season, let’s consider living everything, and together, being okay with some unanswered questions.

“And the point is, to live everything. Live the questions now. Perhaps then, someday far in the future, you will gradually, without even noticing it, live your way into the answer.”

~ From Letters to a Young Poet, by Rainer Maria Rilke
increased lifetime risk for developing breast and ovarian cancers.

While some celebrities have famously made surgical decisions based on a similar genetic testing result, their private struggles have remained just that - private. Consequently, the full impact of living with a high-risk genetic mutation has remained largely unknown to the general public.

This book fills in many of those blanks. Raychel’s compelling and sometimes heartbreaking story begins with childhood memories of the open dressing rooms she visited while shopping with her mother. Comparing the many body types she saw there to her own flat chest, she imagined herself as a mermaid in a seashell brassiere. Before long, she was full of pride at the first development of her “mosquito bites” – her budding breasts.

As the youngest child in her family, Raychel was separated by sixteen years from her next oldest sibling, Lisa, who was “…at times my big sister and at other times my ‘cool mom.’” Lisa eventually married and moved to Rochester, but the sisters shared a close bond that endured through their separation.

Raychel was in college when her mother, and a few months later, Lisa, were diagnosed with breast cancer. Both women responded well to treatment, although her mother eventually succumbed to lung cancer that was not related to her breast cancer. Raychel keenly felt her mother’s absence when she married and began her own family. While she was pregnant with her second child, the news came that Lisa’s cancer had metastasized. By this time, genetic testing was available. Lisa opted for the test and learned she carried the mutation. She urged her sister to be tested, and Raychel eventually complied; she was found to have the same mutation.

Sadly, Lisa, who was a program participant and friend of the Coalition, died in 2009. But before she passed, Raychel promised Lisa she would undergo surgery – a bilateral mastectomy – to reduce her risk of developing breast cancer.

The last part of the book details the surgery, including reconstructive procedures that didn’t go as planned. Although her road had some unexpected detours, Raychel’s healing happened on all levels - physical, emotional, and spiritual. She ends by expressing her hope for her daughters: that they will “…grow not to see their breasts as enemies, but rather view them with the same dream-filled, starry-eyed wonder that I once had as a child…”

*Life in Asymmetry* had me alternately laughing out loud and wiping tears from my eyes. The title of each chapter is a nickname for breasts, and reading through the table of contents is a “Hoot”. This is one woman’s story, and Raychel recalls her journey thus far in an engaging manner that highlights her abiding and complex love for her family, and for life in general. I highly recommend it for anyone affected by a genetic predisposition to cancer and those who care about them.

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**Living With GYN Cancer, continued**

complex encounters. As we spoke, she articulated the mixed emotions of a survivor coming to terms with the end of her treatment: “It’s a feeling like, okay, now what? I finished my chemo. I want to do things but I don’t know what I can do [or] what I can’t do. I don’t know what I should pay attention to [or] what I shouldn’t.” In sharing these difficult feelings with her health care providers and our caring community, Diane continues to work her way through, forging a path that is uniquely her own.

“I’m so thankful that the Coalition exists and I’m thankful for the people I’ve met here and the staff,” Diane emphasized as our conversation drew to a close. We at the Coalition are, in turn, grateful for her honest perspective, as well as her resilience and compassion. And we’ll continue to walk with Diane all the way.
Friends Remembered...

We celebrate all who set an unwilling foot on this path. Most who face a cancer diagnosis will walk through and beyond their experience. These pages are dedicated to the ones whose light and wisdom have inspired and guided us, and who will never be forgotten.

Lena Adams
Claire Allen
Beatrice “Bea” Bell
Irene Berke
Carolyn Carafos
Sheila Gardner
Lauren Bauer Morelle
Barbara Rubble

Sheila L. Gardner - By Francine Monroe (Sheila’s Mom)

On April 9th, 2017, I lost my daughter Sheila to metastatic breast cancer. I am left with just my memories of the battle she courageously waged against breast cancer, and more importantly, her very bright and beautiful smile. My daughter had big, beautiful brown eyes.

Sheila was an artist in her own right. She loved animals and the animals loved her right back. My daughter was somewhat of an introvert. I know she wanted to feel comfortable enough, to be a part of what was going on around her – to join in. Sheila found that comfort in Brown Bag Fridays. When she was there, she was a part of the discussion, and even joined in.

These are just some of my memories of my very gentle, shy daughter. Sheila, there are no words to say how I love you and miss you. No mother should ever lose a child. It wasn’t meant to be that way.

I want to say thank you to the Breast Cancer Coalition. We thought we had no one when Sheila was diagnosed but, as it turned out, we had all of you. We thank you for your support and generosity, as well as giving us a sense of direction.

My love to everyone at the Coalition.

Francine Monroe has resolved to volunteer for the Coalition in memory of her daughter. We welcome an ongoing relationship with this warmhearted woman. Both she and Sheila hold a special place in our hearts. —The Coalition

Cynthia Claire Allen - By Pat Battaglia

Before meeting Claire, as she was known to her family and friends, at the 2016 Pink Ribbon Run and Walk, I had already heard much about her from her proud mom, Deb. As the Coalition’s Development Director at the time, Deb spoke often of her children, Claire and Paul. Claire’s full name was given to her in memory of her paternal grandmother, Cynthia Barden Allen, who passed away from breast cancer before her son Jim met Deb. As one of the top individual fundraisers for the Run and Walk that year – also the youngest one AND a 5K runner - Claire stood by her mother’s side as we were introduced. Mother and daughter wore equally bright smiles. This is the image I will always carry of Claire, a girl full of energy and promise who was lost in a tragic accident on Sept. 7 in her hometown of Geneseo. The hearts of everyone at the Coalition are with Deb, Jim, and Paul. They will always be part of our community.

Friends Remembered...

We celebrate all who set an unwilling foot on this path. Most who face a cancer diagnosis will walk through and beyond their experience. These pages are dedicated to the ones whose light and wisdom have inspired and guided us, and who will never be forgotten.

Lena Adams
Claire Allen
Beatrice “Bea” Bell
Irene Berke
Carolyn Carafos
Sheila Gardner
Lauren Bauer Morelle
Barbara Rubble

Tributes Welcomed

Would you like to write about someone you have lost to breast or gynecologic cancer? We welcome submissions from friends and family members and are particularly interested in stories about how they touched and changed your lives. Please send your submission (200-400 words) with a digital photograph to Pat Battaglia, Voices of the Ribbon Newsletter Editor, at pat@bcr.org.

We would be happy to honor your loved ones.
thought it would be, and with the exception of my hair loss, I felt pretty normal physically. It wasn't until it was all over that I realized how foggy my brain had been and all of the small side effects I was coping with.”

Radiation therapy was Andrea’s next step, and this phase went fairly smoothly, beginning in February of 2014 and lasting through April of the same year. There was also a year of treatment with Herceptin, a drug for cancers that are found to overexpress the HER2 (human epidermal growth factor 2) protein, as Andrea’s was.

The final weapon in the arsenal was – and is - the medication Tamoxifen. Prescribed for cancers that use estrogen and/or progesterone as growth fuel, Andrea is on a ten-year course of the once-daily oral drug. This type of therapy makes a real difference in the recurrence and survival rates for hormone receptor positive breast cancers.

“When I was first diagnosed, people came out of the woodwork,” Andrea noted. “And so many people said to check out the Coalition. So I called.” She was quickly scheduled for a Breast Cancer (BC101) session with Holly Anderson. During that session, Andrea realized that her mother, Lisa Waldman, knows Holly and used to assist her in teaching preparation for childbirth classes. After her BC101 and the “small world” moment it contained, she began to attend Brown Bag Friday lunches, where she found invaluable support and connection with other survivors.

This support and connection deepened when she found kindred spirits at our Young Survivor Soirees, where conversations can run the gamut - such as the complicated issues that can follow a diagnosis. “People want to help but a lot of times they don’t know how to. Or they’ll say ‘Let me know what you need,’ and you’re like ‘I need everything. How am I supposed to say I need everything?’” Andrea found reassurance in the human stories survivors share. “It helped me to hear other people and to connect and see people on the ‘other side.’”

Even in cancer, laughter can often be the best medicine. Andrea recalled, “I used to watch a lot of Ellen DeGeneres clips, and I still do. I just needed something to laugh about.”

Andrea’s gratitude for having found the Coalition is surpassed only by her thankfulness at returning to the joyous but demanding work of full time motherhood. With her children now ages five and eight, she mused, “It’s like people say – the days are long but the years are short. I’m not always the fully present, never-gets-upset mom, because that’s just not possible. But I do put a lot of pressure on myself sometimes because I know how precious it is that I’m actually here with them.”

Andrea took a break from our conversation to calm an upset child. “Take some deep breaths,” she said gently, and the sobbing slowly subsided. When she returned to the phone, we pondered that the very same words could be said to someone whose world has just been turned upside-down by a cancer diagnosis. Motherhood and survivorship mesh beautifully in Andrea.

This sage young woman continued, “The little things don’t matter. Your mind is more powerful than anything you could ever imagine. And the world is full of kind, generous people.”

“We’re grateful that this world includes Andrea Reynolds, and that she has become a part of our world – and our survivor community – at the Coalition. ☀️

Comments from Our Program Participants

“Thank you so much for welcoming me and connecting me to your wonderful resource… the networking has been helpful already and I will continue to use it and hopefully give back once I recover.” -S.R.

“I was overwhelmed by the incredible items in my PALS Pak. I’ve been using each and every item during my recovery…I will continue to stay connected.” -W.F.

“I did not know what would happen when I came to the Coalition and was very nervous. I just want to say I felt glad for the simple care you all gave me.” -L.M.

“Thank you for providing such valuable information and for welcoming me into the ‘sisterhood.’ It has not been my nature to open up and ask for help, but the Coalition has become an important part of my life.” -J.L.

“I look forward to getting involved with your organization as well as giving any support I can to others in need.” -S.T.
Our Fundraising Friends

Getting to Know Lindsay Schreib of Cycle Stop, Inc. - By Lori Meath

When a community business or group decides to dedicate a fundraising effort for our benefit, there is often a personal connection to the Cause. This is the case with Cycle Stop of Rochester’s annual Dice & Bust Run, which took place for the tenth year on August 6.

Cycle Stop is a true family operation. The business was started by Judy and Gary Schreib in 1981 when daughter Lindsay was a child. Cycle Stop represents a passion for motorcycles (Harley Davidson “bikes” in particular) as well as a dedication to a community of riders. By 2008, daughter Lindsay had joined the family business, and was intrigued by the possibility of hosting a charity “Run” as she knew other dealerships had done.

Mom Judy had finished treatment for a breast cancer diagnosis shortly before when Lindsay approached her with a list of groups who provided support for breast cancer survivors including the Breast Cancer Coalition. The decision was easy for Judy- their Rochester business would raise funds for a group offering services locally!

The format of the Run is simple: riders pay an entry fee and follow a prescribed road course with checkpoints at each of which dice are rolled and results recorded. Cycle Stop’s run encompasses approximately 90 miles following a course through the rolling hills south of Rochester and ending at a location near the shop for music, raffles, food, and celebration.

The simple format does not reveal the multitude of details to be addressed. As Lindsay relates “(the challenge is) finding the time to DO everything!” And while reliable friends may pitch in, as Lindsay says, “It’s all in my head!” Chores include plotting the course and arranging the stops, gathering sponsorships, obtaining raffle items, printing materials, planning the post run celebration, registering riders, and compiling extensive notes for the riders - things like “watch out for fresh oil” or “parade scheduled”.

When asked how much the event had raised in the first nine years, Lindsay’s response was a modest, “Well, our event isn’t that big. We raise a couple thousand each year”. In fact Cycle Stop has donated in the neighborhood of $30,000 prior to this August’s Run!

Among those Lindsay mentioned as loyal supporters were Nashville’s (they open their doors early for those who don’t choose to ride, donate food, and provide publicity); The Cancer Law Firm of Canandaigua (motorcycle insurance specialists who also sponsor riding lessons in the community); and especially Federico’s demolition company, who are family friends. “I kind of told him (Federico) in the beginning, “You are GOING to help me!” and he always has.” She also expressed appreciation to many area small businesses that provide gifts certificates, saying “Small businesses get asked for so many things.”

Lindsay thoughtfully laments the challenges of tackling the cancer “epidemic”, saying, “I’m afraid we aren’t going to cure it with the way our environment and foods are. We’re going to have to find ways to deal with it; maybe more of (an approach of) “preventative maintenance.”

As the phones rang and the intercom buzzed, I asked Lindsay what people might be surprised to learn about her, a woman who rides a Harley, sports purple hair and whose email is “Harleychick.” With a resounding laugh she declared, “I’m a very outgoing person, but also very private. Also, I’m a ‘girly girl.’ I HATE camping! I do it, but no tents; it’s gotta be a motorhome and have a shower. I’ll get dirty fixing a bike, but I need my luxuries!”

- By Lori Meath

Lively Links at Midvale

Fervent appeals to the sun to shine on the June 20 annual Midvale Golf Tournament were fulfilled. Dramatic clouds persisted, but the day was primarily dry as the ladies took to the links to benefit our Coalition. Once again, raffles and silent auction items were abundant, spirits were high, and dinner was sumptuous.

Board Liaison Mary Carafos attended the tournament and was able to express the thanks of the Coalition for so many years of effort on our behalf. This year’s successful event raised $4417.

Gifts That Keep On Giving

While we were aware of Knucklehead Brewing special “Kick-It” IPA produced to raise money for the Coalition, we were delighted to receive an unexpected $1000 from Vanguard Charitable as a direct result of a recommendation from Knucklehead! Vanguard is an administrator of donor-advised funds. Thanks to the great people at Knucklehead for this extra giving effort.
Our Fundraising Friends

Alex’s Legacy

Talented. Athletic. Handsome. Funny, kind, gentle. Just a few of the ways those remembering Alex Hendry described him. Alex, the son of the Coalition’s dear artist John Hendry, was a college Freshman in early 2016 when he died tragically. In his memory and honor, his family created The Alex Hendry Memorial Golf Tournament.

The skies on Aug. 12 were dramatic, rolling, and threatening. As the tournament tent was being filled with dozens of auction items and door prizes, rumbles of thunder got closer. And then, with a roar, the rain came, fast and hard, sending everyone scrambling to protect tables of prizes. Eighty-eight golfers were to arrive within the hour...everyone was tense and quiet. And then John proclaimed, “It’s Alex; he’s just softening up the greens for us!” Within ten minutes, the deluge ceased, closely followed by brilliant sunshine. Laughter arrived as golfers checked in. And while shoes got wet and grass stained, the players remained dry. Dinner and festivities followed. Tributes to Alex, an up and coming baseball star with “a wicked arm” brought tears and laughter. The Coalition was humbled to be selected as the first recipient of tournament proceeds and was presented with the generous gift of $3000.

Alex is missed. But on this fine afternoon his friends and family gathered to remember, to laugh, and to GIVE. Alex would have wanted nothing less!

Rallying For Local Services

In another incredible effort on behalf of this area’s breast and GYN cancer survivors, the Clifton Springs Country Club once again held their “Rally”. Blessed with blue skies and puffy white clouds, seventy-five players savored the beauty of this rural course, time with good friends, and the opportunity to help the Coalition continue to provide free programs and services. Capping off the day with a delicious feast, the Club raised and proudly presented a donation to our Coalition of $4975.

Derby Ladies Jammin’

The feisty women of ROC City Roller Derby blocked, whipped, slammed and ultimately lapped the opponents in their May 13 Bout at Genesee Valley Rink. If those terms sound rough and tumble, it’s because they ARE! The Derby is a fast-paced sport of roller skaters repeating laps around an oval track supporting, protecting, and enabling their lead skater - the Jammer - to pass the pack repeatedly to accumulate points. Ample padding cushions the jabs and blocks which are restricted to the body outside of the core area. Bruises, however, are plentiful as are grunts, cheers and wide victorious smiles. The women immerse themselves fully in the alter ego characters they have created, belying the “ordinary” workdays most enjoy. This is certainly one of the more unique ways to raise money to support the Coalition’s services and programs! Thanks to the Derby ladies for a gift of just under $282.

Ongoing Efforts

Leonard’s Express has had a busy quarter sending their four pink rigs across the country as breast cancer ambassadors. Every mile brings one penny for the Coalition. Those pennies add up! This quarter’s contribution is $1252.36.

Thank you and keep on truckin’!

Dressing Down for Dollars

Cheryl Cappon of Tompkins Financial Advisors organized a company jeans day fundraiser June 9. This day of relaxed attire raised $630.05. These simple efforts on our behalf are much appreciated.
Donations ending June 30, 2017

The name of the individual honored or remembered is shown in bold type. The Breast Cancer Coalition thanks donors for these gifts made since our last listing. (Donations made after June 30th will be included in the winter newsletter.) We apologize for any errors and/or omissions on our donor pages. Please notify us if a correction is in order.

In Honor of:

Holly Anderson
Marcia Siewert

The Board & Staff of the Coalition
Pat Battaglia

BCCR
Anonymous

Mel Bianchi
Eleanor Santo

Cheryl Bovard
Rosemarie Salvemini

Molly Branch
Maureen Steffon

Dr. Gunhilde Buchsbaum, MD
Dr. Dianne Edgar, MD

Mary Carofos
Mrs. Frank J. Riedman

Meg Croes-Smith
Janet Schumacher

Carol D’Agostino
Kendall High School Senior National Honor Societies

Frank DiPane
Audrey & Fred Hoffman
Robert Helft & Matthew Trieu
Judy & Jerry Infantino

Father’s Day
Colleen Joseph

Janice Hassett
Anonymous

Jan Hawryluk
Donald Monacell

Judy Hayes
Charlotte Greenwood

Nancy Hiller
Eileen Goldman

Barbara Jackson
Allan Mitchell

Marcia Kaplan
Marcia Stern

Beverly Levy
Phyllis Connelly

Meg Love-Mackey
Iona Mackey

Mary Maggio 90th. Birthday
Bonnie & Ed Wurtz

Sandra Maluta
Sam DeRosa

Kathy Mangione
Agathi Georgiou

Colette McConnell
Beverly Eisenbraun

Cynthia McLaughlin
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Ida Miller
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Nancy Monde
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Lisa Morabito Percy
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Frank Perticone
Audrey & Fred Hoffman
Robert Helft & Matthew Trieu
Judy & Jerry Infantino

Beth Rowe
Beth Rowe

Rita Savella
Mary Rinere

Doreen Secor
Mary Secor

Barbara Swiecki
Kevin Yost

Connie Ventura
Antoninette Capellupo

In Memory of:

Evelyn Bauer
Linda & Richard Cooper

Patricia Bellaire
Colleen Kennedy

Judy Buchanan
Ray Buchanan

Phyllis Burruto
Mary Maggio

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Jan Skuse
Anita Hawkins
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Five Fingers Camping Club
Anna Wegener
Joyce Wegener-Dooley

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Carmen Wallace
Deanna Wallace
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Diana Williams
Kristin Young
Leisa Zanghi
Zeta Tau Alpha

Gifts in Kind:
Carol Camp-Jenkins
Janet Dalke
Val LaForge
Kim Waterbury
Anne Wells
Knitted Knockers
Enjoy the Breast Cancer Coalition’s Resource Library

BROWSE, BORROW & READ

The Coalition’s Current Wish List

- A cure for breast cancer
- Books: about breast, gynecological, prostate or testicular cancers and lymphedema for women, men, children, families (2010 or later)
- Office supplies: copy paper (white, 8½ x 11), white notepads (plain-Staples or Office Max), Post-It notes, mechanical pencils with erasers
- Breast Cancer Research postage stamps
- Gift cards ($10-$25): Wegmans, Tops, DiBella’s, Staples, Target, Barnes & Noble, Michaels, pizza, gas, 10-ride RTS bus passes (available at Tops or Wegmans)
- Paper products: paper towels (Viva), napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam products), unscented tissues
- Batteries (D and AA)
- Cleaning & storage: plastic or glass food storage containers, zip-style storage bags (quart & gallon), aluminum foil, plastic wrap, trash bags (13 and 33 gallon), disinfectant wipes
- Matching LG washer/dryer (contact the Coalition for specs)
- Heavy duty 10x10 pop-up tent with sides

Please note, all items must be new

Let us know what you would like to see in the PALS Pack.

Upcoming Events & Programs at the Coalition 2018

We have so many exciting plans in the works... Stay tuned!

All events unless otherwise noted are held at:
THE BREAST CANCER COALITION
1048 University Avenue

Questions?
Call (585) 473-8177 or email info@bccr.org
Farewells and Welcomes

A New Office Manager

Connie Zeller, our office manager since 2010, recently relocated to her home state, Michigan with her family. We’re happy to know she was welcomed with open arms by her Michigan family and friends, but we will miss her energy and spirit. Connie’s voice was often the first one heard by people calling the Coalition, and her manner was – and still is - unwaveringly friendly, thoughtful, and professional. Connie deftly guided the many facets of our day-to-day operations, leaving an indelible mark on our organization. Our “Stellar Zeller” is a hard act to follow.

Fortunately, we found Michelle Lindsay. We came to know Michelle as a capable volunteer for our ARTrageous Affair. She became involved with us following her mother’s diagnosis of breast cancer in 2008. It is now Michelle’s smiling face and cheerful “hello” that greet those who walk through our doors at the Coalition. Her warmth and kindness have won our hearts, and her intelligence and expertise have inspired our confidence. Michelle has taken the reins handed to her by Connie and handled them deftly. We look forward to working with Michelle for a long time to come. Welcome, Michelle!

A Fond Farewell to our Program Co-Director, Beth Miller

Beth Miller, who came out of retirement to co-direct our survivor programs alongside Jennifer Gaylord, has stepped down from her position. We thank Beth for her steadfast compassion as she oversaw many of our offerings for survivors, particularly our Healing Arts classes. Beth helped see our newest program, Surviving and Thriving on Aromatase Inhibitors, become a reality. Hers was often the reassuring voice on the other end of the phone for those newly diagnosed with breast or gynecologic cancer. We look forward to Beth’s continued presence as a volunteer and a member of our Regional Community Outreach committee. We wish her many happy, fulfilling years of “re-retirement”.

Our Board of Directors: Growth and Change

Patti Cataldi recently stepped aside as the Chair of our Board, having served three two-year terms. We’re grateful for her sagacious and adept leadership, and for the fact that she still sits on the Board as our Past Chair, as well as in her role as Major Fundraiser Chair.

Now at the helm as our Board Chair is Debra Kusse, formerly our Audit Chair. We welcome Deb’s leadership. In her new role, she continues working with renewed purpose to guide our organization toward fulfilling our mission.

Stella Slaight has stepped in as Audit Chair, filling the seat that was vacated when Deb Kusse moved into her current leadership position. Welcome Stella and thank you to each of the hardworking members of our Board of Directors for all they give to the Coalition.
Breast Cancer Coalition of Rochester
1048 University Avenue
Rochester, New York 14607

Voices of the Ribbon
A Quarterly Publication of the Breast Cancer Coalition of Rochester
Tel. 585-473-8177 • Fax 585-473-7689 • E-Mail: info@bccr.org • Online at bccr.org

Voices of the Ribbon is published quarterly by the Breast Cancer Coalition of Rochester for the purpose of providing encouragement and inspiration to those facing a breast cancer diagnosis, their supporters, and care providers. In addition, it is intended to impart accurate, science-based information to enlighten and empower its readership.

Holiday Open House
Please join us Thursday, November 30th 5-7pm