Immunotherapy for Breast and Gynecologic Cancers

Food and Cancer Risk

Pink Ribbon Walk & Run

Presented by VanBortel
With this, our summer issue of Voices of the Ribbon, we officially launch our new logo! As we enter the second half of the year and begin our third decade, we are excited to unveil the new logo here:

As regular readers will remember, though our roots are in breast cancer, we have been reflecting on our mission and deepening our commitment to those living in the aftermath of any of the gynecologic cancers. This past winter, we announced our updated mission statement, inclusive of gynecologic cancer. Behind the scenes, we were also working on our new logo. Combining pink and teal, this logo reflects the strength, vibrancy, and empowerment exhibited by our community of cancer survivors. Together, our new mission and logo give consideration to the direction in which we have moved since we first began providing support and education services to those affected by these gynecologic cancers in 2014.

Gynecologic cancers most familiar to us are ovarian, cervical, endometrial, uterine, vaginal, vulvar, primary peritoneal, and fallopian tube, but there are others. According to the American Cancer Society, there were an estimated 110,070 new cases of gynecologic cancers diagnosed in our country in 2018[1]. By comparison, 268,600 women and 2,670 men will be diagnosed with invasive breast cancer, and another 62,930 women will be diagnosed with in situ breast cancer this year[2]. We have learned that the experiences of both breast and gynecologic survivors have many similarities and, sometimes, similar treatments as well. Consideration of inviting gynecologic cancer survivors to participate in programs and services occurred when some of our most active breast cancer program participants experienced a diagnosis of both types of cancer.

Changing a logo is no easy task. We relied on the experts at Flynn (formerly Martino Flynn) to lay the foundation, and our own in-house graphics designer, Deb Bishop, to ultimately create our new look. You will begin to see this logo in the community and, of course, trickling out on all printed materials as these supplies are replenished. In the meantime, we are refreshing our website at bccr.org and breastcancercoalition.org with a launch scheduled for late summer.

Though the look may change, it’s the service we provide that matters most. Our design goal was ultimately intended to best reflect our values and direction. We are a group dedicated to the inclusion of both cancers, regardless of the color of your ribbon.

In this Issue...

Executive Director ................ 2
A Personal Journey ............... 3
Advocacy Updates ................ 4
Living with Advanced Breast Cancer ... 6
Immunotherapy .................. 8
Living with Gynecologic Cancers ..... 9
BCCR Programs  ................. 10
Programs Update ................. 13
Healthy You ...................... 14
Volunteer Spotlight ............... 16
P.A.L.S. Project Update .......... 16
Pink Ribbon Walk & Run .......... 17
Regional News .................. 20
Friends Remembered ............. 24
Outreach Update & Fundraising Friends ... 26
Research Update ................ 28
Development & Special Events ..... 28
Thank You Donors ............... 29
Wish List, Staff & Board Members ... 31

On the cover: Kim Carlsen and Coby and Kristin Cardinale

Her story begins, as many do, when she found a lump in her breast. It was late February, 2016. Joanna Heard acted quickly and scheduled a mammogram in early March. However, the imaging didn’t reveal anything unusual, and neither did a follow-up mammogram a few weeks afterward. But the lump was still there. So, at her third mammogram, Joanna underwent a biopsy that confirmed her worst fears: she was diagnosed with breast cancer. By this time, it was May. But her memories surrounding these events are vague, so when Joanna and I met to talk about her walk with breast cancer - and her extremely rare reaction to the disease - she was accompanied by her mother, Kay, and sister, Stephanie.

Joanna was living and working in Niagara Falls at the time. “My life was good,” she recalled. But even before the diagnosis came, her family noticed changes in her behavior. “She kept calling and telling me over and over that Prince died,” her mother shared. Each time, Joanna seemed to be relating the news for the first time. “And I mentioned to Stephanie, ‘I think your sister is having a nervous breakdown.’”

After her diagnosis, Joanna and her mother consulted a neurologist who concluded that stress was the cause of her memory difficulties. It seemed a reasonable conclusion; psychological stress is a well-known reaction to any cancer diagnosis. After their visit with the neurologist, the pair went to lunch. “That doctor seemed very nice,” Kay offered. Joanna responded, “What doctor?”

This was a defining moment for Kay who, along with Stephanie, lives in the Rochester area. “We weren’t with her every day to see this,” she explained.

Having consulted a surgeon and plastic surgeon, Joanna scheduled a bilateral mastectomy with reconstructive surgery. However, she does not remember making these plans. A friend flew into town to stay with Joanna during her recovery. Shortly before the surgery date, Joanna, Kay, Stephanie, and her friend planned to go out for breakfast. But, due to Joanna’s increasingly unexplainable behavior, they went instead to the emergency department of a Buffalo hospital, where she was admitted.

In the hospital, Joanna’s condition continued to deteriorate. Multiple medical tests did not reveal the cause of her symptoms and, as time passed, her mother and sister grew weary of their daily commute from Rochester. They had Joanna transferred to Strong Memorial Hospital, where an astute resident suggested a possible explanation for her puzzling symptoms: paraneoplastic syndrome. This extremely rare condition, which affects less than one percent of cancer patients*, results from an immune response to the presence of cancer in the body; its symptoms vary widely among individuals affected. In Joanna’s case, her syndrome caused encephalitis, or inflammation of the brain.

A diagnostic spinal tap was done, and during the two-week waiting period for results, Joanna slipped further from her overwhelmed and frustrated family members. Unable to perform basic functions, including feeding herself, Joanna described feeling in a dream-like state. “I could hear my family speak,” she said. “I could hear the doctors, but I couldn’t always respond to them. And when I did, my speech was slurred. But in my mind, I was holding a conversation.”

When the spinal tap results confirmed the presence of paraneoplastic syndrome, Stephanie began reading about the condition. She learned that treating the cancer would offer the greatest hope for Joanna’s recovery and insisted the surgery take place

Continued on page 25
FROM THE ADVOCACY COMMITTEE CHAIR

What is an Advocate?

By Kathy Guglielmi

An advocate is a person who publicly supports or recommends a particular cause or policy.

For me, advocates are the eight Coalition representatives who descended upon Capitol Hill the morning of Tuesday, April 30. This was the final day of the 2019 National Breast Cancer Coalition Advocate Leadership Summit, a marvelous learning opportunity for us.

One plenary session entitled “The Science of Advocacy” featured speakers from other advocacy groups. Mark Harrington, the Executive Director of Treatment Action Group, took the audience from the 1980s to his current-day quest for research, treatment, prevention, and cure of HIV/AIDS. His words and photos told of advocates who gathered, talked, protested, were arrested, and kept on advocating. To say their tenacity was inspiring would be an understatement.

Armed with knowledge and enthusiasm, we proceeded to visit our representatives. Priorities for the year include:

- $150 million appropriation for the DOD Breast Cancer Research Program
- Support for H.R. 2178, Metastatic Breast Cancer Access to Care Act, a bill to waive waiting periods for Medicare eligibility and SSDI benefits for individuals with metastatic breast cancer
- Preservation of the Breast and Cervical Cancer Treatment Program

Our group started the day meeting with staff members of Senators Charles Schumer and Kirsten Gillibrand. On the House side, we were fortunate to speak with Representatives Chris Collins (NY27) and Joe Morelle (NY25) in person. We also met with staff members of Representatives Brian Higgins (NY26), Tom Reed (NY23), Elise Stefanik (NY21), and Anthony Brindisi (NY22). At each visit, we reviewed our priorities and were able to share personal stories. We also managed to squeeze in a visit to Representative Marcy Kaptur (OH9).

We ended the day exhausted but exhilarated, ready to return home and continue advocating.

Top: Ali Dennison, Miriam Steinberg, Holly Anderson, Phyllis Connelly, Representative Tom Reed, Leni Rayburn, Rebecca Solomon, Cynthia Nelson, Veronica Meadows-Ray, and Kathy Guglielmi

Bottom: Phyllis Connelly, Cynthia Nelson, Rebecca Solomon, Joe Morelle, Holly Anderson, Leni Rayburn, Miriam Steinberg, Kathy Guglielmi, and Ali Dennison

Kathy Guglielmi, Coalition Board Member, Advocacy Committee Chair

Join the conversation. Make a difference!

The Advocacy Committee meets at the Coalition on the first Wednesday of every month from 4:30-6:30 p.m. We’d love to have you!

(585) 473-8177 info@bccr.org

BreastCancerCoalition.org
On April 27, 2019 I had the honor of traveling to Washington, DC, with members of the Coalition’s Advocacy Committee for the National Breast Cancer Coalition’s annual Advocate Leadership Summit.

The Breast Cancer Coalition of Rochester is an independent, local, grassroots organization and not an arm of the NBCC, although we hold similar values and advocate for many of the same legislative initiatives. This four-day summit was an opportunity for advocates from throughout the country to come together and work collaboratively. For the first three days, we focused on educational workshops and plenary sessions; our trip culminated on the fourth day with a visit to Capitol Hill. Joining me were Coalition advocates: Holly Anderson, Phyllis Connolly, Kathy Guglielmi, Cynthia Nelson, Leni Rayburn, Rebecca Solomon, Miriam Steinberg, as well as an advocate from Buffalo, Veronica Meadows-Ray.

Although others in our group were past attendees, this was my first summit. I found each day was packed full of multiple learning opportunities. Many doctors and scientists from around the country spoke about their work, including the latest...
I was diagnosed with metastatic breast cancer (MBC) at 26 years old. In the three years I have lived with MBC, my life has changed in countless ways. Yet, in many important ways, my life still looks the same. I live an active life, and a life of love and connection. This was true before cancer, and it’s true now; in many ways, more so.

My diagnosis came the same week I received my acceptance letters to graduate school for opera performance in 2016. After a year and a half of virtual silence, I am happy to report that I made an appearance as part of the ensemble in the Rochester Philharmonic Orchestra’s semi-staged production of Bizet’s “Carmen”.

This year, I was selected to participate in the small choral ensemble of the opera Cosi Fan Tutte, again with the RPO. I am also undertaking a fundraising project to benefit MBC research in collaboration with the Nazareth College Orchestra: a concert featuring many guest artists. I will be performing along with a very special part of my care team who also has a passion for opera.

I have found a new sense of purpose through advocacy, fundraising, and educating the public on the reality of this disease. Today, the overwhelming majority of money raised for breast cancer goes toward prevention and general awareness. Unfortunately, this does very little to help people whose disease has traveled beyond the breast.

Last October, I marched on Capitol Hill to share my story with legislative officials and advocate for increased funding for MBC research. Last February, I walked the runway in New York Fashion week in lingerie for breast cancer patients, designed by survivor Dana Donofree of Ana Ono Intimates. I am involved in a memoir writing group, and my writing has been published in the Huffington Post, the Underbelly online magazine, and the Coalition newsletter. I am also an active blogger.

This semester, I am taking part in an undergraduate course entitled “Meaning of Death” at Nazareth College. I recently gave a talk in class, sharing my experience of living with a terminal illness as a young person. This class has deepened my desire for spiritual growth and transformation. I believe that spiritual healing is possible, even if a cure for my physical body is not at this time.

Physical activity remains my most favored coping tool. Movement helps me navigate the mental and emotional turbulence involved in living with cancer. Yoga centers and calms me, running helps me defuse, and strength training makes me feel empowered.

The Coalition has been instrumental in my ability to cope with this illness...The women of Common Ground are sources of tremendous encouragement, validation, and love, who enable me to walk this road in my power.

The words of Amy Schnitzler, a featured speaker at our 2019 Advanced Breast Cancer Seminar.

Amy Schnitzler

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I am fortunate to have a dynamite medical team that supports and empowers me. They are my healing co-pilots. I am also grateful to my mother, who has more resilience than anyone I’ve ever known. She is my true Hero; my biggest fan; my greatest source of support, comfort and love. Judy Schnitzler, you are amazing. I am also fortunate to have a patient, gentle, and loving partner. I could not ask for a more wise, and kind-hearted man by my side. And my dad is always available for a terrible joke, or to fix parts of my car that break at regular intervals. I am lucky to have the support of a close-knit family and many, many dear friends. The Coalition has been instrumental in my ability to cope with this illness as well. The women of Common Ground are sources of tremendous encouragement, validation, and love, who enable me to walk this road in my power.

In a situation that has the potential to leave me feeling powerless, I arm myself with information and knowledge. I do lots of research and ask lots of questions. I search for relevant clinical trials. I am an active participant in my healing, and have found there’s less potential to feel like a victim in this position. There is power in acceptance, even if what you are accepting is not desirable.

To the newly diagnosed: breathe. Be gentle with yourself. Don’t be afraid or ashamed to ask for help. Take time in putting together your care team and navigating the world of treatment decisions. And don’t be afraid to leave “cancer land” for a while to engage in things that bring you joy. Your new life with cancer demands large amounts of flexibility. It may feel impossible, but you do not walk this road alone. Should you find yourself facing this diagnosis, pull up a chair; there’s a seat at the table for you at the Coalition.

I’ve found that the “new normal” we often hear about in the context of cancer doesn’t really exist: what’s “normal” is constantly changing. A very wise man helped me to see that it’s not about the monumental in this life, but about grounding oneself in the simple beauty of ordinary, everyday living.

*For information on our Common Ground Groups for those living with metastatic breast or gynecologic cancer, see page 10.
Former President Jimmy Carter announced in August 2015 that he had melanoma (skin cancer) that had spread to his liver and brain; an ominous diagnosis. His treatment included not only surgery and radiation, but also a new drug called Keytruda (pembrolizumab), one of the first approved therapies that unleash the body’s immune system against cancer; an approach called immunotherapy. In December of that year, Carter announced that he had no evidence of cancer. Four years later, he is still doing well.

Carter’s positive experience brought the concept of cancer immunotherapy into public focus. Additional interest was sparked late last year when the Nobel Prize in Physiology or Medicine was awarded to cancer researchers James P. Allison and Tasuku Honjo, whose work led to the development of these groundbreaking drugs. People with all types of cancer started asking “Will immunotherapy work for me?” For those with breast and gynecologic cancers, the response to that question has been some hope, much disappointment, and even more questions.

The immune system is known for its remarkable ability to locate, recognize and attack invaders like bacteria and viruses. However, it is not always able to eliminate cancer cells when they form. Once malignant tumors develop, they use a variety of evasion tactics to outwit the immune system. Immunotherapy is a type of treatment that helps the immune system fight cancer.

Immunotherapy differs from targeted therapies such as Herceptin (trastuzumab) and Perjeta (pertuzumab), which are antibodies that attach to breast cancer cells that overexpress HER2 (human epidermal growth factor receptor 2). They stop the cells from growing but do not activate the immune system.

There are several types of immunotherapy. Some drugs, called checkpoint inhibitors, eliminate the proteins that cancers produce to block the immune system. Other therapies use adoptive cell transfer (ACT): collecting and using patients’ own immune cells to treat their cancer. There are several types of ACT, but the one that has advanced the furthest in clinical development is known as chimeric antigen receptor, or CAR T-cell therapy.

Immunotherapy has been shown to be effective in several types of cancer—lymphoma, melanoma, and lung, kidney, and bladder cancer, for example. However, immunotherapies against cancers of the gastrointestinal tract, breast, and ovary have not been as successful to date. Still, hundreds of clinical trials are ongoing and breakthroughs are starting to occur.

In March 2019, the US Food and Drug Administration approved the first immunotherapy treatment for metastatic triple negative breast cancer, a form of the disease that does not overexpress receptors for estrogen, progesterone, or the HER2 protein. The approved treatment is a combination of an immunotherapy drug, Tecentriq (atezolizumab), a checkpoint inhibitor, with a standard chemotherapy drug, Abraxane (nab-paclitaxel). Approval was based on just one international study of 902 women with metastatic triple-negative breast cancer that could not be surgically removed. All women received chemotherapy, and half of them were randomly assigned to also receive the immunotherapy drug. Tecentriq works by blocking PD-L1, a protein on some cancer cells that helps keep the immune system from attacking them. As part of the study, patients’ tumors were tested for the presence of the PD-L1 protein. Among women who expressed PD-L1 on their tumors, average progression-free survival (how long a patient lives after they start treatment without the tumor getting worse) was 5 months for women who underwent chemotherapy alone compared with 7.5 months for women who received both chemotherapy and Tecentriq. Average overall survival (how long a patient lives after treatment starts) was 15.5 months for those who received chemotherapy alone compared with 25 months for women receiving the chemotherapy in combination with immunotherapy. In this study, the immunotherapy drug extended life by 10 months, but did not provide a cure.

Nearly 300 clinical trials studying immunotherapy in breast cancer are ongoing, according to an April 2019 article in the journal JAMA Oncology. In one of these studies, a woman named Judy Perkins, who had metastatic breast cancer that was estrogen receptor positive, tried an experimental immunotherapy after...
When Micky Markert went for her annual physical exam in November of 2017, she had been experiencing abdominal bloating but wasn’t concerned. “Honestly, I didn’t think anything of it,” she recalled when we met recently to talk about her walk with cancer.

She remembered feeling taken aback when, a couple months before her physical, the Physician’s Assistant at her gastroenterologist’s office noted the bloating and asked if she had seen her gynecologist recently. Micky had, in fact, seen her OB/GYN six months earlier and all appeared to be well. But when her primary care doctor discovered an abdominal mass during her exam, she referred Micky back to her gynecologist, who promptly ordered a CT scan.

“That was the first time I heard the word ‘oncologist’ mentioned,” Micky remembered of that consultation. “I barely remember the conversation. I remember being kind of frozen and taking notes — sort of. I just wrote down key words like ‘large’; ‘concerning’; ‘oncologist.’” It was difficult to process the possibility of cancer.

Two weeks later, Micky underwent the needed surgery. As her doctors predicted, the pathology on the mass showed it was, indeed, cancer: stage IIIC ovarian cancer, to be specific. There were abdominal tumors present as well, but the disease had not spread beyond that point. Despite the unwelcome news, learning that her disease was localized to the abdominal area alleviated some of Micky’s fear. “I felt a little absurd for feeling so relieved,” she confessed. But the emotional toll of her diagnosis was still heavy.

Her sister had traveled from her distant home to stay with Micky during her recovery. “I’m glad she was there, because even though I was kind of prepared for [the diagnosis], it’s still a feeling like the floor’s falling out from under you and at the same time, the ceiling is falling on top of you. It’s like I was being crushed…and all I could really think about was, ‘Am I going to be okay?’”

Fortunately, Micky’s care team ensured she had a strong safety net in place. “My doctors knew exactly what they wanted to do, which was very reassuring,” she noted. “I was relieved that the ball got rolling really, really quickly.” As soon as she had recovered sufficiently from surgery, chemotherapy to shrink the tumor began. After a few months, Micky took a break from this regimen to allow for a complete hysterectomy and recovery from that surgery. This was followed by more chemotherapy, which ended in June of 2018.

With chemo behind her, a few inoperable tumors still remained, so Micky enrolled in a clinical trial involving treatment with two medications. “So far, my scans have been good,” she said with a smile. “Whatever these drugs are doing, they seem to be working very well…you can barely even see [the tumors] any more on the scans.”

Follow-up appointments, scans, and medications have outlined a new way of being for Micky. “It becomes a rhythm, it becomes a routine, and it’s your new normal,” she acknowledged. Still, she has found plenty of space to add color and life to that basic outline. She attended Women’s Wellness, a weekend oncology retreat sponsored by Camp Good Days. During this nurturing experience, Micky befriended two regular participants in the Coalition’s Common Ground group for those living with metastatic disease; one of her new acquaintances shared a similar diagnosis of ovarian cancer. “I had no idea that BCCR also

continued on page 13.
**BREAST OR GYN CANCER 101**

These are one-to-one sessions to assist newly diagnosed individuals manage the complex tasks and emotions of a breast or gynecologic cancer diagnosis. We empower them to be self-advocates as they proceed through treatment, recovery, and survivorship. Our professional facilitators provide a safe, comfortable atmosphere where information can be absorbed and assimilated while the individual formulates a personal strategy for making informed decisions. Also valuable for a gynecologic or breast cancer survivor at any stage of their journey.

**Contact us for an appointment.**

**PALS PROJECT**

Breast Cancer Coalition

In this peer mentoring program, individual breast and gynecologic 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.

**Call today to learn how to join the program and be paired with a mentor who has been there, or if you would like to become involved as a mentor.**

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**HEALING ARTS**

The Healing Arts Initiative is an opportunity to learn a new modality or a complimentary healing practice to relax, de-stress, and increase range of motion. Advance registration is required for Healing Arts programs as classes are limited to 12-14 survivors. Sessions are offered periodically throughout the year. Call today to learn more.

**Gentle Yoga**

Gentle Yoga includes breathing exercises, gentle and restorative yoga postures, and mindfulness exercises. Yoga activates a relaxation response and can help relieve feelings of anxiety and can help people with cancer reconnect with their body.

**Rochester (Breast Cancer Coalition)**
- **Monday** and **Tuesday** morning, afternoon, and evening sessions, instructor **Susan Wood**.
- **Saturday** morning yoga is offered with instructor **Raksha Elmer**.
- **Sunday** morning yoga is offered with instructor **Sunni Ingalls**.

**Albion (Hoag Library)**
- **Thursday** evenings, instructor **Karen Blank, RYT**

**Dansville (Dansville Public Library)**
- **Thursday** evenings, instructor **Kate Drake, RYT/OTR**

**Geneseo (Morgan Estates Community Center)**
- **Wednesday evenings**, instructor **Deb Scodese French, RYT**

**Geneva (Geneva Public Library)**
- **Monday** evenings, instructor **Margaret Newland, RYT**

**Fluid Motion**

A movement-based class helpful for those managing lymphedema and others seeking improved range of motion.

**Rochester (Breast Cancer Coalition)**
- **Saturdays** with **Tracey Boccia**.

**Mindfulness & Meditation**

A way of connecting with your natural state of mind and connect with the breath to bring calmness to the mind.

**Rochester (Breast Cancer Coalition)**
- **Offered Tuesday** or **Thursday** afternoons and **Saturday** mornings in five-week sessions with **Estalyn Walcoff**.

**Canandaigua (First Congregational Church)**
- **Wednesday evenings**, led by **Rick Lynch**.

**Qi Gong**

A practice combining meditation, controlled breathing, and movement to balance the flow of energy (qi) within the body.

**Rochester (Breast Cancer Coalition)**
- **Thursday** afternoons and **Saturday** mornings in four- or five-week sessions. Facilitated by **Raphaela McCormack**.

**Tai Chi**

The slow, rhythmic movements combined with deep, relaxation breathing can help to bring a sense of peace and grounding.

**Rochester (Breast Cancer Coalition)**
- **Offered Saturday** mornings and **Thursday** afternoons, led by **Jean Frances Sica**.
Breast & GYN Cancer Group
Gather, support, network, and discuss your journey with others diagnosed with breast or gynecologic cancer.

**Rochester (Breast Cancer Coalition)**
- **2nd and 4th Tuesday of month,**
  5:30 - 7:00 p.m., led by Joan Mitchell. No registration required.
- **1st and 3rd Thursday of month,**
  5:30 - 7:00 p.m. led by Peg DeBaise, LMFT. No registration required.

**Geneseo (Wadsworth Library)**
- **2nd and 4th Monday of the month,**
  5:30-7:30 p.m., facilitated by Sarah E. Covell LMHC, NCC.
  No registration required.

Brown Bag Fridays
Each week a group of breast and GYN cancer survivors gather to discuss a wide variety of topics. Bring your lunch and we provide delectable treats.

**Rochester (Breast Cancer Coalition)**
- **Fridays at 12:00 noon.** Facilitated by Jennifer Gaylord. No registration required.

LGBTQ+ Breast and GYN Cancer Group
This monthly group offers support to LGBTQ+ breast or gynecologic cancer survivors.

**Rochester (Breast Cancer Coalition)**
- **4th Wednesday of month,**
  4:00 - 5:30 p.m. Facilitated by Kathy Simpson, Mental Health Professional. No registration required.

Common Ground: Living with Metastatic Breast or Gynecologic Cancer
Join others coping with a diagnosis of metastatic breast or gynecologic cancer.

**Rochester (Breast Cancer Coalition)**
- **Lunch Group: 1st and 3rd Thursday of the month,**
  12:00 - 1:30 p.m. Although the discussion is topic-based, all concerns of those present will be addressed. Led by Peg DeBaise, LMFT. Lunch and beverages provided. **Registration is requested.**

Lymphedema Awareness Network
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.

**Rochester (Breast Cancer Coalition)**
- **2nd Wednesday of month,**
  5:30 - 7:00 p.m. Facilitated by Karen Miltner. No registration required.

Parent Networking Group
This discussion-based group supports parents who are coping with the unique challenges as they face their adult child’s breast or gynecologic cancer diagnosis.

**Rochester (Breast Cancer Coalition)**
- **1st Tuesday of the month,**
  5:30 - 7:00 p.m. Facilitated by Theo Munson, MPH. No registration is required.

Surviving & Thriving on Aromatase Inhibitors
Through gentle movement, journaling, and nutrition this ground-breaking program provides information, support, and empowerment for those prescribed aromatase inhibitors* who are experiencing joint pain or other side effects. (*Estrogen blocking medication prescribed for hormone receptor positive breast cancer.)

**Rochester (Breast Cancer Coalition)**
- **Next Session: Wednesdays,** September 4, 11, 18, and October 16, 5:30 - 7:30 p.m. Registrants must commit to all four sessions.

Young Survivor Soiree
A young survivor may identify with those who have faced breast or gyn cancer in the midst of a career climb, while raising children, or perhaps whose family plans have been derailed by treatment. We hold these soirees four times a year as an informal and fun way to connect with others who have walked a similar path.

**Rochester (Breast Cancer Coalition)**
- **Call or email us today to be added to our invitation list.**
A Powerful Experience, continued from page 5

findings regarding breast cancer and what their next steps are in the process to ultimately eradicate the disease. As exciting as it was to hear cutting-edge news, we were still reminded that breast cancer continues to take lives. Each plenary session began with a moment of silence for the ones who have most recently lost their lives. These were moving moments, as each of the women remembered made an unforgettable impact. They have empowered me to continue to be an advocate so we can end breast cancer.

"It was awe-inspiring to see how many survivors have channeled their time and efforts into advocacy for others affected by breast cancer."

Early in the morning on Tuesday, the last day of the summit, our group of eight headed to Capitol Hill. We had nine appointments with key Congressional Representatives from our region. Our main goal was to discuss national agenda items that are so critical in the advancement of breast cancer care and research. We ended the day by meeting with Congressman Joseph Morelle of the 25th District. Congressman Morelle has supported the Coalition in many ways through his years in the New York State Assembly, and most recently, as a member of the US House of Representatives, he has shown his continued commitment to our regional outreach efforts. We presented him with a plaque to honor him for his steadfast support of our organization. It was definitely a highlight of the day!

For me, the most powerful part of the weekend was the time I spent networking with numerous other advocates from around the country, many of whom are breast cancer survivors. It was awe-inspiring to see how many survivors have channeled their time and efforts into advocacy for others affected by breast cancer.

Upcoming issues of our publication will feature submissions from the rest of our summit attendees focusing on information gathered during workshops and plenaries, as well as national agenda items our organization supports. Stay tuned!
PROGRAM UPDATE

Young Survivor Soirees

by Jennifer Gaylord

The median age at breast cancer diagnosis is 62 for Caucasian women and 59 for African American women.¹ Median ages at diagnosis for some gynecologic cancers, including cervical, ovarian, uterine, vulvar, and vaginal, range from 51 to 66.²

But, as we all are aware, cancer does not discriminate. Every day, younger women’s worlds are rocked to the core as they receive a diagnosis of breast or gynecologic cancer. Breast cancer was not on my radar when I was diagnosed at age 37, with four children, ages seven and under, and my fifth child on the way. I was devastated. Friends, family and former co-workers reached out to me to share their mother’s, or aunt’s, or grandmother’s stories of “beating” breast cancer. Although these stories were powerful, they didn’t completely resonate with me at my stage of life. When I reached out to the Coalition sixteen years ago, I was connected with two other young women, both in active treatment, to guide me on my way. We met at parks with our young children and talked about reconstruction options, postsurgical tips, our fears surrounding treatment, and wig advice. I was not alone! I had found my tribe!

As you might expect, younger women diagnosed with cancer best relate to young survivors who are in a similar stage of life. These women are raising children, in the midst of a career climb, or considering re-entering the workforce. The Coalition supports this small but mighty group of young survivors by hosting four Young Survivor Soirees each year. These are held on Friday nights and include light fare, a fun and informative focused activity, and most importantly, lots of time to mingle, network and LAUGH! At past soirees, we have learned to belly-dance; received self-defense tips; learned about aromatherapy and essential oils; infused balsamic vinegars; and were treated to an evening of massage and meditations. One rule rings true: what happens at Young Survivor Soirees, stays at Young Survivor Soirees!

At our most recent soiree, the women created beautiful alcohol ink paintings to take home to WOW their family and friends and display in their homes. It was a great night of fun and creativity with friends!

2.) ncbi.nlm.nih.gov/pmc/articles/PMC3391942/

If you are a young survivor of breast or gynecologic cancer, please consider attending the next Young Survivor Soiree on September 13, 2019 from 6:00 to 8:00 pm! To learn more about our young survivor community, please contact me at jennifer@bccr.org or by calling (585) 473-8177.

Micky Markert, continued from page 9.

included women with gynecologic cancer,” Micky said. Her two new friends “…radiated this gratitude and peacefulness about [the Coalition] when they talked about it.” Her interest was piqued. But it wasn’t until after she retired at the end of 2018 that Micky was able to join the group at the Common Ground table. “I really am very thankful for that.”

Micky adds her warm, supportive presence to the group which, balanced with her sense of humor and spirited approach to life, has brightened the day for many of her fellow Common Ground “Peeps”, as they refer to themselves.

And we at the Coalition are thankful that Micky found us!

BreastCancerCoalition.org
 Considered by many to be the forerunner of modern medicine, the Hippocratic approach treated the patient, not just the disease, and incorporated dietary measures into the treatment of disease. In our modern world, it’s been shown that diets emphasizing a variety of fruits and vegetables, whole grains, legumes, fish and/or poultry while minimizing red and processed meats are associated with a lower risk of developing cancer of all types. And an analysis of data from the Women’s Health Initiative Study concluded that consumption of increased amounts of vegetables, fruits, and whole grains measurably reduced the risk of death from breast cancer in postmenopausal women.

Still, the most prevalent risk factors for breast cancer are being a woman and growing older. Although eating well offers a great number of health benefits, it does not guarantee cancer will never enter the picture. Furthermore, true prevention means stopping the disease before it develops. If preventing breast cancer was simply a matter of making healthy food choices, there would be far fewer people diagnosed each year.

When cancer has been diagnosed, dietary interventions alone have never been shown to affect the course of the disease. Still, the advantages of eating well include potentially minimizing the effects of treatment and facilitating healing after surgery.

But what, exactly, constitutes eating well? If you ask ten different people that question, you will likely hear ten different answers. Regardless of your dietary background, the stressful aftermath of a cancer diagnosis is not a good time to completely revamp your approach to food. Cancer treatments are hard enough your body, and radical dietary changes can compound your physical (and quite possibly your emotional) stress. Focus on balanced eating, and if you and your health care team see the need for improvement, remember that small steps add up to big change.

2. ascopost.com/News/60051; www.whi.org/about/SitePages/Dietary%20Trial.aspx
3. bccr.org/31-things-to-know/
TEN EASY WAYS TO ADD VEGETABLES AND FRUITS TO YOUR DIET

Stir fresh or FROZEN BERRIES, or BANANA slices, into your morning cereal, oatmeal, or yogurt.

Add chopped VEGETABLES to scrambled eggs.

Puree your FAVORITE FRUIT with a small amount of 100 percent fruit juice. Freeze for a refreshing sorbet or pour into popsicle molds.

Keep raw VEGGIE STICKS on hand for quick snacks, such as bell peppers, snow peas, green beans, celery, or carrots.

A colorful basket of MIXED FRUIT on your counter will always be in plain sight when you need to nosh.

A finely GRATED CARROT (or two) cooked with your favorite pasta sauce will be unnoticeable while reducing acidity for sensitive stomachs.

If you don’t like a particular food despite its health benefits, DON’T FORCE YOURSELF to eat it. For instance, if kale isn’t your cup of tea, SUBSTITUTE spinach or another leafy green.

When using the oven to make dinner, throw in a few POTATOES OR SWEET POTATOES as well.

ADD SOME FROZEN VEGETABLES during the last three minutes of cooking rice or pasta.

HERBS – DRIED AND FRESH – are really just flavorful vegetables. Use them liberally.

Parmesan Roasted (or Grilled*) Zucchini

Serve this healthy side with chicken, seafood, or as part of a vegetarian summer meal.

6 medium zucchini
Olive oil as needed
Salt and freshly ground black pepper
1 tablespoon minced garlic (about 3 cloves)
2 tablespoons minced fresh parsley leaves (or 1 teaspoon dry)
2 tablespoons julienned fresh basil leaves (or 1 teaspoon dry)
1/4 teaspoon crushed red pepper, or to taste
1/2 cup grated Parmesan cheese
3/4 cup panko (Japanese bread flakes)

Preheat the oven to 425° F.

Trim the stem end of the zucchini and cut them in half lengthwise. Scoop out a small channel of seeds with a regular teaspoon. Brush the zucchini generously all over with olive oil and place them cut side down on a sheet pan. Sprinkle with 1 teaspoon salt and roast for 12 to 15 minutes or until just tender but still firm when pierced with the tip of a small paring knife.

Meanwhile, in a medium bowl, combine the garlic, parsley, basil, Parmesan, 1 teaspoon salt, and 1/2 teaspoon pepper. Add the panko and about 3 tablespoons of oil; mix well.

Turn the roasted zucchini cut side up and spoon a heaping tablespoon of the panko mixture evenly on each zucchini. Bake for another 8 to 10 minutes, until the topping is crispy. Serve hot, warm, or at room temperature, with lemon wedges if desired.

*To grill, cook the oiled and salted zucchini, uncovered and cut side down, on an oiled grate over high heat for about 5 minutes or until tender-crisp. Flip carefully, spoon the panko mixture evenly over the top, then cover and continue grilling until the topping is golden brown in spots, about 2 to 3 minutes. Gently transfer to a serving platter.

Adapted from foodnetwork.com
P.A.L.S. Project Update

by Pat Battaglia

As I learned after my diagnosis of breast cancer in 2004, the disease is unpredictable. But it is the humanity of those affected by breast and gynecologic cancers that keeps us working so hard at the Coalition to accomplish all we do on behalf of our survivor community. Time and again in forging PALS connections, I’ve witnessed women who were (literally and figuratively) brought to their knees by a recent diagnosis to they’ve learned to stand anew while surrounded by the compassionate presence of others with shared experiences. I wouldn’t wish cancer on anyone, but these stories of resilience realized through human connection are beautiful to see.

And so I knew where to turn when I learned earlier this year, to my complete shock, my breast cancer has returned. It has, in fact, metastasized to a number of areas within my body. The women of Common Ground, our group for those living with metastatic disease, have opened their arms, extended their wisdom, listened deeply, and shared their stories along with healthy doses of laughter, which will always remain the best medicine.

I’ve always known in my head what these connections mean among those who will live with this disease for the remainder of their lives, and now I know it in my heart.

I’m tolerating my treatments well, my Coalition colleagues have been outstandingly generous and kind, and I will continue facilitating PALS connections for the foreseeable future.

I extend my profound gratitude to all my companions on this ride: my family, friends, colleagues, and Common Ground Peeps. We will see this through together – and what a ride it will be!

PALS©M PROGRAM

(585) 473-8177 x 302 pat@bccr.org

BreastCancerCoalition.org
Our buckets were overflowing on Mother’s Day ... and it had nothing to do with the weather. Not even Mother Nature could dampen our spirits, as thousands gathered at Genesee Valley Park for a meaningful morning filled with hope, inspiration and motivation.

From the photographs pinned on walkers’ backs to the beautiful faces that lined our Warrior Walkways, it was clear that this wasn’t just any old day in the park. Our community truly came together to remember those we’ve lost to breast cancer and to rally behind those who are fighting. And we couldn’t be more grateful.

NEW COURSE RECORD
Kathryn Potter, 17:15

YOUTH AMBASSADORS
Sloane Miller and Shelby Boise

TOP INDIVIDUAL FUNDRAISERS
Holly Anderson
Sloane Miller
Pam Polashenski

TOP TEAM FUNDRAISERS
Team BFF
Sloane’s Squad
Spry Warriors

OVERALL TOP FINISHERS
1. Kathryn Potter (17:15)
2. Trisha Byler (18:30)
3. Laine DiNoto (18:52)

TOP SURVIVOR FINISHERS
1. Lesley James (27:10)
2. Leslie Orr (27:27)
4. Sonia Hahn (28:47)

ONE LUCKY GUY
Anthony Guglielmo

MARK YOUR CALENDARS!
2020 Pink Ribbon Walk and Run
SUNDAY, MAY 10

Congrats Kathryn on a new course record!
Why we WALK. Why we RUN.

685 RUNNERS

1,864 WALKERS

Special thank you to our photographers:
• John Blotzer
• Daniel DeLucenay
• Lori Killian
• Lisa Gressens
Youth Ambassadors Inspire Us!

by Lauren Della Stua

This Mother’s Day we were lucky enough to have two Youth Ambassadors spread their smiles while raising awareness and funds.

Shelby Boise, a student at Spry Middle School, raised nearly $1,500 in just two days through her infectious smile. According to her teachers, she is the personification of perseverance! While not directly affected by breast cancer, she is an avid advocate for others and was excited to bring her positive voice, heartwarming smile, and never-give-up attitude to this year’s Pink Ribbon Walk & Run.

Sloane Miller, a student in Churchville-Chili, is no stranger to overcoming challenges. In 2015, she lost her mother to breast cancer. This year, she raised over $5,000 for the Coalition to honor her mother while taking a stand against bullying. Sloane’s Squad showed up in overwhelming numbers to celebrate her first ever 5K.
FROM THE REGIONAL SERVICES DIRECTOR
Miriam Steinberg

On Tuesday, March 19, nineteen advocates set out before dawn to travel to Albany in support of the Breast Cancer Coalition’s regional programming. We had survivors, supporters, Board members, staff, and regional program participants on board.

The reason for our visit was twofold:
• To thank our Senators for the diligent work they do to ensure funding for our regional programming.
• To ask for their continued support of our programs.

In addition to Senate meetings this year, we met with Assembly members. We would like to extend our appreciation and gratitude to the following elected officials and their staffs for taking the time to meet with us regarding the work we do for the Upstate New York survivor community.
• Senator Pamela Helming
• Senator Patrick Gallivan
• Senator Rich Funke
• Senator Gustavo Rivera (Chair of the Senate Health Committee)
• Senator Julia Salazar (Chair of the Senate Committee on Women’s Health)
• Assemblyman Harry Bronson
• Assemblyman Richard Gottfried (Chair of the Assembly Health Committee)
• Assemblywoman Jamie Romeo

Coalition Advocates on the trip:
• Holly Anderson
• Melisande Bianchi
• Phyllis Connelly
• Betsy Crumity
• Lauren Della Stua
• Ali Dennison
• Cyndy Harnett
• Deb Hennekey
• Peg Jacobs
• Shannon Kinkaid
• Carol Kistner
• Michelle Lindsay
• Eileen McConville
• Lori Meath
• Leni Rayburn
• Rebecca Solomon
• Kim Smith
• Miriam Steinberg
• Dennise Webster

All 19 Coalition Advocates met with Sherri Salvione, Legislative Associate in Assemblyman Richard Gottfried’s office (NYS District 75)

Coalition representatives met with staff from Senator Richard Funke’s office. (NYS 55th District)

A group of Coalition Advocates were welcomed by Senator Patrick Gallivan (NYS 59th District)

More photos on page 22
As the President/CEO of Noyes Memorial Hospital in Dansville, Amy Pollard is the personification of a woman who is cool under pressure. Raised in Bradford, Pennsylvania (near Olean, NY), she attended the University of Pittsburgh School of Nursing. A Registered Nurse who has worked in medical, surgical, maternity nursing, nursing education, and nursing administration, Amy came to Noyes in 2007 as the Chief Nursing Officer. When the President/CEO position opened, she saw it as a unique opportunity. After a rigorous process, she was appointed to the position in 2011.

Amy's nursing background served her well when she received the news on May 7, 2018 that she had been diagnosed with breast cancer. Having regularly gone for screening mammography every year, Amy considered skipping her 2018 exam because her results had always been normal and no follow-up had ever been required. Fortunately, she decided to keep the appointment and went for her mammogram on April 30. The next day, Amy received a phone call to let her know the radiologist had spotted an area of concern and would need more imaging, and possibly an ultrasound, to determine what it was.

At her follow up appointment, Amy's radiologist said there was a small architectural deformity that should probably be biopsied. Since Amy had taken the whole day off, she said, “Let’s just do it now.” That was a Friday; the results would be available on Monday. Amy was doing well and not worried that weekend because of her characteristic defense mechanism; she believed everything was fine.

The doctor told Amy that she should be receiving a call by 4:00, and as the time drew near, she began to feel nervous. Sure enough, the phone rang at 4:00; she did, indeed have breast cancer. Amy recalls how shocking it was to hear those words. Even though she is a registered nurse, she knew she didn’t know enough about what her diagnosis meant. Information was coming at her quickly, and Amy tried to make sense of it all; there were treatment decisions she needed to make. She asked a lot of questions and read everything she could about the treatment options available to her and the side effects of those treatments.

Amy learned her cancer was a subtype called invasive lobular carcinoma, it was estrogen receptor positive, and was contained in her left breast.

At this point, she took a breath to tell her husband and two grown sons the news. The three of them each dealt with it and worried about it in their own ways, but Amy said that without their love and support, she would never have gotten through it.

Another part of her after care is ... taking the Gentle Yoga class offered by the Breast Cancer Coalition ... "there is something special about being in a roomful of women who all have a shared experience."
Now it was time for the next steps: an MRI and a consultation with a surgeon. Afterwards, Amy made her surgical decision and had a lumpectomy on the morning of May 31st. That evening, she was on her way home with minimal pain. That was a Thursday and on Monday, she was back to work.

Amy made a conscious decision not to make her breast cancer treatment a main focus of her life. So she began her twenty-one rounds of radiation treatments with plans to continue working her regular hours at the hospital. This went well for about three weeks. After the third week, she started feeling the effects of the radiation, and scheduled a day or two off each week to rest and recover. This turned out to be just what she needed.

During the preliminary workup for radiation at Noyes Hospital, Amy learned that her heart is very close to her chest wall, so she was offered DIBH (Deep Inhalation Breath Hold) radiation. At that time, Noyes didn’t have the equipment and staff to do that procedure, so she came to Rochester for her radiation treatments. She was amazed that there was a linear accelerator 30 seconds from her office but she couldn’t use it. That has since changed, as Noyes now has both the equipment and a doctor trained in DIBH treatments thanks to Amy!

Now in the monitoring phase, Amy is taking the hormonal drug Arimidex for her estrogen-receptor-positive disease and goes for follow up mammograms every three months. “So far so good,” she says; she is experiencing no side effects from Arimidex and her mammography images have been clear.

Another part of her after care is something Amy has wanted to do for a while; she started taking the Gentle Yoga class offered by the Breast Cancer Coalition in Dansville. She went into it not knowing what yoga would do for her, but she wanted to do something for herself and to be in a group of survivors. It’s proved to be a great fit for her. Amy says that there is something special about being in a roomful of women who all have a shared experience. She is thoroughly enjoying it and in her words “At the end of a work week, that time was like someone pulled the plug and all my stress went away.”

Amy is back to her full schedule at the hospital, busily overseeing the services they provide and grateful for the opportunity to serve the residents in Dansville and the surrounding areas.
Rick Lynch, E-RYT

By Miriam Steinberg

Rick has been our instructor for the Mindfulness & Meditation classes in Canandaigua since 2017 and we are ever grateful for his commitment to our regional survivor community.

Rick, E-RYT 500 [Registered Yoga Teacher with over 500 hrs of training] is a yoga teacher’s teacher. He has studied, practiced and experienced yoga for over 30 years with a focus since 1985 in the tradition of B.K.S. Iyengar. In an effort to introduce our regional facilitators to the larger Coalition community, I have done a series of short ‘interviews’ with them. Read below to find out more about Rick.

What inspired you to become a Yoga/Meditation instructor?

RL: After taking my first yoga class in 1978 I realized this is what I had been searching for; mind, body, and spirit! Practicing yoga (the settling of the mind towards stillness) in the Iyengar tradition and teaching my first class in 1989 at Open Sky Yoga Center, I felt it had profoundly changed my life and I could offer and share insights for others. [Yoga is] a simple practice and road map using breath & body to find clarity and stability in life.

Can you tell us about your ‘day job’ when you’re not facilitating the Mindfulness & Meditation classes in Canandaigua for the Coalition?

RL: My day job since 1999 (I was a massage therapist before) is full time sharing yoga and meditation to the community. I have started programs and continue to teach at Thompson Hospital in Canandaigua, Wegmans Corporation employees, and many others. I’m still teaching at Open Sky and my own studio, Finger Lakes Yoga Center in Canandaigua, since 1993. I have led people to Thailand and India on yoga retreats.

How did you become involved with the Breast Cancer Coalition?

RL: Over the years, so many women in my classes have had breast cancer and I have adapted the practices for them. In 2015, I was certified as Shamatha Mindfulness Meditation teacher with David Nichtern. Yoga is mindfulness, yet I wanted more grounding in the practice. A client was working at the Coalition and they were doing wonderful things with their offerings to people. I offered my services when they were starting regional programs, and here I am!

What are some things you like to do when you have free time?

RL: In my free time, I ride my motorcycle, enjoy the beauty our area has to offer and relax in a wonderful back yard with my wife, Pamela. I also enjoy traveling to places around the world.

Is there anything else you’d like to share?

RL: I would like to encourage people that the mindfulness meditation program is a practice of peace and abiding, giving everyone the ability to be grounded in this present moment! It’s using the breath to bring the mind back home.
We will miss you, Sarge.

As I've told you before, I’m glad our paths in that shirt. Jean, may you rest in peace. Did I know it was her plan to be laid to rest if I happened to have one of last year’s t-shirts from the Pink Ribbon Walk. Little did I know it was her plan to be laid to rest in that shirt. Jean, may you rest in peace. As I’ve told you before, I’m glad our paths crossed.

We will miss you, Sarge.

Jean Rosier

By Peg DeBaise

We were saddened when our very special friend, Jean Rosier, aka “Sarge”, died on April 20th, 2019. She made a huge impression on everyone she met at the Coalition. Whether it was as a member of The Common Ground Group or in her role as a volunteer, Jean’s big heart always filled the room.

Common Ground member Jen Bergstrom wrote: “I remember Jean fondly. We were both sisters who had metastatic inflammatory breast cancer. My last memory of her was at the Common Ground retreat last fall, and centered on our love of the Red Sox. We watched the game in our Red Sox gear! Jean was a kind woman who was able to give valuable insight. She will never be forgotten.”

Kim Smith, Director of Development wrote: “Jean struggled as her disease progressed, yet she made the effort to give back where she could, often reaching out with an idea or thought about an event. She also asked if I happened to have one of last year’s t-shirts from the Pink Ribbon Walk. Little did I know it was her plan to be laid to rest in that shirt. Jean, may you rest in peace. As I’ve told you before, I’m glad our paths crossed.”

We will miss you, Sarge.

IMMUNOTHERAPY, continued from page 8.

many rounds of chemotherapy and several experimental treatments had failed. In a study at the National Cancer Institute (NCI), researchers used the ACT technique to identify and then grow in the lab billions of immune cells shown to fight Perkin’s specific cancer. These T-cells were then infused back into her body; her tumors shrunk and disappeared. Three years later, she still has no evidence of cancer. However, two other women with breast cancer received the same treatment as Perkins without benefit. The team at the NCI has treated more than 40 patients with solid tumors over the last 4 years using this highly personalized therapy; about 15% have responded in some way.5

Immunotherapy can carry adverse consequences. The most common side effects are skin reactions such as redness and blistering, and flu-like symptoms such as fever, nausea, weakness, and body aches.6 Some types of immunotherapy can have serious or life-threatening effects, a result of the immune system being overstimulated and unable to shut itself down after treatment. For example, one national CAR T-cell study was temporarily halted due to patient deaths from side effects.7

Cost is another consideration for patients. The currently approved checkpoint inhibitors each have a list price near $150,000 a year. The federal government is currently considering whether or not Medicare will cover immunotherapy. Patients with private health insurance can be denied coverage for immunotherapies, even when it’s recommended by their oncologists. But even when patients are covered by insurance, the price of these new drugs is so high that copays can be exorbitant. A patient might face a 20% or 25% copay. For example, when a drug costs $10,000 a month, it leaves patients responsible for up to $2,500 per month. The total cost of a CAR-T treatment, including the infusion, doctors’ services, and hospital stays, can easily exceed $750,000.8

The immune system is intricate, and researchers are working to discover ways to harness it in the fight against cancer. But there is a long way to go before we can be certain whether immunotherapies will play a significant role in the treatment of breast and gynecologic cancers.

References

as soon as possible. Joanna soon underwent a single mastectomy with no reconstruction; removing the tumor took priority. Shortly afterward, chemotherapy treatments began. And at last the tide began to turn for Joanna.

“After about two weeks, I could say little words,” she noted. Her progress was slow but steady. “As I got better, I started realizing they were saying, ‘You have cancer.’ And I thought, ‘What? I have cancer?’” It was difficult to come to terms with, and as Joanna made her way along an uneven road to recovery, a thought sustained her: “Just get me home.”

Finally, four months after she entered the Buffalo hospital, Joanna went home. In need of assistance with daily tasks, her home was now in Rochester with her mother. Most heartbreaking to Joanna are lost memories of her three children’s childhoods; memories she has yet to recover.

But Joanna was – and is - determined. She began attending a cancer support group in Rochester, where she befriended a frequent Brown Bag attendee who told Joanna about these weekly survivor gatherings at the Coalition. Joanna and her mother joined the group one Friday, and after that, Joanna continued attending on her own. She is now a beloved member of the Coalition’s survivor community and has mentored others newly diagnosed with breast cancer.

About a year after her surgery, Joanna opted for prophylactic removal of her remaining breast. Reducing her risk of breast cancer - and the potential return of her paraneoplastic symptoms – was foremost in her mind. This time, she decided against reconstructive surgery. “I’m really comfortable with it,” Joanna said about her surgical choice, and is considering a tattoo over her scars to celebrate her “new normal.”

In early 2018, Joanna accepted a position in the Pediatric Specialty Division at Golisano Children’s Hospital. “Going back to work was a big deal for me,” she said. At first, there were job-related memory challenges to overcome. Joanna rose to the occasion; her warmth and compassion have made her a valued member of her team. “I couldn’t do my job without having gone through everything I’ve been through,” she acknowledged.

When asked what she may have gained through her experience, Joanna responded without hesitation: “Patience. You have to give yourself time to accept what has happened, what is going to happen, and what is going to be.”

Joanna’s long road to recovery continues. “At first it was hard trying to get back, learning how to walk again, learning how to be me. And I’m still not there,” she shared.

“Don’t say ‘never’ at this point,” Stephanie chimed in.

And we all agreed: never say never.

*www.ncbi.nlm.nih.gov/pmc/articles/PMC2931619/
OUTREACH COORDINATOR

Find Your People!
Lori Meath

For many (most?) of us, the relationships we cultivate are the anchors that moor us through the crazy storms life inevitably brings.

In times of celebration, our friends multiply our joys by sharing them- it’s a collective energy that boosts the moment, blocking, at least temporarily, the cares and stresses that still exist. In times of trial and challenge we once again can turn to OUR PEOPLE.

Who are your people? Are they the same ones who share your happy moments? Sometimes, this isn’t the case, or you may shy away from leaning too much on them, anxious not to make the relationship about your difficulties. It isn’t unusual to discover that you need and enjoy different “tribes” of people for different facets of your life.

It can be a remarkable gift to find a new tribe. Your tribe can foster tremendous growth by simply being there and encouraging you to be your very-best-right-now self. They can help you to figure out what you need, and make sense of who you are in the face of challenging changes.

We have so many opportunities to find “your people” here at the Coalition; and they aren’t destined to become just your “sob sisters (or brothers)”. They will cry and laugh with you, cheer you on, listen well, and chide you when needed. Come to the Coalition and watch as something beautiful grows out of the “dirt” of tough circumstances.

LEARN MORE ABOUT OUTREACH

(585) 473-8177 x 304  lori@bccr.org

(MORE OF) OCTOBER’S OUTSTANDING SUPPORTERS

Webster’s Gold’s Gym challenged their dedicated fitness community to try out a wide variety of activities in honor of breast cancer month. For a donation directed to our Coalition, athletes could participate in a program called A Taste of Group X. Their sweat resulted in a donation of $748.

Recognizing Breast Reconstruction Awareness (BRA) Day, our friends at Vega Plastic Surgery honored our survivors with a donation of $550. For your generosity, and for the kind and expert care you give so many women in our Coalition community, thank you!

A jewel of the downtown Rochester social scene is the beautiful Center City Terrace & Lounge at the Hyatt Regency, where an evening of delicious complimentary appetizers and a signature pink drink was held on October 4, 2018. The festive evening featured some of Rochester’s most popular bartenders, brought in for some good natured competition. The lineup included Char Steak’s Josh Miles and Shelby, Mulconry’s Damien Mulconry, and Center City’s own Kalika. Thanks to all who took part in making this a successful event that raised $329 for the Coalition.

ON THE FAST TRACK

An evening of live harness racing enjoyed from the comfort of the Clubhouse, surrounded by friends and fellow supporters; a delectable buffet of hot and cold favorites

BreastCancerCoalition.org
as well as dessert; exciting Silent Auction items; free-play dollars to get you started in the newly renovated gaming and slot machine hall. It’s truly the best of a fine Summer evening, and it happened once again on August 17, 2018 when nearly 160 Coalition friends gathered at Batavia Downs for the annual Night at the Races.

Under the guidance of Batavia’s Todd Haight, Director of Live Racing and Mary Buccieri, Group Sales Manager, and with the unending support of our Board member Melisande Bianchi and husband Richard, this is a celebration that has grown each year and become one of our largest community fundraisers.

Thanks to all who joined in the fun and helped to make the event an incredible success. With YOUR help, A Night at the Races raised $12,874!

Area schools represent some of our most enthusiastic and faithful supporters. Often centered around sports teams, these young people generously give to those in need throughout their communities. We are proud and grateful for their ongoing efforts.

In recent years, we have been able to expand select programs to communities throughout the Finger Lakes region. We are grateful for the support of groups such as the Seneca Falls Football League, who donated $319.52 in support of these programs.

Coach Amy Colosimo once again shepherded her Harley/Allendale-Columbia (H/AC) volleyball team to victory in the annual Dig for Pink game on October 13. The young women and their fans held a variety of events during and leading up to the game and raised $1,400 for the Coalition this year. Community service is a vital part of the H/AC experience, and the students embrace this ideal with great enthusiasm. 2018 marked the Fifth year of HAC’s Dig for Pink event.

Spencerport High School once again hosted their October Pink in the Pool Invitational. Swimmer athletes from our area faced off as teams and also as individuals, and offered dedication ribbon cards to the crowd for a donation. The walls filled with cards that honored and remembered grandmothers, moms, teachers, and friends whose families have faced a breast cancer diagnosis. These gestures of love resulted in a wonderful donation of $1,000.

Barbara Swiecki was a woman on a mission—God’s mission. She shared her talents as a Parish Administrator throughout the Diocese of Rochester, building bridges, caring for her communities, and creating deep and lasting friendships. When Barb died from breast cancer in 2018, dozens donated to the Coalition in her memory. But nowhere did she leave as deep an impression and sense of loss than within the St. Marianne Cope Catholic cluster of parishes where she was Parish Administrator until her death.

On March 31, 2019 the St. Marianne Cope Rosary Altar Society’s Annual Tea was held in her honor. Through donations and raffles, the Society raised $1,000 in loving memory of Barb.

FC Dynamo ROC girls’s competitive Soccer teams participated in a community project to benefit the Breast Cancer Coalition of Rochester. FCDR’s mission is to educate and develop the following outstanding citizenship values through the game of competitive soccer by teaching: soccer skills, honesty, fellowship, discipline, team play, work ethic, sportsmanship, and self-reliance of youth in western NY.

Players from the GU12 and GU13 teams used fundraising money to purchase items from the Coalition’s “wish list”. Items donated ranged from the practical essentials like paper goods, to the comfort items used to fill our PALS packs. We were truly awed as box after box brimming with much-needed items was carried in!

A big THANK YOU to Umbereen Mustafa and Amy Peterson for coordinating this service project and to all the parent volunteers who made donations and helped the girls collect items.
Discovering the Latest Research

By Helene Snihur

Not all research findings get news write-ups in traditional media. Where can you go if you’re interested in the latest breast or gynecological cancer studies?

Professional journals often have searchable online versions. In addition, there are a number of online sites that publicize research findings. Members of the public can visit these sites and search for breast and gynecologic cancer topics:

- BREASTCANCER.ORG (breastcancer.org)
- National Cancer Institute (cancer.net)
- Journal of Clinical Oncology (ascopubs.org)
- Journal of Clinical Pathways (journalofclinicalpathways.com)
- PubMed (ncbi.nlm.nih.gov/pubmed)
- Cancer Therapy Advisor (cancertherapyadvisor.com)
- Contemporary OB/GYN (contemporaryobgyn.net)
- MedPage Today (medpagetoday.com)

In addition, many institutions now “push out” their own science news. You can learn what’s being done at area institutions on their own websites:

- University of Rochester (rochester.edu/research/)
- SUNY Upstate Medical University (whatsupatupstate.wordpress.com/cancer-care/blogs.upstate.edu/healthlinkonair/category/cancer/)
- Roswell Park Cancer Institute (roswellpark.org/newsroom and roswellpark.org/cancertalk)
- Cornell University (cornell.edu/research/andnews.cornell.edu/)

Like the national sites, you can easily search for breast or gynecologic cancer or other specific topics on those pages. In addition, the University of Rochester participates in a consortium that produces the online publication Futurity, spotlighting research at member institutions worldwide. You can read and sign up for the daily newsletter at www.futurity.org.

And if you’re interested in learning about the Breast Cancer Coalition of Rochester’s Research Initiative, please contact me at helene@bccr.org or (585) 473-8177.

DEVELOPMENT AND SPECIAL EVENTS

As with most of you, I have a bulletin board alongside my desk that is filled with family photos, race stickers and drawings from my not-so-little ones. Tucked in amidst it all is a lovely calligraphed envelope Terri Kerr created last fall to use at our ARTrageous Affair. As luck would have it, it wasn’t used the night of the event, but it was too beautiful to tuck away. And now, since Terri has passed, I am thankful it wasn’t. Every time I glance at it, her artwork reminds me why we do what we do.

It serves as motivation to bring our mission — our why — to the forefront of all our special events. Whether you take part as a participant, volunteer, or sponsor, we want you to know that you are making an impact in the lives of others right here in our community.

One of the ways we’re doing this is by adding Warrior Walkways to our events. Did you happen to notice them at Pink Ribbon Walk & Run? In exchange for a $100 donation to our event, we produced a beautiful four-color poster of your loved one. We’ll also be adding them to the Tee’d Off at Breast Cancer Golf Tournament and, quite possibly, the ARTrageous Affair.

For more information, please contact kim@bccr.org.

In Loving Memory Of
JOYCE NORTHROP

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Thank You, Donors!

We are truly amazed at the many ways our generous donors find to 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. Please join us in thanking the following individuals, companies, and organizations for their generous contributions between October 1, 2018 and December 31, 2018.

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We are so grateful for all the ways our community gives to the Breast Cancer Coalition. If you have questions about this list or want to donate an item please call us at (585) 473-8177.

- Books for our lending library (2016 or later) about:
  - breast cancer for women, men, children, families
  - endometrial, ovarian, cervical, fallopian, or other gynecologic cancers
  - triple negative and Her2+ breast cancer
- Burt’s Bees Lip Balm (sealed, no mint)
- Computer paper, white
- Ear plugs (individually wrapped)
- Fleece throws/blankets, lap quilts (no juvenile fabrics, please)
- Gift cards: Wegmans, Tops, DiBella’s, Staples, Target, Barnes & Noble, pizza, etc. for our PALS pack and program supplies
- JoAnn Fabric gift cards
- Journals for writing
- Lotions: Alaffia Purely Coconut lotion, Hugo & Debra Naturals All Over lotions: creamy coconut or unscented
- Note cards, notepads (bound at the top)
- Paper products: napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam products)
- Wired ribbon, pink
- Sleeping masks, lavender or unscented only
- Sponsorship of ink pens with our logo
- Tea: black pekoe, green, herbal, and flavored, in unopened boxes or tins
- Thank you cards (unopened packs)
- Velcro tape, 3/4", white and/or black
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In addition, it is intended to impart accurate, science-based information to enlighten and empower its readership.

Our inhouse 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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