Breast Cancer Coalition

VOICES of the RIBBON

Winter 2022 • Volume 23, Number 1

Serving those with breast and gynecologic cancers

FEATURE STORY

Safer Cosmetics

Immunotherapy & Cervical Cancer

Pink Ribbon Walk & Run
As we take down last year’s calendar and position the new, it may be time to ponder…are you a person who makes resolutions? Do you set goals for each new year? Where are you on your list of priorities?

I listen to a lot of stories over the course of a year. Once, I sat across from a woman who wondered how she could possibly squeeze cancer treatment into her busy life. As I quietly listened, I wondered too. She worked full time while attending classes at night. Her spouse had been diagnosed with a life-changing disease. Two of her three children were in college. Her mother had recently died and, with her siblings out of state, she felt deeply responsible for her father’s care and well-being. As she listed how she had been balancing these responsibilities, she caught herself. “I am so used to being on the back burner,” she said. “Having this diagnosis at this point in my life is like a cruel joke.”

Listening closely to her, even I was dazed. She wasn’t dramatizing her story. She wasn’t exaggerating in any way. She was tired, afraid, and overwhelmed. She was exhausted. “You aren’t on the back burner,” I carefully replied. “You aren’t even on the stove.”

The point of sharing this story is that cancer doesn’t care where you are on the trajectory of your life. It arrives when it arrives. For many, cancer never arrives. Something else arrives. We get so comfortable in chaos that we don’t even recognize how out of balance things have become. We just learn to balance… dangerously.

There are a lot of stories on these pages. Personal stories. Gritty stories. Some exemplify the struggle. Some may seem like a walk in the park. Some you might strongly identify with… while others, definitely not. Breast cancer stories. Gynecologic cancer stories. Some scary. Some less so. But one thing these stories have in common is hope, empowerment, and the realization that the storyteller isn’t alone.

Those of us at the Breast Cancer Coalition will never sugarcoat cancer. We won’t hand you your pink or teal ribbon and help you into the line. Cancer is daunting. Raw. Time-consuming. Most of us find that we need to carefully realign our priorities. We need to delegate so we can fit everything in. We need to take care of ourselves so that we can survive – and thrive – even under the worst of circumstances.

Consider this an invitation. Make time for yourself. Attend a networking group. Sign up for Gentle Yoga or Voices & Vision… or any of our offerings. Groups aren’t your thing? Join a committee. Our Advocacy and Research Committees are just two of the places to learn about cancer and cancer survivorship, and take action.


What’s your story? A simple email to info@bccc.org or a quick call to (585) 473-8177 is all it takes to get survivorship simmering. We need you. They need you too.

FROM THE DESK OF THE EXECUTIVE DIRECTOR

Holly Anderson

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Cover photo by Lisa Gresens Photography.
A PERSONAL JOURNEY: VIL O.
By Vil O.

We Walk This Path Together

“You have cancer.” Those were the three words I heard that seared into my brain along with the howling cry from our 11 year old daughter, who was listening to our conversation, during the phone call on the evening of March 18th, 2021.

About a week and a half prior, I was lying in bed for the evening and doing my breast self-examination. My left breast was normal, but I felt a lump in my right breast that I hadn’t remembered feeling before. When I asked my husband to feel it, he wanted me to make an appointment immediately. I had an upcoming mammogram and ultrasound scheduled in a few days, so I decided to wait until then. I was in denial. I told myself there was nothing to be concerned about. When my appointment came, I decided not to say anything about the lump. If they didn’t notice anything, then I was good. After the mammogram, came an ultrasound. The technician kept going over the same area where we found the lump. Images and videos were sent to the doctor. I was asked to return the following week, when I underwent a biopsy that confirmed I had breast cancer.

After hearing those three words over the phone, I was in a panic. It felt like my life was sucked out of my body; time froze in a haze of uncertainty. I was devastated. How could my breast that nurtured and fed our children be killing me from the inside out? What was I supposed to do now? I had only just turned 44. I expected to live to at least 80 before any serious medical conditions developed. But that’s not what life had in store.

The next few weeks were a whirlwind of appointments to find the right breast surgeon, plastic surgeon, and medical oncologist. Once we felt absolutely confident with the plan and the care team, my surgeries were scheduled. We opted for bilateral mastectomies with reconstructive surgery to follow. We needed that peace of mind that we were doing everything to eliminate any possibility of breast cancer developing in my left breast; my doctor agreed it was a good plan. The post-surgery pathology report showed a total of seven masses and positive surgical margins, meaning the cancer extended to the edge of the area that had been removed. But luckily, my lymph nodes were clear. My oncotype* score was extremely low, which meant my risk of recurrence was also extremely low, and we were relieved that chemotherapy would not be a part of the treatment plan.

I completed twenty-eight rounds of Image-guided Radiation Therapy (IGRT) on September 10th, 2021. It wasn’t without its own hiccups. I had a difficult time with the deep inspiration breath hold technique. It was an ebb and flow of good rounds of treatments and bad. The days that I felt anxious and panicky, my appointments lasted longer due to several attempts to hold my “just right” position so the radiation could begin. Needless to say, on those days I felt defeated and down. The technicians and doctors at the cancer center were phenomenal; they were patient and caring. Once we found the right plan to get me through the daily treatments, it was less stressful and ran smoothly. It was such a gift to ring the bell that signaled the end of treatment with my family surrounding me. The staff who cared for my well-being ultimately became family.

Continued on page 16.
Humans are infinitely creative. We build our homes and create our communities, surrounding ourselves with the things necessary for our survival along with creature comforts. From the food we eat to the clothes we wear, to the products we use for home and garden maintenance, to the cars we drive, to our electronic devices, to the personal care items we use on a daily basis, people have devised often ingenious ways to overcome obstacles large and small as we go about our daily lives.

However, our ingenuity has sometimes had unintended consequences. Many common household and personal care/cosmetic products contain chemicals that have been found to negatively impact human health. Some have been associated with increased cancer risks. Many have not been adequately tested for safety, and their effects are unknown.

In the area of personal care items and cosmetics, we come into direct contact daily with products designed to cleanse, moisturize, condition, deodorize, perfume, minimize flaws, enhance our features, add color, and more. According to the Environmental Working Group, women use an average number of twelve personal care products every day, exposing them to approximately 168 different chemical ingredients. Men use about half that amount, exposing them to about 85 chemicals.1

The inadequate nature of laws regulating ingredients in cosmetics and personal care products allows for the inclusion of known carcinogens, endocrine disruptors, and other chemicals of concern without legal consequences. Some of these chemicals, such as formaldehyde and formaldehyde-releasing preservatives, are frequently included in personal care products, while others are less common but still used.2 And the nearly ubiquitous presence of fragrance in cosmetics has raised some singularly complex concerns.

Some Unfragrant Facts

When the word “fragrance” appears on an ingredient label, it can mean any one of the thousands of proprietary blends currently used in over 95% of cosmetics and personal care products marketed in the U.S.. Individual fragrances are blended from a palette of approximately 4,000 chemicals, which are combined in varying amounts. Each blend contains between 50 and 250 ingredients.3 According to the Environmental Working Group, there is a fair amount of data supporting concerns that certain fragrance ingredients can contribute to cancer, cause reproductive harm, and trigger allergic reactions.4 There are currently no federal or state mandates for manufacturers to disclose fragrance ingredients on product labels.

Sometimes natural fragrance is listed as an ingredient on labels. Since there is no consistent, widely-accepted definition of the word “natural”, it cannot be assumed these are safe alternatives. Included in the category of natural fragrances are essential oils, which are extracted from a wide range of plants and have been associated with myriad health effects. While many of these oils have been shown to be beneficial,1 others have raised red flags. Lavender and tea tree oils, for example, have demonstrated hormonal activity and could potentially contribute to endocrine disruption. However, diluting these oils reduced these effects, prompting the suggestion that if you choose to use pure essential oils, mix them with a neutral oil first.5

Change is in the Air

In an effort to update antiquated laws, four new bills have been introduced in Congress to help make beauty and personal care products safer. Known collectively as The Safer Beauty Bill Package, this legislation includes:

- The Toxic-Free Beauty Act of

BreastCancerCoalition.org
2021, which would prohibit the use of eleven hazardous chemicals from beauty and personal care products sold in the U.S. These substances are already banned in the European Union, California, and Maryland. The bill would also ban the use of the entire class of perfluoroalkyl and polyfluoroalkyl substances (PFAS). This family of chemicals includes thousands of nonstick, stain-repellent, and waterproof compounds, some of which have been linked to serious health effects including cancer. These incredibly persistent chemicals (i.e., they do not break down in the environment) are sometimes used in makeup, sunscreen, shampoo, and shaving cream.¹

• The Cosmetic Supply Chain Transparency Act of 2021 would require upstream suppliers of cosmetic ingredients to provide brand owners with the information needed to make safer beauty and personal care products, including ingredient disclosure, toxicity and safety data, and the certificates of analysis. Currently, no federal law requires any transparency between different entities in the cosmetic industry supply chain.

• The Cosmetic Safety for Communities of Color and Professional Salon Workers Act of 2021 would create a specific set of cosmetic safety measures for women of color, professional hairstylists, and workers in nail and beauty salons. These populations bear a disproportionate burden of toxic exposures because of where they work, the products they work with, and/or the products commonly marketed to them.

• The Cosmetic Fragrance and Flavor Ingredient Right to Know Act of 2021 would require companies selling beauty or personal care products to publicly disclose the presence of fragrance and flavor ingredients. Some of these substances have been linked to negative health impacts ranging from allergic reactions to reproductive harm to increased risk of breast cancer.³

For more complete information on the Safer Beauty Bill Package, including links to the original legislation, visit the Breast Cancer Prevention Partners website: bcpp.org.

You Can Help

There is no end to the blame game, and those diagnosed with cancer are not at fault. Environmental exposures, while associated with increased cancer rates, are just one piece of a highly complex puzzle when it comes to carcinogenic processes. Still, there is power to be gained in controlling the factors that are ours to control. Seeking safer personal care and cosmetic products is one way to do this. Adding your voice to those advocating to update laws ensuring the safety of these products is another.

Write, call, or email your national representatives in the Senate and House of Representatives and ask them to support the Safer Beauty Bill Package. You can find their contact information here: usa.gov/elected-officials/.

Making Choices, Making Changes

Fortunately for consumers, there are a number of companies producing personal care products and cosmetics that meet much higher safety standards than required under current regulations. Informative databases exist that can be helpful in finding cosmetic products that are safe and effective. The following sources have been shared by members of our survivor community, who have found them to be informative and useful.

• Skin Deep, a searchable website and mobile app offered by the Environmental Working Group: ewg.org/skindeep

• The Campaign for Safe Cosmetics, offered by Breast Cancer Prevention Partners, includes a Red List of safecosmetics.org

• The California Safe Cosmetics Program Product Database is a searchable website that lists many (but not all) products available nationally: cscpsearch.cdph.ca.gov/search/publicsearch

While beauty may be in the eye of the beholder, there is more contained in many beauty products than meets the eye. However, cosmetic and personal care items can contribute to an enjoyable quality of life while offering the reassurance of safety. Informed consumers and advocates are making individual decisions and adding their voices to measures that can make a big difference for everyone.

Join Us!

Those interested in learning more about the Safer Beauty Bill Package and ways to advocate for its implementation are invited to attend the Safe Cosmetic Act Workshop with Coalition Advocates. Offered virtually by Breast Cancer Prevention Partners, this informative training opportunity is divided into two sessions:

• Wednesday, January 19, 2022 from 1:00 – 2:30pm
• Wednesday, January 26, 2022 from 1:00 – 2:30pm

For more information or to register, email info@bccr.org

1. ewg.org
2. safecosmetics.org
3. bcpp.org
4. niehs.nih.gov/health/topics/agents/essential-oils/index.cfm
LIVING LIFE &
MAKING THE MOST OF IT

By Pam Polashenski, M.D.

When Pam Polashenski shared these honest and wise words at the Coalition’s most recent Advanced Breast Cancer: Tools for the Journey seminar on October 13, 2021, she struck a resounding chord among those affected by this diagnosis throughout the Western New York region and beyond. Her words speak just as powerfully now. Pam’s wholehearted compassion for her fellow travelers on this unwelcome path and her steadfast commitment to make the kind of waves that result in meaningful change have had an enduring impact on our survivor community. She remains always in our hearts.

WHAT ARE THE GREATEST CHALLENGES OF LIVING WITH METASTATIC BREAST CANCER?

For me it’s definitely the uncertainty. Is my treatment working? If it is working, for how long? When it stops working how will my cancer progress? Is this headache a tension headache? Or has the cancer spread to my brain? For me it’s been a constant struggle not to attribute every ache and pain to cancer progression.

This uncertainty has also made it very difficult for me to plan for the future. Should I return to work knowing this treatment could stop working at any time? How can I plan a vacation when I have no idea what my health will be like or what treatment I’ll be receiving 6 months from now?

I don’t have a great solution to these challenges but I’m hoping (with fingers crossed) that after a few more months of stability these fears will become less prominent.

MY SUGGESTIONS FOR NEWLY DIAGNOSED

You can live with this diagnosis.

Yes your life will be different but I was surprised by all of the things I’ve been able to do. Since my stage IV diagnosis, I’ve ridden my bike from Rochester to Albany, summited five high peaks in the Adirondacks and competed in multiple beach volleyball matches and tournaments. Try to continue your hobbies to the best of your ability—I’ve found it’s the only way to retain some semblance of normalcy in my life.

Find a support group.

I think it’s second nature to turn towards the people who love us most when we need support. And of course I still do that. But every time I shared my worst fears or my current struggles with my family or my closest friends, I would see the look on their faces and it would break my heart. It began to feel cruel; no one can take this disease

Continued on page 14.
In September of 2021, the Coalition offered a retreat to members of our Common Ground group for those living with metastatic breast or gynecologic cancer. A number of our Common Ground “Peeps,” as we affectionately know them, shared a full day together at Shimmering Light Farm and Renewal Center in Naples, NY.

Andrea Reynolds, one of our treasured Peeps, was there and had this to say in her blog, Terminally Young (terminallyyoung.wordpress.com):

“I can’t remember a day more relaxing. We enjoyed a beautiful setting, forest-bathing, yoga with our beloved instructor Susan from the Coalition, making an herb-filled dream pillow, time and space dedicated to our angel sisters, delicious local food (including a face-sized cookie!), and best of all, connection with each other...The sunbeams and light breeze enveloping me combined with meditative reflections and a relaxed pace felt like a pause button on life to literally plug into Mother Earth and recharge. It was so life-giving and peaceful and warm fuzzy and gratifying and soul-filling...”

Common Ground is open to all in our region who are living with breast or gynecologic cancer that has spread beyond the original site to other areas within the body. Call the Coalition or see pages 12-13 for more information about this group or any of our program offerings.

Photos by Lisa Gressens.
The immune system is delicately balanced and highly complex. Researchers are continually discovering new ways to harness this intricate system to stop certain cancers in their tracks.

One important feature of the immune system is its ability to distinguish normal, healthy cells in the body from those that are “foreign.” The system is then able to respond by sending T-cells to destroy the invaders while leaving the normal cells alone. To determine which cells should be eliminated, the immune system uses immune “checkpoints.” These are molecules on certain immune cells that need to be activated or inactivated in order for an immune response to begin.1

One of these checkpoint proteins is called programmed death protein 1, known as PD-1. It keeps “killer” T-cells from attacking healthy cells by attaching to a protein called programmed death ligand-1, or PD-L1, which is found on the surface of healthy cells and certain cancer cells. When PD-1 binds to PD-L1, T-cells receive the message to leave that cell alone. Some cancer cells test positive for the presence of PD-L1, meaning they have higher than normal amounts of protein; they “overexpress” it. This serves to camouflage them from an immune attack.

Both PD-1 and PD-L1 are overexpressed in a significant percentage of cervical cancers, making them potential targets for a class of immunotherapy drugs known as PD-1/PD-L1 inhibitors.2 These therapies are making their way into the mainstream. In October 2021, the FDA granted approval to a PD-L1 inhibitor called pembrolizumab (brand name Keytruda) in combination with chemotherapy as a first-line treatment for those with persistent, recurrent, or metastatic cervical cancer. This approval is based on the results of a phase 3, multicenter, randomized, double-blind, placebo-controlled clinical trial called the KEYNOTE trial. The results showed both progression-free and overall survival to be notably longer with pembrolizumab than with placebo among study participants who had a PD-L1 combined positive score of 1 or more. This score reflects the number of PD-L1–staining cells in a tumor sample divided by the total number of viable tumor cells, multiplied by 100.

Cervical cancer is usually slow-growing and may not have symptoms. It is almost always caused by human papillomavirus (HPV) infection. Fortunately, it is easily detected at early, curable stages with regular Pap tests. While screenings and preventive vaccines have resulted in declining rates of the disease, cervical cancer continues to affect many people throughout the world. In the U.S., early estimates show nearly 14,500 new cases of invasive cervical cancer and almost 4,300 deaths from the disease in 2021.3 The role of immunotherapy in treating invasive cervical cancer is expanding with the recent approval of pembrolizumab for PD-L1 positive cases of the disease. It offers a treatment option with a lower toxicity profile than chemotherapy that has demonstrably impacted survival rates in a positive direction. Questions remain to be answered about this approach, including the length of time pembrolizumab can be safely administered, its interactions...
January is Cervical Cancer Awareness Month

Know the signs and discuss any persistent symptoms with your doctor.

Symptoms of Cervical Cancer

- Vaginal bleeding between periods or after menopause
- Menstrual bleeding that is longer than usual
- Bleeding after intercourse
- Pain during sexual intercourse
- Persistent pelvic and/or back pain
- Pain during urination
- Needing to urinate more often
- Vaginal discharge that may be heavy and have a foul odor
- Weight loss

with other therapies not included in the KEYNOTE trial, and the potential role of the treatment in PD-L1 negative cancers.2

Finally, pembrolizumab has not been shown to be curative. However, until a cure can be found, it represents a new treatment consideration for many who are currently diagnosed with cervical cancer. And it exemplifies our increasing understanding of the role the immune system can play in the development of cancer and in treating certain forms of the disease.

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1. cancer.org/treatment/treatments-and-side-effects/treatment-types/immunotherapy/immune-checkpoint-inhibitors.html
2. ncbi.nlm.nih.gov/pmc/articles/PMC6367228/
3. seer.cancer.gov/
Collaborating for Safer Consumer Products

By Kathy Guglielmi, Advocacy Chair

The longer we engage in advocacy work, the clearer it becomes that we do not and cannot work in a vacuum. The more we collaborate with and learn from others, the more effective we are. One of the facets of our mission is to collaborate with national groups to further our goal of ending breast cancer. In this article we will look at some of the organizations we follow. I encourage you to visit their websites to learn more about them and their work.

**Breast Cancer Action**'s mission is to achieve health justice for all women living with breast cancer or at risk for the disease. One of BCA’s better-known campaigns is Think Before You Pink®. Introduced in 2002, this campaign is aimed at increasing transparency and accountability of companies that raise funds for breast cancer. BCA also coined the term ‘pinkwashing’. According to their website, a pinkwasher is “A company or organization that claims to care about breast cancer by promoting a pink ribbon product, but at the same time produces, manufactures and/or sells products that are linked to the disease.” As advocates, we educate ourselves about pinkwashing and encourage others to look at the details of a fundraising campaign before deciding whether to participate.

**Breast Cancer Prevention Partners**, formerly Breast Cancer Fund, works to prevent breast cancer by eliminating our exposure to toxic chemicals and radiation. BCPP provides tips for helping to reduce your risks for exposures to substances that are linked to breast cancer. Tips cover topics such as cleaning products, personal care products, food packaging and workplace health. Recently Coalition advocates met with BCPP to learn more about their Campaign for Safer Cosmetics. In October, the Safer Beauty Bill Package, consisting of four bills, was introduced in Congress. Advocates will continue to follow the progress of this legislation as it moves forward.

The **Environmental Working Group** is another organization followed by the committee. The environment and its effects on breast cancer are of primary interest to our members. EWG’s mission is to empower individuals through research to make informed choices and live a healthy life in a healthy environment.

EWG provides consumer guides to various products. Perhaps best known is EWG’s annual Dirty Dozen/Clean Fifteen lists, which are a shopper’s guide to pesticides in produce. Among its other offerings, EWG produces a tap water database, a cosmetic database called Skin Deep®, and a guide to healthy cleaning products. These resources are available to help make decisions about what products to use.

In addition to helping us make healthy choices, these organizations provide information used by the Advocacy Committee to help determine which legislation to investigate and support. If this is something that interests you, please contact the Coalition or any member of the Advocacy Committee for more information.

- [Breast Cancer Action – bcaction.org](bcaction.org)
- [Breast Cancer Prevention Partners – bcpp.org](bcpp.org)
- [Environmental Working Group – ewg.org](ewg.org)
Applying mRNA Technology to Develop a Breast Cancer Vaccine

By Silvia Gambacorta-Hoffman

In the past, vaccines have taken years and sometime decades to develop. Recently, the success and the speed of execution of mRNA COVID vaccines has opened many doors and possibilities.

I am particularly interested in the ongoing efforts toward the development of an mRNA vaccine for breast cancer, a topic introduced during the 2021 National Breast Cancer Coalition* Advocate Leadership Summit. This workshop was presented by Nathaniel Wang PhD, Chief Executive Officer and Chief Scientific Officer of Replicate Bioscience.

Messenger RNA (mRNA) technology has been around for decades and the recent COVID vaccines were developed using this innovation. Self-replicating RNA was utilized by the Imperial College of London to produce one of these vaccines. This technology is derived from viruses. All the genes responsible for the viral shell are taken out and replaced with genes that have therapeutic effects. These vaccines are fully synthetic and, because they mimic a viral infection, they replicate quickly, thereby achieving a superior immunological response.

Ninety percent of cancer deaths are attributed to drug resistance, which develops over time. Injecting patients with an mRNA breast cancer vaccine before the drugs fail would give the immune system a chance to ramp up production of T-cells. These cells recognize mutations within our body, destroying the affected cells and thereby stopping the disease from progressing to more advanced stages. The mRNA vaccine can also intercept and prevent transition events that lead to breast cancer in the first place.

The mRNA vaccine for Breast Cancer was designed with the following requirements:

- To be usable by all breast cancer patients
- To be applicable to all breast cancer mutations
- To be very low in cost ($300 for a course of treatment)

The vaccine is manufactured using a completely synthetic process that begins by combining different enzymes in an aqueous solution of salt and mRNA components. After an eight-hour reaction and a sterile filtration, the active pharmaceutical ingredients are produced. It’s a rapid process with a high yield (99.5% pure RNA, 5-6 mg/mL for each reaction).

The breast cancer vaccine is safe, cost accessible, and easy to administer. In addition, it is well tolerated and can be combined with other therapies thanks to its low toxicity profile. With a per-dose price tag between $30 and $100, the low cost is another attractive component of this technology. Similar to the COVID vaccine, the breast cancer vaccine is easy to dispense through injection into the patient’s arm.

The side effects are comparable to those experienced with the COVID vaccine: fatigue, chills, and low grade fever for the first 36 - 48 hours, and no long-term side effects.

Phase I clinical trials, which use a small number of patients, have already shown some promising results. One study showed that the patients who received the vaccine had active T-cells that were able to kill cancer, as well as develop “T-cell memory”. In other words, the effects are long-lasting. In fact, one of the functions of T-cells is to patrol the body looking for future cells with mutations and helping to kill them. The vaccinated patients showed improvement in late stage cancers as well as those with early stage breast cancer.

I feel it is important to invest in this new technology and in research with the goal of eradicating breast cancer. Hopefully, breast cancer will one day be, like smallpox, an extremely rare disease.

*The Breast Cancer Coalition of Rochester is an independent, local organization unaffiliated with any national group, including the National Breast Cancer Coalition. Some of our goals are similar to those of NBCC and our Advocates attend their annual Advocate Leadership Summit; however, the similarities in the names are coincidental.
Healing Arts programming is offered in block series of 4 - 6 weeks throughout the year. Call or email us today if you are interested in registering for these beneficial offerings.

**Gentle Yoga**
Gentle Yoga includes breathing exercises, restorative yoga postures, and mindfulness exercises. Yoga activates a relaxation response and can help relieve feelings of anxiety. The goal of the class is to relax, be mindful, and to improve range of motion and flexibility. Classes are 75 minutes long. Participants benefit most when they are present for the full duration of each class.

*Offered throughout the year on:*
- Monday mornings
- Monday afternoons
- Monday evenings
- Tuesday mornings
- Tuesday afternoons
- Wednesday mornings
- Saturday mornings
- Sunday mornings

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

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

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

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

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

*Offered throughout the year on:*
- Saturday mornings

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

*Offered throughout the year.*

Please visit www.breastcancercoalition.org to view our program calendar for a current listing of available classes. Call us at (585) 473-8177 or email us at info@BreastCancerCoalition.org if you have any questions, want to enroll in a class, or want to be added to our mailing list.
### GIVE AND GET SUPPORT

Our Support/Networking Groups can be an important resource for people diagnosed with breast or gynecologic cancer. Some support groups are led by professionals. Others are more informal and discussion based.

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Description</th>
<th>Virtual/In Person Options</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Breast &amp; GYN Cancer Group</strong></td>
<td>Gather, support, network, and discuss your journey with others diagnosed with breast or gynecologic cancer. Professionally facilitated.</td>
<td>VIRTUAL Discussion Groups: • 2nd and 4th Mondays at 5:30pm • 2nd and 4th Tuesdays at 5:30pm IN PERSON Discussion Group: • 1st and 3rd Thursdays at 5:30</td>
</tr>
<tr>
<td><strong>Newly Diagnosed or In Active Treatment Networking Group</strong></td>
<td>A professionally facilitated group to discuss your experience/questions.</td>
<td>VIRTUAL Discussion Group: • 1st and 3rd Wednesdays at 10:00am VIRTUAL links online.</td>
</tr>
<tr>
<td><strong>Friends, Family, and Caregivers Networking Group</strong></td>
<td>Find camaraderie with others supporting a loved one diagnosed with breast or gynecologic cancer.</td>
<td>IN PERSON: 1st Tuesdays at 5:30pm VIRTUAL: 3rd Tuesdays at 5:30pm VIRTUAL links online.</td>
</tr>
<tr>
<td><strong>Brown Bag Discussion Group</strong></td>
<td>A weekly discussion group over lunch!</td>
<td>VIRTUAL Discussion Group: • 1st and 3rd Fridays at 12:00noon IN PERSON Lunch Group: • 2nd and 4th Fridays at 12:00noon. Bring your lunch; dessert is on us!</td>
</tr>
<tr>
<td><strong>Common Ground: Living with Metastatic Breast or Gynecologic Cancer</strong></td>
<td>Join others coping with a diagnosis of metastatic breast or gynecologic cancer. Professionally facilitated.</td>
<td>Register with <a href="mailto:Christina@bccr.org">Christina@bccr.org</a>. IN PERSON Lunch: • 1st and 3rd Thursdays at 12:00noon</td>
</tr>
<tr>
<td><strong>Common Ground Partners: Partners of Metastatic Individuals</strong></td>
<td>Professionally facilitated group.</td>
<td>Register with <a href="mailto:Christina@bccr.org">Christina@bccr.org</a>. IN PERSON Discussion Group: • 3rd Tuesdays at 5:30</td>
</tr>
<tr>
<td><strong>Young Survivor Gatherings</strong></td>
<td>An informal and fun way to connect with others who walk a similar path. Call or email to be added to our invitation list.</td>
<td></td>
</tr>
<tr>
<td><strong>Book Club</strong></td>
<td>Join our monthly Book Club. January 27 at 6:00pm: Braiding Sweetgrass, by Robin Wall Kimmerer; facilitated by Ren VanMeenen VIRTUAL links online.</td>
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<tr>
<td><strong>Lymphedema Networking Group</strong></td>
<td>For those living with lymphedema and caregivers, therapists, medical personnel, and those at risk for developing lymphedema. Professionally facilitated.</td>
<td>VIRTUAL links online.</td>
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### LEARN

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

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<th>Event Name</th>
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<tr>
<td><strong>Evening Seminar</strong></td>
<td>Evening Educational Seminars bring information and education to our survivors and community friends. VIRTUAL; register online. January 26: &quot;Interruption Fasting, Keto Diet, Supplements in Correlation to Cancer Treatment and Survivorship&quot; Presenter: Lesley James February 23: &quot;Relationships and Cancer – Survey questions open-ended: What would have been helpful to know as a caregiver?” Panel of caregivers; moderators Theo and Steve Munson</td>
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<tr>
<td><strong>Surviving &amp; Thriving on Aromatase Inhibitors</strong></td>
<td>Through increased movement, stretching exercises, and nutrition, this program provides information, support, and empowerment for those prescribed aromatase inhibitors who are experiencing joint pain or other side effects. VIRTUAL; contact <a href="mailto:Christina@bccr.org">Christina@bccr.org</a> to register. Wednesdays with series beginning in January, March, May, and September 2022, Registrants must commit to all four sessions in a series. The January series is supported with funds from the State of New York Department of Health.</td>
</tr>
<tr>
<td><strong>Book Club</strong></td>
<td>Join our monthly Book Club. January 27 at 6:00pm: Braiding Sweetgrass, by Robin Wall Kimmerer; facilitated by Ren VanMeenen VIRTUAL links online.</td>
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**BreastCancerCoalition.org**

Winter 2022 • 13
As the new year begins, I celebrate the wonderful programs available at the Coalition to those diagnosed with breast or gynecologic cancer. In September of 2021, we hosted the first annual Gynecologic Cancer Seminar. In a format similar to our Advanced Breast Cancer Seminar: Tools for the Journey (which turned 18 this year!), three area providers presented on new and emerging trends, updates in treatment, and sexuality & intimacy: moving beyond cancer. Two gynecologic cancer survivors shared their personal journeys, and a Q&A session engaged our virtual participants. In October, we introduced a Newly Diagnosed / In Active Treatment Discussion Group. This group meets virtually on the first and third Wednesdays of the month at 10:00AM, and is facilitated by Vicki Nugent, Nurse Practitioner. The participants of this group offer support to one another while Vicki helps answer questions that present early in diagnosis or as treatment ensues. Those who are newly diagnosed, in active treatment (chemotherapy, radiation, aromatase inhibitors, hormonal medication), and those anticipating or recovering from surgery are welcome.

I look forward to new programs that will be offered in 2022, including a networking group for Friends, Family and Caregivers of those diagnosed with breast or gynecologic cancer. This group will meet twice monthly; once in person and once virtually on Tuesday evenings at 5:30pm. Kathy Simpson, a beloved facilitator, will help navigate discussions on how we can support our loved ones as they go through treatment.

We welcome several new facilitators to our talented team: Martha Neubert will facilitate the Thursday Evening Networking Group, held the first and third Thursday evenings in person at 5:30; Vicki Nugent joins us with the Newly Diagnosed / In Active Treatment Group; and LANROC (Lymphedema Awareness Network of Rochester) will transition to Lymphedema Networking Group as we say goodbye to the adored Karen Miltner and welcome Melissa Clark as the group’s facilitator.

We thank all the participants who provide feedback on program surveys for the ideas that generate new programs and help morph others. Our program staff pores over the comments as we strive to provide that which is most meaningful to our survivors.

I extend a heartfelt thank you to those who help support the Coalition financially. Your gifts allow us to offer these amazing programs free of charge to those in 24 counties in Western and Central New York.

Common Ground, continued from page 7

from me, so why share these feelings when all it does is cause pain to the people I love? But keeping it bottled up didn’t help me, nor was it realistic. Fortunately, we have the Breast Cancer Coalition. Joining support groups has been incredibly helpful to me. These are women who feel the same way I feel and are dealing with the same struggles. When we share with each other (and believe me, we share) we get back helpful advice or at least camaraderie without feeling as if we’re inflicting pain.

**Talk to your oncologist about genomic testing of your cancer.**

Or if your cancer is not amenable to biopsy, have the test performed on a blood sample. There are many clinical trials testing targeted chemotherapies to specific cancer mutations. Hopefully this will never be necessary for you. I know many people with metastatic breast cancer who have been stable for years on first or second line therapy. But having that information may help you down the road.

**Don’t be afraid to get a second opinion.**

I have received superb recommendations from my breast cancer specialist at Dana Farber Cancer Institute. She works closely with my local oncologist whenever decisions need to be made regarding change in therapy.

Continued on next page.

**Lymphedema Networking Group** as we say goodbye to the adored Karen Miltner and welcome Melissa Clark as the group’s facilitator.

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Continued on next page.
The Research Committee has continued to meet via Zoom, and we have hosted two virtual lab visits.

In September, we visited the lab of Toa Dai. A third-year PhD student at Roswell Park Comprehensive Cancer Institute and a 2021 grant recipient, Tao’s study is focused on the function of PFKFB4 (6-phosphofructo-2-kinase/fructose-2,6-bisphosphatase 4). This is one of the enzymes that regulates glucose metabolism. It also drives cancer progression and metastasis in patients with triple negative breast cancer (TNBC). His research has two aims: first, to determine the function, mechanism and physiological impact of this enzyme; and second, to uncover the effect of PFKFB4 on CD8+ T cells, which are important for killing cancerous cells. He believes that PFKFB4 plays a significant role in compromising the response of CD8+ T cells.

Tao indicated that his research is progressing well, although one challenge he encountered is that there are not many drugs on the market that can suppress PFKFB4 activity. The presentation was followed by a brief Q&A session, a virtual tour of his laboratory, and an introduction of his colleagues and mentor.

At the end of October, Dr. Sagar Shah updated Research Committee members on the progress of his work, then conducted a virtual lab visit. Dr. Shah, another 2020-2021 grant recipient, is a postdoctoral associate in the Department of Molecular Biology and Genetics at Cornell University. His study is focused on identifying and characterizing enhancers, which are associated with activated oncogenes (mutated genes that contribute to the development of cancer). The aim of this research is to develop new methods to uncover enhancer mutations that make TNBC more aggressive and negatively impact responses to treatment.

Our 2021 grant recipients are furthering the understanding of basic cellular process that can contribute to the initiation of cancer.

Advocate for yourself.

If you are having difficulty getting your questions answered or action taken reach out to people who can help you. I have found the Breast Cancer Coalition to be a wealth of information, as well as my fellow stage IV thrivers.

WHAT HELPS ME COPE?

LIVING IN THE MOMENT.

When I was first diagnosed with stage IV cancer, I was devastated. That first night I was wide awake at 4 am in complete panic mode. All I could think about was my death and dying. Leaving behind my family. Letting go of my ultimate goals of growing old with my husband, seeing my daughters thrive in their careers and relationships and being there for them during their struggles. I wanted grandchildren, and I wanted them to know me. In an effort to try to combat my anxiety, I put some headphones on and downloaded a meditation app for cancer patients. The focus of this particular meditation exercise was to live in the moment, stay in the present. This idea seems cliché and obvious but at the time it was very powerful. The gist was “you woke up breathing, you’re alive today, focus on the present”. That’s become the mantra with which I literally start every day: “I woke up breathing. I feel good. I’m going to have a great day”. And whenever my mind starts to move towards that unknowable, scary future, I do my best to bring it back to focus on today.

And finally, I’ve learned how to live.

Obviously, cancer is ever present in my life. I take chemotherapy pills twice a day. I plan my activities around oncology visits, CT scans, blood draws. The reality is I will always have cancer and I will always have cancer treatments. My hope is to live with cancer well into old age. And while I’m at it I am doing my best to focus more on the living and less on the cancer.

There’s a saying from Confucius that states, “We have two lives. And the second begins when we realize we only have one.” I am living that second life and making the most of it. I wish you all the same.
I also reached out to a wonderful friend and photographer, Courtney Maltman of Momentologie Photography, to help me through. I didn’t know how else to “journal” my experience. She has documented my journey from the beginning and captured personal moments of our lives since the diagnosis. There are parts I missed because I was so deep in the cancer hole, I lost touch with the here and now. I am eternally thankful for her friendship, love, and gift for allowing me to “see” what my eyes failed to capture. A picture is truly worth a thousand words. This process has been extremely therapeutic for us. We can see how far I’ve come in such a short amount of time and know that there is nothing I wouldn’t do to grow old with my loves. I highly recommend it!

I'm still in shock to this day that I'm a breast cancer survivor. In the midst of the rush to see doctors and to collect all the information our brains could absorb, our daughter had her 12th birthday. That day was beyond heartache. The reality of mortality slapped me in the face, and I felt gutted. Could this be our last family birthday celebration I'll ever enjoy? I had no idea. But I was willing to do whatever it took to see my family grow old together. I started counseling again shortly after my diagnosis and have had a plethora of ups and downs since that time. It's truly a traumatic experience to go through. I don’t believe anyone has ever said “Yay! I have cancer!” It can take a toll on your mental, emotional and physical wellbeing. Counseling is not always openly discussed, but it's OK to just be OK and seek support.

As you may have noticed, I use the words “we,” “our,” “us” often. That's because we've been completely open and transparent about OUR cancer journey right from the beginning with our friends and family near and far, and especially with our children. We needed them - and everyone around us - to know it is not a taboo subject to bring up or ask questions about, no matter how personal it is. Cancer is not, and never should be a forbidden topic. The more we talk, the more we learn, the more we're able to help and support one another through this journey. We walk this path together; I, as a survivor, my family and friends as our support system. Our paths are parallel, each with its different twists and turns. Sometimes I take the lead to let loved ones know what I need. Sometimes I’m alongside everyone because I don’t have the strength to push forward alone and need to be carried. And sometimes I fall behind to allow others to lead the way so I don’t have to be “the one” to make all the decisions for us and help with my mental, emotional and physical health. This is OUR journey together, and we are truly grateful for the love and strength pulling us through.

After my diagnosis, Karen V., a fellow survivor sister, was the first person I reached out to for help. She was also the only breast cancer survivor I personally knew. Through her openness, she referred me to the Coalition. Holly Anderson provided so much love and support in the hour that we spoke. I was connected with a PALS mentor, Annie M., who’s also been my rock and go-to for emotional support. She was a big part of helping put together the best care team we could ever have and we are so thankful for her. I began to make wonderful connections within the support groups and attended informational zoom seminars offered through the Coalition. We've learned so much in such a short amount of time, and there's still so much more to learn. I can’t believe I’ve only just hit the six-month mark in September since the diagnosis. I’m now looking forward to being part of the PALS program as a mentor and hope to be more involved with the Coalition, supporting other survivors as much as they’ve supported me. The urge and NEED to pay it forward have never been stronger. I am ready for the calling and ready to support, love, and cherish fellow survivors as we have been gifted.

*OncotypeDX is a genomic test conducted on certain breast cancer tumors that assigns a “recurrence score”, which can help guide treatment decisions.
Join Us in the fight against breast and gyn cancer!
Mother’s Day Weekend • SATURDAY, MAY 7 • Genesee Valley Park!

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

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

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

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**PINK RIBBON WALK**
Everybody Welcome!
9:00am start

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

**EVENT REGISTRATION:**
- Pink Ribbon Walk Registration ($25)
- Pink Ribbon Run Registration ($30)

**VIRTUAL REGISTRATION:**
- Pink Ribbon Walk Registration ($25)
- Pink Ribbon Run Registration ($30)
- Additional Donation of $ ________

**TOTAL AMOUNT ENCLOSED:** $ ____________

Thank you for supporting our mission!
Breast Cancer
COALITION

PARTICIPANT NAME: ____________________________________________

TEAM NAME: __________________________________________________

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REGISTER AND DONATE
ONLINE TODAY!

https://runsignup.com/Race/NY/Rochester/PinkRibbonWalkandRun

ALL PARTICIPANTS MUST READ & AGREE TO THE FOLLOWING:
I certify that I am physically fit and have not been advised otherwise by a qualified healthcare provider. I acknowledge that walking and running are potentially hazardous activities. I assume all risks associated with walking/running in this event. These risks include, but are not limited to, those caused by terrain, water, weather, actions of participants, spectators and/or producers of this event and lack of hydration. I hereby assume the risks of participating in the Pink Ribbon Run Walk & Run. I hereby take action for myself, my executors, administrators, heirs and next of kin, successors and assigns as follows: a) release and discharge from any and all liability, damage, property theft or actions of any participation in this event or my traveling to this event, the Breast Cancer Coalition of Rochester, all sponsors, event directors, and all municipalities in which the event is conducted; b) indemnify and hold harmless the persons or entities mentioned in this paragraph from any and all liabilities or claims made by other individuals or entities as a result of my actions during the Pink Ribbon Walk & Run and in any other activities connected with it in which I may participate. I give full permission for use of my name and photograph in connection with this event. I understand that all entry fees are non-refundable.

By signing below, I agree to the waiver and that I am 18 or older, or that I have the authority to register this participant and agree to the waiver for them.

Printed Name: _____________________________  Signature: _____________________________

BreastCancerCoalition.org
By Pat Battaglia

Mentor Training

The most important feature of the PALS program and the reason for its success is the presence of a long-standing, dedicated, carefully trained group of peer mentors. These are breast and gynecologic cancers who make a commitment to reach out to those who are more recently diagnosed. Every year, we hold an intensive, day-long training session for new mentors entering the program. The challenges of COVID made 2021 an exceptional year in many ways, including the fact that we were unable to schedule a mentor training. So, in the face of ongoing pandemic concerns, our 2022 training will be held virtually on two consecutive Saturday mornings in late January and early February.

The basic qualifications for our PALS mentors include having a personal diagnosis of breast or gynecologic cancer and a basic understanding of their particular form or subtype of the disease. (Being a cancer “expert” is not required!) Mentors need to know the reasons certain treatments were recommended for them and to be at peace with their treatment decisions. A high degree of compassion and empathy, as well as solid listening and communication skills, are absolutely necessary. So is the ability to follow through on commitments. Last but not least, unconditional respect for an individual’s right to privacy is essential.

Mentors do not make medical recommendations or question the validity of medical advice. Rather, they empower informed decision-making through active listening, brainstorming solutions to dilemmas, sharing the relevant parts of their own experiences, and offering a level of empathy that only one who has “been there” can provide.

Whether you might be considering joining our group of mentors, or you could use the support of someone who faced a diagnosis similar to your own, or you just want more information about PALS, email info@bccr.org.

We’re here for you!

PALS Update

By Pat Battaglia, Associate Program Director

If you have been a reader of our newsletter in recent years, you have enjoyed the wonderful work of the talented and compassionate photographer, Lisa Gresens. Since 2015, Lisa has donated her services to the Coalition, lending her remarkable photographer’s eye and capturing the action at many of our events, including the Pink Ribbon Walk and Run (with her daughter Becca lending a hand), our Tee’d Off at Breast Cancer Golf Tournament, and the ARTrageous Affair (now ACTober), among many others. Lisa’s photos have found their way into our newsletter coverage of events and other occasions. The survivor portraits for our 2019 Lives Touched Lived Changed initiative, in which six high-quality images are donated by a local photographer to add to the powerful collection on display in our great gathering room, are Lisa’s work. Most recently, she was on hand during the soul-nurturing retreat for members of our Common Ground group for those living with metastatic breast or gynecologic cancer. Some of her photos from that day can be seen on page 7 of this issue.

Lisa’s images reflect the spirit of each individual and every occasion she photographs. She was connected with our organization thanks to her friend, Ali Dennison, our treasured Program Assistant. Ali says, “Lisa is an amazing photographer and a wonderful neighbor and friend. She is always eager to give back and donates so much of her time to the community. We are truly blessed to have her sharing her talents with the Coalition. Being able to look back on so many special events and relive the memories through her pictures is priceless.”

In addition to her talents, Lisa connects easily and warmly with others, and has found many new friends at the Coalition. She is indeed a priceless asset to our organization and a beloved presence in our survivor community.

Thank you Lisa!

View Lisa’s work, including her photographic contributions to the Coalition, here: lisagresens.smugmug.com

BreastCancerCoalition.org
ACTober

By Carly Euler

Breast Cancer Awareness Month has come and gone, and as usual, the crisp fall air was filled with excitement and support from all the friends of the Coalition. Local businesses, sports teams, and community members committed to raising funds to support survivors in our area – they took action.

This spirit is exactly why we seized the opportunity to rebrand our annual fall event - now titled ACTober – because awareness has never been enough.

We kicked off ACTober with a fun, short virtual program on October 1 featuring members of the Board of Directors, our presenting sponsor, reflections from survivors, and a special message from our Executive Director, Holly Anderson. The night honored our 2021 award winners: Congressman John Katko, recipient of the Harriet Susskind-Rosenblum Advocate’s Spirit award, and Dr. Kristin A. Skinner, who received the Laurie Pask Heart & Hands Award. 13WHAM anchor Ginny Ryan served as the emcee, sending a virtual “cheers” to all who tuned in.

The event was celebrated from the comfort of people’s homes, with the option to purchase delicious dinners from Root Catering and/or a “Party Box,” which contained all the things needed to feel like you were at a fancy event – even if you were wearing pajamas! October 1st also marked the launch of our 20-day online auction in honor of the 20th anniversary of our autumn gala event. With nearly 250 items donated from local artists and businesses, there was truly something for everyone!

The night concluded with an invitation to check out our “After Party,” which allowed viewers to keep the party going and learn all the ways they could take ACTion throughout the month.

Thanks to our sponsors, donors, and auction participants, more than $125,000 was raised! We are so grateful for everyone’s support. We’d also like to give a very special thank you to Flynn for their gorgeous artwork and the incredibly produced show.

Did you miss the program? That’s ok! You can watch it anytime on the Breast Cancer Coalition’s YouTube channel.
PRESENTED BY
Van Bortel

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Generation Capital Management, LLC
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Martin Nott Photography
Ryan’s Wine & Spirits
Roswell Park Comprehensive Cancer Center

UR Medicine Plastic Surgery

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Holly & Tom Anderson
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Nancy Gadziala, MD & John Looney, MD
Melinda Goldberg & Ron Turk
Kathy & Don Guglielmi
Highland Hospital
RDG+ Partners

WE ARE SO GRATEFUL FOR OUR SPONSORS!

Our path is clear.

because awareness has never been enough.
Be kind to yourself.
Treat yourself as you would any other cherished person in your life. What would you say to a good friend or family member who was facing a cancer diagnosis? What would you do for them? Say and do the same for yourself.

Focus on the things that are yours to control.
Your diagnosis isn’t your fault. But all that comes in its aftermath can result in a sense of loss of control. When that happens, take a deep breath. Then focus on the first step you need to take – just a single step. Once it’s taken, the next step you need to take will become clearer. And so on.

Learn as much as you need to know about your cancer and its treatment.
Your health care team and fellow survivors can be helpful in finding the resources and information you need to take that next step forward.

Ask for help.
Managing multiple medical appointments while making treatment decisions takes a great deal of time and emotional resources. Family and friends can help with day-to-day tasks such as meals, cleaning, and running errands. Connecting with other survivors can help you feel more grounded and less alone. And consider consulting a mental health professional if needed. Caring for your emotional health is as important as attending to your physical health.
Engage in self-care.
Make efforts to eat well, exercise, and get enough sleep. Many people find stress release in practices such as yoga and meditation. Social support is important, so reach out to family, friends, and to us at the Coalition. In addition to providing a community of survivors, our support, education, and healing arts offerings are built on a solid foundation of survivor feedback.

Limit your exposure to the internet.
While online resources can be helpful and informative, they can also be sources of stress, and even fear. Compulsively checking the internet is seldom, if ever, what you really need to do at any given moment.

Asian Pear Salad with Orange Ginger Dressing*
*This dressing is so delicious!

ASIAN PEAR SALAD
- 1 large orange cut into segments and peel removed (8-10 segments)
- 1 ¼ cups red bell pepper, sliced thin or minced
- 1 cup carrots, shredded (fresh peeled is worth it)
- 1 Asian Pear cut into thin slices (or any ripe pear)
- ½ cup edamame, shelled and cooked
- 1 ½ cups red cabbage, thinly sliced/shaved
- 1 cup seedless cucumber, cut in half, thinly sliced

ORANGE GINGER DRESSING
- 1 t. shallots, minced
- 1 t. orange zest
- ¼ cup orange juice, freshly squeezed
- 1 t. ginger, finely grated
- 2 T. rice vinegar
- 2 t. cilantro, finely chopped
- ¼ cup grapeseed oil
- Black pepper to taste
- Salt to taste

INSTRUCTIONS
- Combine all salad ingredients in a large bowl.
- Whisk together all dressing ingredients in a medium-size bowl gradually adding the oil until dressing is slightly thickened.
- Add the desired amount of dressing to the salad and gently combine. Add more salt and pepper as needed.
- Enjoy immediately once dressing is added.

Created by Holly Anderson
Friends Remembered

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

Carol Buddendeck  Patricia Hettrich  Leo Elden Ostberg
Jennifer Goyette  Lane Holding  Pamela Polashenski, M.D.
Doris Ann Green (Woodard)  Mary Keenan  Mary Rappenecker
Elmer (Al) Henretta  Philip Lapani  Mackenzie Sanford

BOOK REVIEW

My Terminal Life by Amy Schnitzler

By Pat Battaglia

“To be a warrior is to learn to be genuine in every moment of your life.”

– Chogyam Trungpa

In the spring of 2016, 26-year-old Amy Schnitzler was simultaneously grieving the recent passing of her beloved grandmother and celebrating her acceptance into graduate school. An aspiring opera singer, she was ready to spread her wings and fly. However, it soon became clear that life had other plans when Amy received an untimely diagnosis of breast cancer.

She turned to blogging to process her complex emotions. In words that are eloquent, unflinchingly honest, occasionally humorous, and always genuine, Amy detailed each step forward and every setback on her trek into unfamiliar territory.

It was through her writing that I first encountered this authentic warrior spirit. Amy had turned to the Coalition with her mom, Judy, at her side, and together they attended a BC101 session. As our support staff discussed her situation and how best we could serve her needs, her blog was mentioned and, intrigued, I looked it up. I found her thoughtful, candid, profoundly human, and wise beyond her years; qualities that were affirmed when we met in person a short time afterward.

As she encountered obstacle after discouraging obstacle, Amy chronicled it all in her blog. Through surgery, recovery, treatment decisions, and stepping outside the realm of conventional therapies into the role of diet, exercise, supplements, and medical marijuana, she left no stone unturned in her quest for wellness. It became her dream to see her blog gathered into book form, and she began to work toward that end. Sadly, Amy was not able to see her dream realized; her life ended in late 2019.

Judy continued where Amy left off and saw the book through to publication. It is now available in book stores and through online outlets, and a portion of the profits are donated to the Coalition.

Even as I followed Amy’s blog, we forged a warm personal connection through our interactions at the Coalition. Our connection deepened in early 2019, when Amy was one of the first people to reach out to me after my own diagnosis of metastatic breast cancer. So I cannot say this is an unbiased review. I can say that Amy delved deep into her inner experiences and intense personal struggles as she forged a way uniquely her own. Her book is an illuminating read for metastatic cancer patients and their families, friends, health care providers, and anyone wishing to understand the impact of this disease from one whose life was blown off course again and again, but who (with a few epithets thrown in for good measure) picked herself up, dusted herself off, and set about forging a new path.

Ultimately, My Terminal Life is a life-affirming testimonial to the power an individual can exert over impossible circumstances. Cancer did not defeat this warrior.
As we continue to welcome 2022, we at the Coalition are planning our first ‘in-person’ walk since 2019! We look forward to seeing all of you in May at Genesee Valley Park for the 21st annual Pink Ribbon Walk & Run!

This year’s event will be a hybrid offering. Those who wish to gather together to walk or run on Mother’s Day Weekend are welcome to join family, friends, fellow survivors, volunteers and Coalition staff on (Saturday, May 7) at the park. If you are unable to attend that day, still feel a bit uncomfortable in large crowds, live out of the area or simply prefer to walk on your own, you can still register, receive your t-shirt from the Coalition, fundraise to support programs and services for survivors and complete your walk or run anytime and anywhere from Friday, May 6 through Sunday, May 9. It’s up to you. You are the designer of your personal Pink Ribbon Walk & Run experience!

No matter how you choose to participate, we thank you for your continued support of this important fundraising event.

As you save the date for the Pink Ribbon Walk & Run, also circle Monday, August 1 for the 20th annual Tee’d Off at Breast Cancer Golf Tournament, now at Midvale Country Club in Penfield. The Golf Tournament Planning Committee is excited to play 18 at this new location. We hope you will join us!

Our event calendar would not be complete without ACTober, our re-imagined fall fundraiser. Stay tuned for information about this fun evening that encourages everyone to take ACTion throughout October (Breast Cancer Awareness Month).

Thank you for your support of the Coalition. We look forward to seeing you – soon!

DONOR SPOTLIGHT: Quilt Donors

In 2020, the Breast Cancer Coalition distributed numerous PALS Paks to breast and gynecologic cancer survivors. As of this writing in November 2021, 142 PALS Paks have been given in this year alone. A PALS Pak is a canvas bag filled with items that are useful and comforting for those facing a breast or gynecologic cancer diagnosis – including handmade quilts.

All the quilts included in the PALS Paks are made by local volunteers and donated to the Coalition. Many are made by the Webster Quilt Guild, an organization whose mission is to share quilt making experiences; encourage friendships; promote the history, art, and skill of quilt making; and support community services. Michele Sanderson, who makes quilts as part of the Webster Quilt Guild, said:

“After hearing the stories of family and friends who have battled breast cancer, I don’t know too many people who are not affected by cancer in some way. I felt that homemade quilts could bring warmth and comfort along with letting others know that we are thinking of them and sending positive thoughts.”

Jennifer Ulrich, also a member of the Webster Quilt Guild, explained, “Members of the Guild selflessly contribute their time, talent, and treasure (fabric) to making these quilts in support of the Coalition every single month, and these efforts even continued throughout the Covid-19 lockdown. I make quilts for the Coalition throughout the year, and I think about the person who will receive each one as I work. Even though I may never know who specifically receives my quilts, I trust that recipients realize they are made with love and understanding from one ‘sister’ to another. There’s a hug with every stitch.”

In October 2021, an additional 51 quilts were contributed to the Coalition by Doris Clevenger and Charl Isham. It was their fourth year making and donating the quilts for PALS Paks. Doris explained, “As a former hairstylist, I witnessed more than a dozen clients with cancer. I would go to their homes to help shave their heads. I would listen, and it took a lot for me not to cry. Women value their hair, and losing it through chemo can take a lot out of them, both physically and emotionally. I’d rather be giving than on the receiving end.”

Charl added, “Doris and I met while swimming at the Y every morning and quickly discovered our shared love of quilting. We have donated to many charities, but have found the Breast Cancer Coalition to be our favorite recipient. It warms our hearts to know that our quilts are warming others’ hearts.”

In addition, Carol Giffi has been a quilt donor for several years and, in 2021, Barb Boehly made her first donation of 14 quilts to the Coalition.

PALS Paks also include seat belt covers, which make the use of a seat belt more comfortable for survivors post-surgery. They are created and donated each year by Amy Moyer, who also makes and contributes post-surgical pillows.

The Coalition is grateful to all of these quilters and seamstresses for their beautiful and very useful items. Thank you for all that you do for survivors.
FUNDRAISING FRIENDS

A ROUND OF GOLF TO SUPPORT THE COALITION

Tipsy Tees Golf League at Timber Ridge Golf Course in Spencerport is a team of 24 ladies who enjoy having themed ‘events’ throughout the golf season. One of their events this year was for Breast Cancer Awareness. They decorated golf cards, dressed in pink and asked their team members to make a donation to fight breast cancer. This also sparked interest from the men’s league that played the same night, who also contributed. Congrats on collecting a total of $330!

A RACE TO RAISE FUNDS

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 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 Fall evening, and it happened once again on September, 10 2021! 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 $19,403!

REFRESHING INDEED

Our lovely young friends, Marina Compitello & Clara Kneezel, offered sweet refreshments for their community this summer including scrumptious pink ribbon cookies and pink lemonade to raise money for the Coalition. We were thrilled to have them stop by recently to deliver the $643.25 they raised!

FOR THE WIN

Touchdown! A big thank you to the Webster Thomas Titans Football team for sending a few teammates to the Coalition on October 5 to present a check from their recent t-shirt fundraiser. Congratulations on raising $610! You rock!

CHEERING FOR PIE

We were thrilled to have the coaches and friends from Cheer Athletics Rochester stop by to present a check from their October “Pie Your Coach” fundraiser benefitting the Coalition! What a unique and fun idea. Congratulations on raising $1,100!!

JUST KEEP SWIMMING

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. This event resulted in a wonderful donation of $551.

VOLLY FOR BREAST CANCER

The Irondequoit Girls Volleyball 2nd Annual PINK OUT game was held on Wednesday, October 20, and they continued to raise money during the month of October for the Breast Cancer Coalition! Congratulations to the team for raising $3,635!

STRIKING OUT CANCER

The Rochester Lady Lions and Webster Xtreme came together in October to host the Showcase at the Ridge – Strike out Cancer softball tournament. They hosted 30 teams and had 20 colleges attending for recruiting. The gift basket raffle at the event raised a total of $2,200!

THANKS TO OUR PALS

Due to COVID restrictions, in lieu of their annual fundraiser, the Fairport Girl’s Field Hockey team collected items for our PALS Paks given to newly diagnosed individuals. We were blown away when they dropped off all they had collected!

RAISE THE FLAG

We were thrilled when our friend Mike Stoerger from Monroe County Fire Hockey & Ridge Road Fire District stopped by to do his drawing

Continued on next page.
for THREE American flags – handmade from used fire hoses. In lieu of MCFH’s normal tournament, which was not held due to the pandemic, Mike cuts, dies and creates the flags and raffled them off in October to support of the Coalition. Congratulations on raising $2,900 and thank you for your continued support.

FOR(E) A GOOD CAUSE

This year was the 25th anniversary of the Sodus Bay Heights Ladies Association Golf Tournament to benefit the Breast Cancer Coalition. Organized by Sharon Lilla and the Ladies Association, the event, which was held on September 3, 2021, raised a record $22,000! Sharon and her team did a wonderful job ‘bouncing back’ after a scaled back golf tournament in 2020 due to the Covid-19 pandemic. This year was a return to ‘normal’ with a full slate of golfers, food, lots of sunshine and plenty of fun and competition. The Coalition is grateful for the loyal and generous support from the Sodus Bay Heights Ladies Association. THANK YOU.

SPIKE OUT BREAST CANCER

A big thank you and high five to Chau Nguyen and Eric St. Denis for their efforts to organize the Spike Out Breast Cancer Volleyball Tournament. They smashed their previous years’ totals, raising $3,100 for the Coalition. Thank you for serving this generous donation to the Coalition to support our programs and services.

MASTERING COMMUNITY SERVICE

Character building plays a central role in the martial arts program at Master Kim’s Taekwondo Institute in Rochester. As part of the program, throughout the month of October, the students at Master Kim’s participated in a fundraiser for the Breast Cancer Coalition (as they have done for the past several years). All students who brought in a donation of $1 or more for the Coalition during October received one pink character stripe! Their donations resulted in a gift of $2,173 to the Coalition, easily besting last year’s total of $1,525. Thank you to Master Kim’s and all of the students for your generous support!

TAKING “PRIDE” IN OUR COMMUNITY

After a successful turn last year raising funds for the Breast Cancer Coalition, Pride Plumbing returned this year with a series of promotions to encourage customers to give to the Coalition throughout October – with all of those gifts matched by Pride Plumbing. All staff work pink shirts and ribbons throughout the month; a video encouraging customers to make a gift was created by Pride and posted to their website and socials; and cards with a QR code were given to all customers with their invoices so that they could go directly to the Coalition’s page to make a gift. All of these efforts paid off with Pride Plumbing making a donation of $2,160 to the Coalition. Thank you, Pride Plumbing, for all of your work on this fundraising campaign.

DOUG DOES IT AGAIN

A big thank you to Doug Phelps for completing not one, but two, fundraisers for the Breast Cancer Coalition for the second year in a row. The first event was his second annual golf tournament (established in 2020!) on September 20 at Salmon Creek Country Club. Congratulations to Doug and all of the golfers and volunteers who made this day a success.

Not satisfied to rest on his success, Doug and his team also presented the 11th annual Strike Out Breast Cancer Tournament on October 23 at the Bowl-a-Roll Lanes in Henrietta. Both events raised an amazing $22,000 this year and overall Doug has raised $107,000 for the Coalition throughout his 11-year run.

Thank you to Doug, all of the participants, volunteers, donors and supporters who did all of the work to make these events happen. We are grateful.

Continued on next page.
Students at Bay Trail Middle School in the Penfield School District participated in the second annual “Pink Week” in October. Students, staff and teachers wore pink throughout the week, and offered ribbons in remembrance of all who have faced breast cancer. The different grade levels also competed in ‘jar wars’ to raise funds for the Coalition. In one week, the Bay Trail Middle School family raised an amazing $1303.98! Thank you!

SALES SUPPORT
And thank you to Salon ROC on Pattonwood Drive for donating 20% of all of their sales in the month of October to the Coalition. Your gift of $218 is greatly appreciated.

KICKING OUT BREAST CANCER
From October 1 - 10, the Hilton Girls Soccer Program ran a 10-Day Breast Cancer Awareness Challenge. On October 9, they participated in their annual Breast Cancer Awareness Games, bringing the entire community together and raising $2,369 for the Coalition! As Pam Stadtmiller explained, “This is an opportunity to raise awareness and to give back. The Hilton community has always been so generous toward this fundraiser. We have family, friends, former players and coaches who are currently in the fight, whom we have lost and those we celebrate as survivors. We will continue to promote the importance of Breast Cancer Awareness in our program. Go Cadets!”

In 2021, hundreds of companies, teams, and individuals planned, prepared, participated in, and supported over 100 Community Fundraisers benefitting the Breast Cancer Coalition.

We thank you all for your dedication, support, and awesomeness!

Your fundraisers help to support local breast and gynecologic cancer survivors.
We are truly amazed at the many ways our generous donors support our work at the Coalition.

Some host fundraisers among their peers on social media or in person; others donate directly through their payroll with the help of an employer and/or the United Way. And there are those who respond to our annual fund campaigns, honor a loved one with an honorary or memorial gift, or simply return the donation envelope enclosed in this newsletter.

We are grateful to all donors for their valuable contributions and their commitment to our mission. Every effort has been made to ensure the accuracy of this list. We apologize for any errors. Please join us in thanking the following individuals, companies, and organizations for their contributions between July 1 - September 30, 2021.

**IN HONOR OF**

All breast cancer patients and survivors  
Mary Reed  
Diane, Debbie, Chris P. & Julie  
Estelle Hitzfield

Cathy Albin’s Birthday Fundraiser  
Karen Burgstahler Pritchard  
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Jeff Bellanca’s 5 years of service in the Hilton Fire Department  
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• Burt’s Bees Lip Balm (sealed, no mint)
• Coloring books (pocket or travel size preferred)
• Colored pencils (unopened packs of 12)
• Ear plugs (individually wrapped)
• Note cards, notepads (bound at top)
• Sleeping masks, lavender or unscented only
• Thank-you cards (unopened packs)
• Computer paper, white
• Joann Fabrics gift cards
• Ear plugs (individually wrapped pairs)

President’s Circle
The Coalition recognizes individuals who have made leadership level annual fund or United Way gifts of $1,000 or more in the calendar year through the President’s Circle.

Coalition GEMs
are a special group of dedicated supporters who help the Coalition throughout the year by making a monthly gift. Monthly gifts offer a steady and cost-effective source of income.

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Individuals who make an annual fund or United Way gift – of any amount – for two or more consecutive years are part of our Coalition Loyal Giving Society.

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BreastCancerCoalition.org

Winter 2022 • 31
Breast Cancer Coalition
Mission Statement

To cultivate community among those touched by breast or gynecologic cancer; to empower informed decision-making through education, support, and advocacy; and to advance research in our region with the goal of eradicating breast cancer.

Voices of the Ribbon is published quarterly by the Breast Cancer Coalition to provide encouragement and inspiration to those facing a breast or gynecologic cancer diagnoses, their supporters, and care providers.

In addition, it is intended to impart accurate, evidence-based information to enlighten and empower our readership.

Our in-house editor, graphic designer, writers, and support staff work together to ensure our publication is economically produced and our printers assure us that we are getting the best rates possible.

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Online at www.BreastCancerCoalition.org

To keep up to date on all BCCR happenings, follow us on social media:

Breast Cancer Coalition Inclusion Statement:

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