Serving those with breast and gynecologic cancers

Informed Consent

New Developments in Treatment

JOIN US ON MOTHER'S DAY SIGN UP TODAY!

Pink Ribbon Walk & Run NOW VIRTUAL - SEE WEBSITE FOR DETAILS

SIGN UP TODAY BreastCancerCoalition.org

Pink Ribbon Walk & Run
As I sit by the window pecking away at the keyboard, the sun is shining outside and signs of spring are everywhere. I have no delusions and, likely, neither do you. There will be more snow coming to our region, as sure as the sap runs!

Along with the arrival of a fresh, bright, new season, we have re-launched our website! Have you visited recently? If you haven’t, please check out www.breastcancercoalition.org and let us know what you think.

Often these first signs of spring signal a nearing of the end of flu season. Perhaps not this year as uncertainty abounds regarding COVID-19, a novel coronavirus.

According to the Centers for Disease Control (CDC), flu season typically occurs in the fall and winter. While influenza viruses circulate year-round with most cases occurring between December and February, the season can last as late as May. When it comes to this novel coronavirus, no one truly knows what lies ahead. Though we have no reason to believe that any visitors to the Coalition have been exposed to or carry the COVID-19 virus, as always, we follow best practices to help keep our staff and visitors safe.

How are we ensuring that the common areas at the Coalition are as safe as possible? We provide an abundance of hand sanitizer at the Coalition. We ask that you make use of these frequently while visiting, both as you arrive and as you depart. Bathrooms are also available for hand washing. Please note that, while we make every effort to regularly clean and sanitize surfaces in common areas, viruses can live on surfaces for days.

With thanks to the Monroe County Medical Society, following these important steps can help keep all of us safe:

1. **Stay home when you are ill.** If you are ill or have symptoms of any illness, even if you believe you are on the road to recovery, stay home. Many of our visitors are immune-compromised due to their treatment. It has always been our policy to instruct those who are ill to stay away.

2. **Avoid close contact.** Greet each other with fist or elbow bumps.

3. **Keep hands away from your eyes, nose, and mouth.** When coughing or sneezing, aim for the bend of your elbow or cover your mouth with a tissue (also plentiful at the Coalition). Dispose of the tissue in waste containers. Germs spread when a person touches something that is contaminated and then touches the mucosa of eyes, nose and mouth.

4. **Wash your hands.** Wash often with soap and water for at least 20 seconds, especially after going to the bathroom; before and after eating; and after blowing your nose, coughing, or sneezing.

5. **Practice other good health habits.** Get plenty of rest, stay physically active, drink plenty of fluids, manage your stress, and make healthy dietary choices.

6. **Watch for email and social media postings.** Though there are currently no plans to do so, should we need to cancel or postpone programs or events at the Coalition, we will alert you via email, social media, and television and radio announcements.

If these seem like common sense approaches to reducing risk of contracting any illness, it’s because they are. Please continue to feel confident about visiting the Coalition!
When Annie and I recently sat down together to discuss her walk with breast cancer, I was struck by the sunny disposition, resilience, and empathy of this remarkable young survivor. It is an honor to share her story with our community.

It was the last thing Annie Murphy expected. Breast cancer was just not on the radar for this 37-year-old mother of a toddler. But one day in early 2017, Annie returned home after a run to shower and change. This was when she noticed a lump in her breast. “That seems odd,” she thought. Although normally fluctuating hormone levels during her monthly cycle were the most likely explanation, she wasn’t going to leave anything to chance. Annie called her obstetrician-gynecologist; the same doctor who had been there through the birth of her daughter, Frances. “I want you to come in this week,” the doctor said, knowing the odds were in Annie’s favor while hoping to offer reassurance and certainty. But after examining the lump, she referred Annie to a breast imaging center for a mammogram that same day. “She didn’t want to alarm me,” Annie recalled. Both doctor and patient simply sought answers that would ease any concern.

So it was then that Annie found herself undergoing a mammogram at a younger age than most. Afterward, she settled into the waiting area expecting a long interval before learning her results. But five minutes later, Annie was called back to speak with the radiologist, who recommended an ultrasound. When that procedure was completed, the radiologist shared her concern that she was seeing cancer in Annie’s right breast and nearby lymph nodes. A needle biopsy would be needed, and that could be performed right away. “I started crying,” Annie recalled. The possibility of cancer was overwhelming.

When the biopsy was finished, Annie went home to await the result. It had been a long, emotionally draining day. She and her husband Michael took the following day off work to await the expected phone call from the radiologist. When that call came, the couple learned together that Annie did indeed have breast cancer.

“I was shocked,” she said. “This was out of the realm of anything I was considering.” Still, she was grateful the physicians involved in reaching this unwelcome diagnosis had taken her concerns seriously. While breast cancer most often occurs in middle-aged and older women1, it can and does affect people of all ages. Annie was aware of this fact. And with the support of her attentive health care providers, she received her diagnosis shortly after noticing her first symptom. Now her medical team was about to grow.

With the assistance of her OB-GYN, Annie soon scheduled consultations with a surgeon and an oncologist. More referrals and appointments followed. Before long, Annie had assembled the team of medical providers that would see her through whatever lay ahead. Her team consisted of a surgeon, plastic surgeon, medical oncologist, and radiation oncologist; all were females, according to Annie’s preference. “They got it. I can’t express how grateful I am for this amazing team of women.”

Annie’s treatment plan was soon in place. She would undergo chemotherapy first, followed by surgery and radiation. All of this would be accompanied by a year-long regimen of drug infusions that target HER2 receptors, a distinguishing feature of Annie’s particular form of cancer, known as HER2 positive.
As the year began, the Advocacy Committee reviewed our state representation and the changes that will be happening with the 2020 election. In the 10-county area served by the Coalition (see map), we have already learned of three State Senators and three Assembly Members who will not be running for reelection.

Part of the Advocacy Committee’s mission is to create and maintain relationships with our elected officials. One of the ways we do this is to meet with candidates for Federal and State office. These brief, informal meetings are opportunities for members of our committee to introduce the Coalition to the candidates and inform them about our programs and services. Additionally, we discuss our legislative priorities and explore the candidate’s thoughts on health care, research, cost of drugs, medical marijuana, and myriad other cancer and health related issues. By introducing ourselves in this manner, constituents are laying the groundwork for ongoing relationships with the successful candidates.

During the year we, along with members of the Regional Community Outreach Committee, visit State Senators, Assembly Members, and their staffs in their local offices and in Albany. We update our legislators on our local programs and discuss continued support of our regional programs. We use these meetings as opportunities to share information and learn about pending legislation relevant to breast and or gynecologic cancers. In the coming year, the Advocacy Committee looks forward to continued meetings with our current representatives and to getting to know those vying for state office.
Informed Consent in Clinical Trials

By Leni Rayburn with editorial support provided by Pat Battaglia

Each year, several members of the Coalition’s Advocacy Committee attend a Leadership Summit provided by the National Breast Cancer Coalition* for scientific presentations and networking. In 2019, I was asked to act as moderator for the workshop at the 2019 Summit: Informed Consent and Clinical Trials. In my research to prepare for this presentation, I quickly learned that the consent form and all the information presented to patients interested in participating in clinical trials are more precise, complex, and standardized than one might think.

The two presenters explained that the consent document must provide sufficient information about the study, including potential risk and benefits to participants, so that every patient enrolling in a trial can make their own informed decision on whether or not to participate. Informed consent is a crucial part of enrolling in a clinical trial because it gives the potential participant all the information they need to understand what they are volunteering for. It is very important for people thinking about participating in a clinical trial to understand their role in the study.

Clinical trials are studies using human subjects, and are often intended to test the safety and effectiveness of new treatments and therapies. Participants must understand that they are acting as subjects in a research study and not as patients. Every clinical trial has a detailed plan, a protocol, which explains how the study will work. The trial is led by a principal investigator (PI), a clinician/researcher who prepares the protocol, outlining what will be done during the trial and why. Each medical center that participates in the study uses the same protocol, which is reviewed and approved by various committees. This information is included in the consent form that is finally in the patient’s hands.

Because of the complex regulations pertaining to clinical studies, consent forms were becoming unwieldy and confusing to the average patient. So the National Cancer Institute (NCI) developed an informed consent template to ensure readability and patient satisfaction. Plain language has been developed to address potential barriers to patient understanding of trials in which they might participate. Ensuring the clarity of consent forms has led to less patient anxiety and increased willingness to join clinical trials. The consent forms must also be approved by the study’s Institutional Review Board (IRB), which checks their compliance in explaining the science, as well as the content. The IRB and other safeguards are in place to ensure patient protection in studies with some potential to learn new information or benefit patients. Federal law makes informed consent mandatory in all clinical studies.

*The Breast Cancer Coalition is an independent, unaffiliated grassroots organization that shares many of the same goals as the NBCC.

Correction: In the Winter 2020 issue of our publication, an article entitled Working to STOP Breast Cancer in its Tracks, which appeared on page 5 of our print edition, was written by treasured Coalition advocate, Cynthia Nelson. The piece was erroneously attributed to Rebecca Solomon. Our editorial staff extends our sincere apologies to both women. This oversight has been corrected in the digital edition on our website.

We are grateful to both Cynthia and Rebecca for their adept and long-running advocacy efforts. It was Cynthia, however, who authored the excellent article that appeared in our previous issue.
A Survivor’s Story: Barbara O'Connell
By Pat Battaglia

The gently smiling face of Barbara O'Connell is a frequent and welcome sight at our Common Ground table. It was an honor to sit down with her and listen as she spoke of the joys and challenges of her life; a life well lived... with metastatic breast cancer.

A diagnosis of breast cancer is always unwelcome. But Barbara O'Connell’s original diagnosis came at an especially bad time: in the immediate aftermath of her mother’s death in 2005. “I actually was in Syracuse for her service when I got a phone call to come back in [to the imaging center] for additional scans after my mammogram. That was definitely out of the blue,” she recalled. “The tumor was not palpable, so it wasn’t anything I was aware of.”

As soon as she could, Barbara underwent additional testing and biopsies that revealed early-stage breast cancer. She underwent a lumpectomy and qualified to receive a specialized, targeted form of radiation therapy called MammoSite*, which was brand-new at the time. When her radiation therapy ended, Barbara’s treatment was finished. However, after reading a magazine article about lymphedema and realizing she might be at risk for the condition, she approached her surgeon for a referral to a physical therapist/lymphedema specialist. In an effort to gather as much information as she could, Barbara also attended an evening seminar at the Coalition at which her physical therapist spoke; this was her introduction to our organization. But it would be a long time before she walked through our doors again.

Life went on for Barbara and her family and good times returned. But there were exquisitely painful times as well. “We went through a lot of profound sadness because of the death of my eighteen-year-old granddaughter in 2013, followed in 2015 by the death of my daughter - my granddaughter’s mother - from gynecologic cancer,” she shared. The family coped as best they could, forging deep bonds through their shared loss.

In 2017, Barbara consulted her doctor about abdominal pain she was experiencing. Cancer was the furthest thing from her mind. But imaging showed masses in her liver...
that, when biopsied, proved to be metastatic breast cancer. Revealing this news to her loved ones was particularly difficult. “Having to tell my family that I had a diagnosis of metastatic cancer was not something I wanted for them. I didn’t want my family to have to go through cancer again.”

But Barbara and her family rallied as best they could as she prepared for her first chemotherapy treatment. When an uncommon reaction to her chemo drugs meant hospitalization for Barbara, she and her doctors worked together to adjust her medications and the dosages of those medications so her treatment could continue without further incident. This has proved to be an ongoing challenge, as Barbara’s body reacts strongly to many chemo drugs. Still, her chemotherapy has continued, although with occasional delays.

She takes it all in stride. Her family ties help. “I have two little great-grandchildren. They keep me laughing,” she beamed. “It helps that I’m feeling okay. I’m tolerating the side effects of my treatment well. Those side effects don’t keep me from being able to do anything.”

In the spring of 2018, Barbara attended her first Common Ground lunch. “I still keep coming!” she exclaimed. “It’s a wonderful group of women. We learn from each other through sharing and listening. Everyone’s story is different, and you might learn something you didn’t know. It helps each of us to cope with the anxiety and fear and stress that come with this diagnosis. A lot of that has an opportunity to be relieved through sharing it with a group of people who know what you’re going through.”

“We’re living with uncertainty, but living,” Barbara continued. “As daunting as that seems, you can figure out how to live with metastatic breast cancer. Each of us does it a little differently. The reality may be what it is but you can feel happiness at the same time. You can wake up every morning with a smile on your face and go to bed at night saying ‘Thank you, thank you.’”

Ever grateful, ever living life to the fullest, Barbara deftly navigates the uncertain waters of metastatic breast cancer. Although no one chooses to live with this diagnosis, she reminds us that the choice of HOW to live with it is within our grasp.

* A targeted form of partial breast radiation.
Last December, clinicians, researchers, and patient advocates gathered at the San Antonio Breast Cancer Symposium (SABCS) to discuss the results of numerous ongoing breast cancer studies. In the search for information that is meaningful to patients, sifting through the abstracts and presentations from this highly-regarded annual symposium can be a daunting task, not unlike the proverbial needle-in-a-haystack conundrum.

But there is help for lay advocates reading about advances in breast cancer treatment (or treatment of any disease or condition). Whether that information comes in the form of original research articles or the news releases that often follow them, it’s important to consider the quality of the evidence being presented.

Understanding Clinical Trials: A Short Primer

Clinical trials of new drugs fall into three main categories:

• **Phase I:** These studies, which use a small number of subjects, are concerned primarily with the safety of the proposed therapy.

• **Phase II:** Conducted on a larger number of patients, these studies are designed to gather preliminary data on how well the new therapy works while measuring its short-term side effects, including any adverse reactions that might occur.

• **Phase III:** Using a much larger patient population frequently recruited from multiple cancer centers, these studies compare the safety and effectiveness of the new treatment against the current standard of care.

When measuring the effectiveness of a new drug, researchers take a number of factors into account such as:

• **Overall survival (OS)** is arguably the most significant criteria for those affected by the disease. This is the length of time a patient is alive from the beginning of the trial until death from any cause.

• **Disease-free survival (DFS)** is the interval between beginning the therapy and progression of the disease.

• **Progression-free survival (PFS)** is the length of time a patient lives with the disease but it does not get worse.

Other considerations to take into account when reading research reports and news stories include the side effects of the new drug and their impact on quality of life, as well as the cost of the therapy. Extended survival in the absence of a meaningful quality of life is not a welcome prospect for many. And the financial toxicity of cancer treatment has long been a bone of contention among patient advocates. Many medical providers, insurers, and researchers are paying attention to this as well. Still, cancer remains one of the most expensive diseases to treat in the United States.

Case in Point: the HER2CIMB Study

A number of reports emerged from the 2019 SABCS. Many involve the results of phase I and II trials and the promise of further investigation they contain, pointing the way to potential advances in breast cancer treatment of. But the results of one phase III study reported at the symposium may have more immediate ramifications for those with HER2 positive metastatic disease* that has stopped responding to other therapies.
In late 2019, the results of a trial called HER2CLIMB were reported at the SABCS. This randomized, double-blind, placebo-controlled, phase III clinical trial enrolled 612 patients at 155 sites in 15 countries with locally advanced or metastatic HER2 positive breast cancer. All had experienced disease progression after at least two previous lines of HER2-targeted therapy. Significantly, nearly half of patients in the study had brain metastases, a group that is poorly represented in many clinical trials. Subjects were randomly assigned to receive the chemotherapy agents trastuzumab and capecitabine with or without tucatinib, which is an experimental tyrosine kinase inhibitor that targets HER2 receptors.

Tucatinib improved overall survival as well as progression-free survival when compared to the control arm, and these results included those with brain metastases. The most common side effects were diarrhea, hand-foot syndrome, nausea, fatigue, vomiting, and reversible elevation of liver enzymes. About 6% of study participants discontinued the therapy due to side effects, compared to about 3% in the control arm, and the researchers concluded that tucatinib is well tolerated by most.

These findings led the researchers to unblind the study and offer tucatinib to all the patients enrolled. The drug’s manufacturer has applied for and received FDA approval of the medication for all HER2 positive metastatic breast cancer patients with previously treated disease. However, the cost of tucatinib therapy is unclear at this time, and it remains to be seen whether those in financial need will have access to this therapy.

**Real Survivor Concerns**

For those dealing with a breast cancer diagnosis, new treatment options can offer hope. The challenges are to know which reports about new therapies actually represent a step toward that hope and to ensure patient access to these therapies. Health News Review (healthnewsreview.org) contains helpful criteria and questions to ask when reading news in the media.

But the questions that arise immediately after a diagnosis deserve equal attention. “How did this happen?” and “Will I survive?” speak to survivor concerns about primary prevention of the disease as well as understanding how to halt its spread. As we at the Coalition seek answers to these questions, we will keep paying attention to developments in treatment, knowing that breast cancer will not end until we can prevent it from happening in the first place and/or stop if it does occur.

**We’re listening.**

* In approximately 20 percent of breast cancers, the tumor cells have too much of a protein called human epidermal growth factor 2, or HER2, on their surfaces. With an overabundance of this growth factor, these cells tend to grow and spread quickly.

**Sources:**
- https://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials
- https://www.healthnewsreview.org/
THE LIMITATIONS OF SURGERY IN RECURRENT OVARIAN CANCER

By Pat Battaglia

A randomized, multinational, phase III clinical trial called GOG-0213, which was conducted by researchers at the MD Anderson Cancer Center, took a look at surgical cytoreduction, also known as debulking surgery, in women with recurrent ovarian cancer tumors that were small, operable, and had responded to previous platinum-based chemotherapy with a disease-free interval of at least six months. The primary endpoint of this study was overall survival. From December 2007 until June 2017, 485 eligible women were randomized to receive one of two regimens: surgery followed by platinum-based chemotherapy (with or without the addition of bevacizumab, a drug that blocks the formation of blood vessels) or the same regimen without surgery.

The researchers found that within their carefully selected patient population, surgery followed by chemotherapy did not result in longer overall survival than chemotherapy alone. After recovering from their procedures, those who underwent surgery had a similar quality of life as members of the control group, and surgery remains a consideration for some individuals, depending on their circumstances.

Patients with shorter progression-free intervals and/or a larger disease burden account for a significant number of those experiencing recurrent ovarian cancer, and the ramifications of this study for that population are unclear. Additionally, the use of bevacizumab is a reflection of current practice and may have had a role in minimizing the effects of surgery.

Ongoing research adds to our knowledge base about cancer, whether or not the results lead to new therapies or change any standards of care. The GOG-0213 trial opens the door to a new understanding of the role of surgery for those with recurrent ovarian cancer. Overall survival and quality of life matter to patients, and this recent research may lead to a more cautious approach to surgery for some whose disease recurs.

As always, individual treatment decisions are a matter of careful discussion between patients and their health care providers, and take into account a host of personal factors. If you or someone you know has experienced recurrent ovarian cancer and would like the support of knowledgeable, compassionate survivors and advocates, call us at the Coalition. We’re here to empower you to make the best decisions for yourself.

Sources:
https://ascopost.com/issues/february-10-2020

Investigating a Potential Biomarker for Early Stage Ovarian Cancer

By Leni Rayburn

Last year, I was asked to join a patient advocate panel by a research faculty member I knew through my participation in Project LEAD®, a science training program for breast cancer advocates. The DoD and SPORE Ovarian Cancer Omics Consortium (DSOCOC) is a unique multi-site research project that depends on crowd-sourcing to reach women who have had their fallopian tubes removed due to ovarian cancer. These women are asked to consider allowing their surgical specimens to be donated for research. The specimens will then be de-identified to protect patient privacy. The DSOCOC is looking at serous tubal intraepithelial carcinoma (STIC) lesions as an early marker for ovarian cancer.

Healthcare facilities have many thousands of fallopian tube specimens already in storage, which will be needed for this large data research. But informed consent from patients is needed and recruitment continues. Eligible women who might consider donating their bio-specimens can learn more about the project through informational packets and informed consent forms.

For more information about the project, read this press release from the Roswell Park Cancer Institute: roswellpark.org/newsroom/201911-stars-cancer-research-align-develop-ovarian-cancer-detection-test
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.

HEALING ARTS
Learn a new modality or a complementary healing practice to relax, de-stress, and increase range of motion. Advance registration is required 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. The goal of the class is to relax, be mindful, and to improve range of motion and flexibility.
Classes are 75 minutes in length and participants benefit the most when they are present for the full duration of the class. Sessions are 4 to 6 weeks in duration.

Rochester (1048 University Avenue)
- Monday morning and evening
- Tuesday morning and afternoon
- Saturday morning
- Sunday morning

Albion (Hoag Library)
- Thursday evenings

Dansville (Dansville Public Library)
- Thursday evenings

Geneseo (Morgan Estates Community Center)
- Wednesday evenings

Geneva (Geneva Public Library)
- Monday evenings

Fluid Motion
A movement class designed to improve range of motion, balance, endurance, and strength. Decreasing lymphatic swelling is another goal of this class. Fluid Motion is 1 hour and 15 minutes.

Rochester (1048 University Avenue)
- Saturday morning

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.

Rochester (1048 University Avenue)
- Offered Tuesday or Thursday afternoons and Saturday mornings

Canandaigua (First Congregational Church)
- Wednesday evenings

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.

Rochester (1048 University Avenue)
- Thursday afternoons or 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.

Rochester (1048 University Avenue)
- Offered Saturday mornings and Thursday afternoons

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 engaging 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.

Rochester (1048 University Avenue)
- Offered throughout the year; runs for five week series.
The Breast Cancer Coalition provides **FREE** programming to breast and gynecologic cancer survivors in Rochester and our nine-county region. If you have any questions, would like to enroll in a class or workshop, or would like to be added to our mailing list, call us at (585) 473-8177 or email us at info@BreastCancerCoalition.org.

**GIVE AND GET SUPPORT**

**Breast & GYN Cancer Group**  
Gather, support, network, and discuss your journey with others diagnosed with breast or gynecologic cancer. Professionally facilitated.  
**No registration required.**

**Rochester** (1048 University Avenue)  
- **Discussion Group:** 2nd and 4th Tuesday of the month, 5:30-7:00 p.m.  
- **Discussion Group:** 1st and 3rd Thursday of the month, 5:30-7:00 p.m.

**Geneseo (Goodwill Community Room)**  
- **Discussion Group:** 2nd and 4th Monday of the month, 5:30-7:00 p.m.

**Brown Bag Discussion Group**  
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.  
**No registration required.**

**Rochester** (1048 University Avenue)  
- **Fridays at 12:00 noon.**

**Batavia (First Presbyterian Church)**  
- 2nd and 4th Thursday of the month, 12:00 noon.

**LGBTQ+ Breast and GYN Cancer Group**  
This monthly group offers support to LGBTQ+ breast or gynecologic cancer survivors and their partners. Professionally facilitated.  
**No registration required.**

**Rochester** (1048 University Avenue)  
- **Discussion Group:** 4th Wednesday of every month, 5:00-6:30 p.m.  
  - **NEW! NEW! NEW! NEW! NEW!**

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

**Rochester** (1048 University Avenue)  
- **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 are addressed. Lunch and beverages provided.  
  - **Registration is requested.**

**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. Professionally facilitated. **No registration required.**

**Rochester** (1048 University Avenue)  
- **Discussion Group:** 1st Tuesday of the month, 5:30-7:00 p.m.

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

**Rochester** (1048 University Avenue)  
- **Mondays:** May 4, 11, 18, June 15, 1:00 - 3:00 p.m.  
- **Wednesdays:** September 2, 9, 16, October 14, 5:30 - 7:30 p.m.  
  - **Registrants must commit to all four sessions.**

**Lymphedema Awareness Network (LANROC)**  
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 welcome. Professionally facilitated.  
**No registration required.**

**Rochester** (1048 University Avenue)  
- **2nd Wednesday of the month, 5:30-7:00 p.m.**

**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** (1048 University Avenue)  
- **Call or email today to be added to our invitation list.**

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*continued on page 13.*
An important part of our mission is to empower our survivor and caregiver community through education on cancer related issues such as prevention, risks, treatment, survivorship, and other concerns that may arise.

Surviving and Thriving on Aromatase Inhibitors

By Jennifer Gaylord

The Coalition is in our fourth year of offering “Surviving & Thriving on Aromatase Inhibitors”! The program was carefully developed to serve the 60% of breast cancer survivors whose cancers use estrogen as a growth factor, and who are prescribed this class of drugs over a five to ten year course. Aromatase inhibitors are estrogen-blocking drugs that have proven to be highly effective at reducing the rate of recurrence and disease progression. Unfortunately, many women who take them experience joint pain and consider discontinuing use of the drug.

“Surviving & Thriving on Aromatase Inhibitors” is a mix of education, support, and tools to help survivors stay their aromatase inhibitor. This four-session, grant-funded program is offered four times each year and is facilitated by an Occupational Therapist, a physician, an oncology Social Worker, and a Nurse Practitioner. Each participant receives a Fitbit, an exercise band and a stress ball. Participants are encouraged to increase their daily movement; they learn stretches, resistance exercises, nutritional and supplement strategies — all with the goal of reducing arthralgia like joint pain.

On February 27, 2020 the Coalition invited the 127 “graduates” of “Surviving & Thriving on Aromatase Inhibitors” program to a reunion. The discussion that day revolved around challenges and successes over the past months. Reunion attendees were sporting their Fitbits and sharing how using what they learned decreased joint pain.

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

Read Closely to Understand Research News

Sometimes it seems like there are news stories about breast cancer research discoveries almost every week. How can a reader judge whether reports are hype?

HEALTHNEWSREVIEW.ORG is an online site that evaluates media stories and news releases about research findings. Its editorial team is composed of journalists with a science background as well as scientific professionals themselves.

These writers consider 10 different elements in their reviews. The criteria address basic issues consumers should know to make informed opinions about new discoveries. Though some criteria may not be applicable to a particular story, they still provide good guideposts for the layperson, too.

Consider: Does the story discuss costs? Does it explain the effectiveness and benefits of a new treatment? Does it discuss potential harmful effects? Does it leave out important details about the evidence? Does it exaggerate or oversell conditions? (The site calls this “disease-mongering.”)

Are independent sources used to comment on the research and the findings, and are conflicts of interest identified? Does the story mention treatment alternatives? Does it mention if this new treatment, test, product or procedure is available? Does it explain how the research findings are new or better? Does the story sound like the writer just used a news release without any additional effort? Or does the writer note that the information came from a news release?

Critically approaching a science story will help a layperson evaluate the information – or lack of information – and help them make an informed opinion.

Breast Cancer Coalition Receives $20,000 to Support Research

The Breast Cancer Coalition of Rochester has received $20,000 from the Breast Cancer Network of WNY Inc. (BCN) to support the Coalition’s Breast Cancer Research Initiative. The donation will be used to help fund the research grants, which are presented annually for innovative new projects with the potential to yield significant medical breakthroughs in one of two of their research priorities—prevention of breast cancer altogether (initiation) and/or addressing metastatic disease (cure).

Since 2003, the Breast Cancer Coalition has awarded more than $850,000 to researchers in Central and Western New York. Proposals are solicited from medical and research institutions, with recipients selected through a competitive review process. Recipients of this year’s Coalition grants will be announced in April.

“At the Breast Cancer Network of Western New York, we have a strong commitment to those living with advanced stage breast cancer, and donating funds for research is an important part of that,” said Executive Director Rob Jones. “We were inspired by the Coalition’s research initiative and wanted to be more purposeful by giving people the opportunity to contribute to research and know where and how their gifts would be used. But without the resources to create our own grant program, we decided instead to contribute to the excellent job the Coalition was already doing in identifying scientists and proposals to fund.”

BCN was founded in 1988 by a group of breast cancer survivors to provide support and education to other survivors and their families. Based in Depew, BCN offers educational and wellness programs, support groups, TLC Totes to newly diagnosed patients and other services, and conducts advocacy efforts and fundraising for metastatic breast cancer research.
Recently, I saw a term that was new to me, but probably many are already familiar with it: subscription economy. It was in a newspaper article that offered advice on living in a subscription economy, which is one based on offering subscriptions to consumers. Consider Netflix, Amazon Prime, Pandora, Dollar Shave Club, the variety of meal delivery services – all of them require an annual or monthly subscription fee. As I thought about it, I realized, nonprofits are part of the subscription economy, too.

Although not new to nonprofits, the concept of monthly giving seems to be gaining momentum in recent years. Monthly gifts are recurring gifts to a nonprofit that offer a steady and cost-effective source of income to the organization. Many supporters prefer to become monthly donors because their gifts are processed automatically, thereby reducing the nonprofit’s costs. Some interesting facts:

- 60% of donors under the age of 35 give monthly
- 50% of those between the ages of 49 and 67 give monthly
- The average monthly gift is $24

Please consider becoming a Coalition GEM (Giving Every Month) by making a monthly donation! The option to give monthly is available through our online donation form on the Coalition’s website – www.BreastCancerCoalition.org.

No gift is too small. As always, your gifts help the Coalition continue to offer our programs and services free of charge to all who need them in our 10-county region. If you have questions about monthly giving – or any donation to the Coalition – please do not hesitate to call us. Thank you for your consideration and support!
Everyone gets tired. And whether it happens after strenuous activity or at the end of a busy day, a good night’s sleep will leave you feeling refreshed and ready to start anew.

Fatigue is different. If your low energy reserves aren’t replenished by sleep, it can affect your ability to function and, in turn, impact your quality of life. Cancer-related fatigue is a common effect of the disease and its treatments\(^1\), one that isn’t thoroughly understood. Even when treatment is finished, lingering fatigue can take a long time to resolve. As the body repairs and rebuilds healthy cells and tissues, it draws on energy reserves, which can contribute to ongoing fatigue\(^2\).

While you can’t speed up the healing process, you can take supportive measures. Here are some suggestions to get you started:

- **Talk with your health care team.** They can help rule out or manage any physical causes of fatigue, such as anemia, electrolyte imbalance, and side effects of medications you might be taking. They can also provide appropriate referrals if anxiety or depression might be contributing to fatigue.

- **Get moving.** It can be hard to find the motivation to be physically active when you’re feeling fatigued but the rewards are great. A daily walk counts. So does a host of other activities such swimming, bicycling, and yoga, along with working out at the gym. A preliminary but increasingly substantial body of research points to exercise as an effective strategy for managing fatigue\(^3\).

- **Get enough rest.** While exercise can be invigorating, it’s also important to rest when you need to. Daytime naps are helpful and may even become essential for you, but limit them to one hour or less so they don’t interfere with your sleep at night. Turn off the TV, computer screen, and your phone one hour before you go to bed and avoid caffeine in the afternoon and evening.

\(^1\) Cancer-related fatigue is a common effect of the disease and its treatments.
\(^2\) As the body repairs and rebuilds healthy cells and tissues, it draws on energy reserves, which can contribute to ongoing fatigue.
\(^3\) A preliminary but increasingly substantial body of research points to exercise as an effective strategy for managing fatigue.
Join us in raising funds that stay LOCAL!
Sunday, May 10, 2020 • Genesee Valley Park

This Mother’s Day, start your day with us and help provide free programs for those in our community touched by breast cancer at this two-in-one event!

All proceeds from this event benefit the Breast Cancer Coalition.
You may also register and fundraise online at www.BreastCancerCoalition.org.
Contact Meredith@BreastCancerCoalition.org with questions.
Registration fee waived for individuals who collect $50 or more in donations to the Breast Cancer Coalition—learn more at BreastCancerCoalition.org.

Register by Monday, April 20 to guarantee your event shirt!
PARTICIPANT NAME: ________________________________________________

TEAM NAME: _____________________________________________________

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Donations can also be made online at: https://runsignup.com/Race/Donate/NY/Rochester/PinkRibbonWalkandRun.

ALL PARTICIPANTS MUST READ & AGREE TO THE FOLLOWING:

I certify that I am physically fit, have sufficiently trained for participation in this event and have not been advised otherwise by a qualified health care 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, volunteers, spectators and/or producers of this event and lack of hydration. I hereby assume the risks of participating in the Pink Ribbon 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, the County of Monroe, the City of Rochester, the Erie Canal Heritage Trail, the University of Rochester and Marketplace Mall, all sponsors, event directors, vendors, volunteers 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 understand that no roller blades, bicycles, iPods, music players, running strollers or dogs are allowed on the course. I also 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: __________________________
FROM THE REGIONAL SERVICES DIRECTOR

Updates from the Region

By Miriam Steinberg

Our regional programming began in 2016 and has been growing steadily ever since. We have added new programs and participation has been progressively increasing. Our most recent offering is a Brown Bag Discussion Group in Batavia, which began in early January and meets on the 2nd and 4th Thursday of each month. Upcoming for Fall 2020, I’m excited to announce than an outdoor event is in the planning stages for our regional survivor community. Deb Denome, a Certified Forest Therapy Guide from Finger Lakes Forest Immersion will be leading a walk for us. Location and other details will follow!

Enlightening our elected representatives about our services and programs in the ten county region we serve is an important and ongoing process for us. We make it a priority to visit them in their districts and in Albany often. These face to face meetings are the best way to keep them up to date about the supportive and educational programming we offer to their constituents who are breast or gynecologic cancer survivors. This past January we visited Senator Pamela Helming at her office in Geneva to update her on the Gentle Yoga, Mindfulness & Meditation, and Evening Seminars we have planned for 2020 in her district, which includes Geneva and Canandaigua.

On January 28, Holly Anderson, Carol Kistner, and I braved early morning cold temperatures and boarded the 5:41am train to Albany for a day of meetings. We met with Assemblymembers Richard Gottfried, Didi Barrett, Harry Bronson, Jamie Romeo, as well as Senators Gustavo Rivera and Julia Salazar. We spent the day bringing awareness of our work in the Finger Lakes and Central NY region and building relationships with these elected representatives and their staff in an effort to brainstorm the most effective ways to keep survivors throughout our region informed about our programming.

Tuesday, March 10th will bring another trip to Albany for a day of meetings with our elected officials. This time, we are bringing eighteen advocates. Look for photos and follow-ups in the next issue of our newsletter!

Our Healing Arts initiative is important to so many survivors' self-care. Participants from the Geneseo Gentle Yoga class strike a pose before the start of their class with instructor Deb Scodes-French.
As a twenty-three-year, two-time survivor of breast cancer, Marien Canale is grateful for every day. At the age of forty, she and her husband Mike, already the parents of two young daughters, received the wonderful news that Marien was pregnant again, this time with twins. Marien and Mike were the busy parents of four daughters ages eight, five, and two (the twins), when breast cancer made an unwelcome appearance in their lives.

Marien had gone for her routine mammogram when her doctor told her that a small area of concern had been found. A biopsy of the spot revealed DCIS (Ductal Carcinoma in Situ), an early-stage breast cancer.

Although her own mother had a history of breast cancer, these were words Marien hoped never to hear again. She was in college when her mother underwent a mastectomy during the 1970’s. Her mother did not know if the area was cancerous until she woke up from the procedure. At that time, diagnosis, treatment, and care plans were very different than those of today. Marien doesn’t know many details about mother’s diagnosis, but recalls that her mother did not have any treatments after surgery and lived forty healthy years afterward.

With a rush of emotion and worry, Marien felt she didn’t know where to start in her own journey. Her feelings of uncertainty and fear kept her reserved in speaking out about her diagnosis. Although a neighbor and a school colleague did reach out to her, she struggled to build the confidence to face this new reality. Amidst raising her young children, balancing family and career, and fitting in doctor appointments, she felt overwhelmed and isolated. Back then, Marien says, breast cancer was a taboo topic. She remembers running into people she knew, who were often uneasy and didn’t ask how she was feeling. They waited and asked others for updates.

As she prepared for her lumpectomy and radiation treatments, Marien relied on her family to help her through. Mike came to every appointment with her armed with a notebook to write everything down so the couple could go over it when they got home. The surgery went well; there were clean margins around the lumpectomy site. And Marien experienced no noticeable side effects from her radiation treatments. Afterward, she was given a clean bill of health and continued her life as a Spanish teacher at Geneva High School, her own alma mater, where she taught for thirty-three years.

Eighteen months later, at a follow up mammogram appointment, another suspicious spot was found on the same breast. This time, Marien and her surgeon agreed that the best option was a mastectomy on her right side. After careful consideration, she chose to have reconstructive surgery using the latissimus muscle from her back and a breast implant. This procedure was done at the same time as the mastectomy. (In latissimus dorsi flap breast reconstruction the surgeon uses muscle, fat, and skin from the upper back to create a new breast.)

Because her cancer was fueled by estrogen, Marien took the anti-estrogen drug Tamoxifen for five years after her recurrence and tolerated it without any problems. Her follow-up care now consists of annual mammograms, which have been clear since her second surgery.

Marien recalls being afraid to say she was a survivor; she was nervous her cancer could recur at any time. Then, as time passed, close friends of hers were diagnosed and turned to Marien for strength and support. Through these conversations, she came to embrace the fact that she could say she was — and is — a survivor. She’s amazed at how far the science has come and attitudes about
discussing breast cancer have changed since her mother’s diagnosis and, later, her own.

Marien became involved with the Coalition after seeing a Facebook post about a gentle yoga class offered at the Geneva Library for breast and gynecologic cancer survivors. She signed up and has been a regular at the classes ever since. She appreciates having a program close to her home in Romulus and says that yoga has helped tremendously with regaining her range of motion after her surgeries, even all these years later.

The importance of Marien’s family life, their assistance and love when she most needed them, along with her faith and prayers, helped get her through the difficult journey. Although side effects from the surgeries, treatments, and medications were minimal (including rashes, numbness, and body aches), Marien says those symptoms were nothing compared to the internal emotional stress she endured. Her life has been forever changed. She has found that personal strength is displayed in various ways.

Marien feels that although she is often perceived as easy going and calm, her inner strength is fierce! She is living proof that one should "never mistake kindness for weakness."

"Marien became involved with the Coalition after seeing a Facebook post about a gentle yoga class offered at the Geneva Library for breast and gynecologic cancer survivors. "I appreciate having a program close to home, it has helped me tremendously with regaining my range of motion even after all these years."
Amy Schnitzler

By Judy Schnitzler (Amy’s Mom)

Amy—beloved daughter and partner, compassionate protective big sister, “dog-sister,” niece, cousin, godmother, friend, spokesperson, artist, poet, writer, singer, fluent communicator… Her story lives on.

Amy-zing Amy… so difficult to describe. Amy evoked feelings. Strong feelings. Her passion for life, her knowledge, gentle nature (paired with four-letter “sentence enhancers” as needed), questioning ability, assertiveness, and informed decision-making facilitated her growth as a compassionate woman and a strong advocate for herself and other Metastatic Breast Cancer (MBC) survivors.

Amy has appeared in several news clips thanks to her Coalition connections. Her writings were published in magazines to raise awareness about MBC, the value of exercise during treatment, and the rising number of young women being diagnosed with the disease. She recently appeared in the documentary “Not Just One”, which was filmed during the 2019 New York AnaOno Fashion Week runway show featuring women with MBC. It is available on Amazon Video.

Amy decided to make prints of her watercolor paintings and publish her book, *My Terminal Life: Cancer Habitation and Other Life Adventures*, to help raise money for MBC research. We will continue her dream by making prints and books available in the spring.

Cancer Fatigue, Continued From Page 16

- **Eat well.** This can be a challenge if the side effects of treatment interfere with your ability to enjoy food. It may be worthwhile to schedule an appointment with the nutritionist at your treatment center, who can help you develop an individualized approach to ensure you’re getting the nutrients you need.

- **Be mindful.** Notice the ways in which your energy ebbs and flows throughout the day, and plan accordingly. Pace yourself, delegate tasks, and say “no” to activities that drain your energy. Techniques such as Mindfulness/Meditation, yoga, and qi gong have been helpful for many.

- **Talk with others who “get it.”** Support/networking groups are a great opportunity to connect with others who have dealt with fatigue. As you learn the coping strategies that worked for them, you may find that growing your circle of support is helpful in many other ways as well.

Fatigue doesn’t have to be an obstacle to living your best life. Reach out. You are not alone in this.

1. my.clevelandclinic.org/health/diseases/5230-cancer-fatigue
3. www.ncbi.nlm.nih.gov/pmc/articles/PMC3156559/
A PERSONAL JOURNEY, continued from page 3.

HER2 positive breast cancer is a subtype of the disease characterized by tumor cells with too much of a protein called human epidermal growth factor receptor 2 (HER2) on their surface. HER2 is present in small amounts on healthy cells and helps regulate their growth. But in the larger-than-normal amounts that occur in about 20 to 30 percent of breast cancers, it can cause uncontrolled cell growth². Fortunately, HER2 receptors are ready targets for certain drugs designed to zero in on them. Along with standard chemotherapy, Annie would receive infusions of two of these drugs: Herceptin and Perjeta.

“It seemed hard to understand at first,” Annie shared. Breast cancer isn’t a single disease, as she had learned, and each individual affected is unique. But Annie had gathered her information, assembled the medical team that would see her through, and was determined to survive.

The months of chemo were a challenging time. “I’m glad I was able to go on disability,” Annie recalled. “I needed my rest. I was really sidelined with some difficult side effects.” Through fatigue and other effects of her treatment, Annie relied on the support of her family and friends. “My husband Mike was amazing,” she recalled. So were her parents, in-laws, and her sister Kim, who — along with Mike — attended each of her doctor’s appointments. Frances remained in day care to help maintain a sense of normalcy in her life and ensure mama could get some much-needed rest.

“I was okay with losing my hair,” Annie shared. “It wasn’t a priority for me.” When her hair began falling out, Mike shaved her head. “We laughed and cried. It was surreal.”

She and Frances had fun taking turns wearing her wig. “Frances didn’t really know what was going on, which was a blessing. But she knew things were different. I needed to get through this for her.”

While at her treatment center, Annie learned of the Coalition. She attended a Breast Cancer 101 session shortly after her first chemo treatment and stayed afterward to attend a Brown Bag lunch. “I was so blown away by the kindness of everyone at the Coalition. I felt a sense of community that I will always be grateful for,” Annie reflected. She was soon connected with a PALS mentor; another young mother who had finished her treatment and was doing well. It helped. “It was extremely comforting to talk to someone who really understood my fears and how I was feeling both physically and mentally.”

When chemotherapy ended, it was time for Annie to consider her next steps. She and her surgeon came to the conclusion that a mastectomy would be in her best interest. Annie also made a difficult but well-considered decision to remove the other breast at the same time. In addition, she opted for reconstructive surgery. Tissue expanders would be inserted at the time of surgery and gradually expanded with injections of saline solution over the following months. When this process was complete, the expanders would be surgically removed and replaced with permanent implants. Afterwards, twenty-eight rounds of radiation therapy would take place over a 6-week time period.

“I did well with surgery and radiation,” Annie recalled. Her side effects were minimal, and she felt the light at the end of her tunnel was growing brighter. Chemotherapy had begun in April of 2017 and her bilateral mastectomy took place the following September, followed by several procedures to complete the reconstructive process. Radiation ended in February the following year. All the while, HER2-targeted therapy continued. Annie completed all treatment in May, 2018.

“I am fortunate I have such a good support system. I’m so lucky,” she gratefully noted. Among Annie’s strongest supporters are her loved ones, friends, health care providers, and the Coalition. It was at the Coalition she found healing through Gentle Yoga classes, Mindfulness and Meditation sessions, and Voices and Vision writing workshops.

With her cancer treatment behind her, Annie returned to work. But the axis on which her world revolved had shifted. She began to seek — and soon found — a new position. She is now a staff member at a local cancer center, where she frequently interacts with recently diagnosed patients. It’s a perfect fit for her.

“I’ve always had empathy,” Annie observed. “But now I see everyone differently. I had no concept of what a severe illness meant, and I’m so grateful for all the people who came out of the woodwork to help me and my family.”

As a recent graduate of our PALS Mentor training, Annie is using her experience and hard-won wisdom to reach out to others in our survivor community. She offers her insight and reassuring presence while walking alongside others more recently diagnosed.

“I’m forever changed,” Annie added as our conversation drew to a close. “I feel privileged that I’m doing well and grateful for the connections among survivors.” Those connections make a difference. And Annie is making a difference for others. We at the Coalition are grateful that this empathetic, empowered young survivor chose to walk among us.

1. seer.cancer.gov/statfacts/html/breast.html
2. cancer.gov/publications/dictionaries/cancer-terms/def/her2-positive, cancer.gov/research/progress/discovery/her2
Betty Digby

By Lori Meath

Betty Digby, whose volunteer work has been going on since before I started here seven years ago, is the ultimate unsung hero. A steady, completely reliable, calm, and energetic woman, Betty rises very early each morning. She worked for years at Sam’s Club, and is accustomed to being up and drinking her coffee when many of us still have hours to go before the alarm goes off.

A long time survivor of breast cancer, Betty recently completed treatment for a recurrence of the disease in 2019. In her usual no-nonsense style, she proclaimed it “good timing” as Sam’s Club had recently closed and she would, therefore, have time to dedicate to the needed surgery and chemotherapy!

In September of 2019, Betty missed the Artrageous Affair for the first time in many years. During each previous year, she had been the “ballroom sitter”; a vital role for security reasons, but long, lonely and boring. Betty didn’t mind in the least; she simply brought along a diversion and sat. For hours.

A frequent volunteer at our Lilac Festival booth, Betty generally takes several shifts each year. Rain or shine, cold or blazing hot, she shows up and, with her typical low key humor and steadfast attitude, strikes up conversations with all who stop at our booth.

Betty’s versatility and easy-going nature have equipped her for life’s bumps, and her recent recurrence seems to have dimmed neither her positive attitude nor her energy. Wanting to get back to work, she started work at Churchville-Chili schools last year. Her position, she announces with an impish smile—LUNCH LADY!

Churchville-Chili students are lucky to have her. And so are we. Thank you, Betty!

PALS Update

By Pat Battaglia

Cancer is complex. So are the individuals affected by the disease. And often, so are the decisions patients must make. Relying on evidence-based medical recommendations from health care providers is crucial. It also helps to talk with others who have faced similar decisions and are living with the outcomes of those decisions.

For the newly diagnosed, it is often through connecting with others who are surviving and thriving in the aftermath of their own diagnosis and treatment that a clearer idea of living with the results of their medical decisions begins to emerge. When the only way out is through, it can help to know that others who have made similar decisions are not just somewhere ‘out there’ in the world, one of them will contact you personally and share their experiences. This is what our PALS mentors do for those recently diagnosed with breast or gynecologic cancer. They are the voice of lived experience in the realm of decisions that can be life-changing.

Each year, we hold a training session for a new group of PALS mentors. This past February, we were pleased to welcome fifteen mentors to our program after an intensive, day-long session full of information with a little fun and laughter thrown into the mix. Mentoring is a big commitment, one we take seriously at the Coalition, but who are we if we can’t share some joy as well?

As we welcome our new mentors into the program, we celebrate the wealth of experience they bring to our already diverse group. All our mentors offer their experience to those more recently diagnosed, meeting them where they are and revealing the human side of an unwelcome diagnosis.

To learn more about PALS or connect with one of our mentors, please contact the Coalition.
OUTREACH DIRECTOR UPDATE

Survivors Most Welcome!

In 2019, the Breast Cancer Coalition had a presence at over 80 workplaces, health fairs, festivals, Lunch-n-Learns and other educational events throughout the Rochester area. In addition, a Coalition representative made an appearance at 28 Community-based fundraisers to accept donations and express our gratitude for their support. We personally delivered a couple thousand Voices of the Ribbon each quarter to dozens of area facilities; and we produced three major fundraising events of our own utilizing the people power of a couple hundred volunteers.

It takes a BIG village, and there is no doubt that the voice of a survivor- one who has used and been helped by our services- carries an especially powerful message!

Do YOU, who have benefitted so much from what the Coalition has provided, have the time and the heart to “pay it forward”? Can you spend a few hours with other volunteers at the Lilac festival, listening to the stories of the people who stop by our booth to purchase a ribbon pin or pick up our newsletter? Are you someone who can accept a generous check on our behalf, expressing the gratitude of our Coalition and perhaps sharing a bit of your own story? Can you articulate what it means to be involved with our advocacy or research committees?

We need you. The community needs you. Can you help?

LEARN MORE ABOUT OUTREACH

(585) 473-8177 x 304
Lori@BreastCancerCoalition.org

FASHIONABLY CHARITABLE

Our favorite places to shop just happen to be woman-owned and have become dear friends!

Deb DiShaw-Smith runs Deborah Jean and Company with shops on West Ridge and Park Ave. Her annual Fight Night Fundraiser is a celebration of beautiful, affordable fashion and the fighting spirit of women facing breast cancer. This year’s event was held at her newly opened Park Ave. location and featured two of the Coalition’s survivor staffers, Miriam and Ali. A delightful evening of camaraderie resulted in raising $2,017 for the Coalition.

Pittsford neighbor SJ’s Boutique hosted an October trunk show and month-long promotions for our benefit. In addition to the latest Fall and Winter fashions modeled by loyal customers and breast cancer survivors, attendees enjoyed refreshments and many bargains. Owner Shirley Joseph revels in welcoming new and old friends into her beloved shop, and enjoyed the event as much as the shoppers! Thanks to SJs for raising $2,100.

Chandelier’s of Pittsford hosted a 20% evening in honor of breast cancer awareness month and succeeded in raising a $222 donation.

CARING CAR DEALERS AND SHOPS

Tradition Automotive brothers/owners Dario and Makis Hodge have a strong commitment to the Newark and Geneva communities in which they do business. They support many area charities and we are grateful for their October effort that raised $2,091!

Relative newcomers to Rochester’s business community are the great young entrepreneurs of Balkan Motors, Dino and wife Selma Ramusovic. They are doing business in East Rochester and are anxious to invest in the good works of the community. Thanks to Balkan for their gift of $1,100.

We were thrilled by a visit from West Herr BMW bringing their check for $838.41. What a terrific unexpected pleasure! We really enjoy the chance to show our donors where their donation dollars go.

The local franchise of Auction Direct USA likewise surprised us with a generous donation of $1,800!

Continued on next page.
YOUNG ATHLETES, BIG IMPACT

The Fairport Little League organization is a “family.” Vice President of Operations Lou Bianco is a beloved member of that family and is also the husband and father of breast cancer survivors Diane Bianco and Rosemarie Morrison, diagnosed with breast cancer in 2017 and 2018 respectively.

The organization recognized and honored these women and many more friends and family by raising $1000 for the Coalition, which was presented to us by Lou and Rosemarie.

We are so grateful to the young players of the League for their efforts, supported by your wonderful families and the support of their families - at home and on the field! The Chili Fusion Girls Soccer community hosts a variety of fundraising endeavors for the Coalition leading into October, culminating with a daylong tournament at Davis Park in Chili. These hard working, hard playing young ladies and their parents and coaches raised an astounding $3,000 this year for us. WOW.

And over the net it goes at North Rose-Wolcott School! Their Varsity and JV girls’ teams garnered the enthusiasm and support of their school community and donated $589.75 to us.

Spencerport Swim and Dive teams once again held their Pink in the Pool event. Accepting donations in memory and honor of those who have faced breast cancer, they raised $875. We appreciate your ongoing support, Spencerport.

SCHOOLS WITH HEART

Irondequoit High School staff raised $121 with the ever-popular Jeans Week.

We received $600.08 from the Honeoye Falls PTA. In recent years, they have gathered donations to honor a beloved teacher and other parents and staff who were diagnosed with breast cancer.

The Caledonia-Mumford Teachers Association generously donated $205.

FIT AS A FIDDLE

The Warrior Factory in Henrietta is a Ninja-style training facility that is essentially a gigantic indoor playground of challenges for adults and young people. The efforts and enthusiasm displayed as the athletics climb, swing, jump, maneuver and race is matched only by their generosity. This year’s evening October Evening Gym raised $1,000 to support our programs and services.

Coordinating a multitude of events at both the Pittsford and Greece locations of the Rochester Athletic Club for Women kept Brooke Reed VERY busy in October! Brooke and her hardworking staffs held a variety of classes in a “fitness crawl” format to raise money for our Coalition. They were most certainly successful, raising $2,208.55.

ROC & Soul Fitness is a new, high energy fitness center run by Malena and Joey Guadagnino in Webster. With the help of family and friends, they hosted a drop in fitness class fundraiser and raised $180.

The lovely yogis at Chili’s Yoga and Wellness by Betsy and Jodi donated $50 in honor of breast cancer awareness month.

HAP HAP HAPPY AT THE ARCHIVE

One of Rochester’s most eclectic and fun stores has once again hosted Happy Hour at the Record Archive for our benefit. Thank you to this spirited and unique staff and their customers for raising $400 in October.

STEAKS FOR ALL!

Our longtime supporters the Duke Company once again hosted what has to be the most generous client appreciation event ever when they welcomed nearly 1100 area contractors and municipalities for a steak lunch with all of the trimmings. Welcomed by CO-owner David Terry, guests feasted on charcoal-grilled steaks and enjoyed nearly a dozen accompaniments. They were also invited to purchase high end work clothing at bargain basement prices, with ALL proceeds benefitting the Coalition. This festive winter afternoon resulted in our receiving a gift of $1,406 from Duke’s customers and friends.

FAMILY BUSINESS, SUPER SUPPORT

Triano’s Meat Market is the kind of old-fashioned neighborhood market...
where the service is exceptional and butcher knows just what you want for dinner. A family-run market, they are an integral part of a caring community. When one of their own was recently diagnosed with breast cancer, they invited their customers to show support by making a donation to the Coalition. They ran a variety of specials and raffles and accepted direct contributions, raising $1,067 which will support our regional research initiative. We wish good health and healing to owner Linda.

WORKPLACE GIVING

Fundraising efforts in area workplaces result in vital funds for our work in the Rochester region.

We thank Fairport Savings Bank for a gift of $75.

Kudos to Wester Regional Off-track Betting for your $300 donation.

Worldwide Electric Company had a great time with Blue Jeans Friday in October and sent us $525.

Our friends at Kittleberger’s ran a “cluster of pink roses” special for October and was pleased to give us $420.

Local IT company BioOptronics’ employees donated $237.

The Rochester branch of worldwide TraceLink honored breast cancer awareness month by donating $1,000.

The Gates Fire District raised $648 for us; THANKS!

The “workplace” of the over 500 professional firefighters of the Rochester Fire Department is spread over 18 companies in 15 neighborhoods in Rochester. All the same, they are a tight-knit group whose lives are dedicated to making Rochester a safer, healthier place to live. Together they created a special T shirt for October and managed to raise an incredible $2,065 for the Breast Cancer Coalition.

ART WITH HEART

The considerable talent of Rochester artist Cindy Cowley Folkins was on display at Hector Handmade throughout October where portion of October’s sales benefitted our Coalition. Linda, we are deeply appreciative of your kind donation of $1000 from those sales!

NOSHING IN THE NEIGHBORHOOD

Continuing to gift us with a donation from the sale of each “Pollo Loco” signature dish, our neighbors at Nosh wrapped up 2019 with their last-quarter gift of $963.

LAUGHTER- GREAT MEDICINE!

Finding the (irreverent) humor in just about every situation is the talent of Cindy Arena and her merry friends. Cindy once again gathered Rochester’s best comedians for an evening of side splitting laughter at Flaherty’s in Webster. She also gathered donations of fun raffle items, and Jokes for Jugs managed to raise $718. Now that’s no joke!

LET’S STRIKE OUT BREAST CANCER!

The Breast Cancer Coalition has been blessed to be on the receiving end of the proceeds of not one, but two large bowling tournaments each year. The last issue of Voices of the Ribbon highlighted the indomitable Kathy O’Neill, who has coordinated her Pink Bowl for nearly 18 years and given us over $150,000 in that time.

Like Kathy, Doug Phelps is the single driving force behind his annual Doug Phelps Breast Bowl. On October 19, Doug and a steady group of close friends wrapped up their 9th effort on our behalf. Hosted in recent years by Bowl a Roll Lanes on Jefferson Rd., the effort caps a full year of preparation spent gathering the over-200 silent auction items that have enabled Doug’s cumulative donation to exceed $62,000!

This year, Doug “bested” his own best once again. Because of his hard work, big heart and endless energy, Doug Phelps’ 2019 Breast Bowl raised $15,015. Thanks seems pretty inadequate, Doug, but THANKS!

Planning a fundraiser? For guidelines and assistance contact Lori at (585) 473-8177 x 304 or Lori@BreastCancerCoalition.org.
Thank You, Donors!

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. Please join us in thanking the following individuals, companies, and organizations for their generous contributions between October 1 - December 31, 2019.

IN HONOR OF:

All Breast Cancer Survivors
L. Edith Parris
My 2nd Survivor Anniversary
Linda Rice
Being 5 years cancer-free
Gail Renehan
My 63rd Birthday
Nancy Gramke-Cuer
My mother & sister
Deborah Goodwin
My sisters Jackie & Judy, and friend Courtney
Bonnie Morrison
A friend
Judy-Ann West
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Nancy Weinmann
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Patti Cataldi
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Nancy Gramkee-Cuer
John Gramkee

BCCR Voices & Vision
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Melody Nettinin

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My dear sister, Mary
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My sisters Barb & Kathy
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Terri Schmitt
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LEADERSHIP OPPORTUNITY
The Breast Cancer Coalition is currently considering candidates for service on our Board of Directors. The Coalition is seeking volunteers for the July 2020 cohort interested in advancing the mission of the Coalition via a rewarding leadership opportunity. Service is for a term of two years. Details regarding expectations for directors and the desired qualifications for service can be found at www.breastcancercoalition.org/people. If interested, please contact Executive Director Holly Anderson at holly@bccr.org.

Thank you in advance for your interest in supporting the Breast Cancer Coalition.

W I S H L I S T
- Burt’s Bees Lip Balm (sealed, no mint)
- computer paper, white
- ear plugs (individually wrapped)
- fleece throws/blankets, lap quilts
- journals for writing
- lotion: Alaffia Purely Coconut lotion
- note cards, notepads (bound at top)
- paper products: napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam)
- sleeping masks, lavender or unscented only
- tea: black pekoe, green, herbal, and flavored, in unopened boxes or tins
- thank-you cards (unopened packs)
- Dyson vacuum cleaner (new please)

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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 and gynecologic cancer diagnoses, their supporters, and care providers.

In addition, it is intended to impart accurate, science-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.

All contents of Voices of the Ribbon are the sole property of the Breast Cancer Coalition, and are not to be reprinted or copied, in whole or in part, without the express permission of the Editor. Direct all inquiries to pat@BreastCancerCoalition.org or phone (585) 473-8177. If you prefer to receive Voices of the Ribbon via email please let us know.

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E-Mail: info@BreastCancerCoalition.org
Online at www.BreastCancerCoalition.org

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

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