Breast Cancer Coalition Awards $100,000 to Regional Researchers  -By Dominique Boller

On Tuesday, March 22, 2016, the Breast Cancer Coalition of Rochester hosted a Breast Cancer Research Initiative Grant Award Ceremony, during which two $50,000 grants were awarded to researchers in the Upstate New York Region. Nythia Kartha, Ph.D. Candidate, and John Schimenti, Ph.D., Professor of Genetics at Cornell University, Department of Biomedical Sciences, received funding for work on precision genomic therapy for breast cancer. Sharon S. Evans, Ph.D., Professor of Oncology at Roswell Park Alliance Foundation, Department of Immunology, was awarded for her investigation of the role of T-cell based immunotherapy in metastatic breast cancer.

Grant recipients are selected via a competitive application and review process that begins in

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Scientific Reviewers
Dr. Gunhilde Buchsbaum  
(University of Rochester Medical Center)
Dr. Nick Gonchoroff  
(Retired, Upstate Medical)
Dr. Kelley Madden  
(University of Rochester Medical Center)
Dr. Tracy O’Conner  
(Roswell Cancer Institute)
Dr. Robert Weiss  
(Cornell University)

Survivor Advocate Reviewers
Alison Currie
Jennifer Gravitz
Kathy Simpson
Jeanne Verhulst

Tee'd Off At Breast Cancer Golf Tournament 7.25.16 Brook-Lea Country Club
I am writing this column on the very first day of SPRING. We made it! Spring, especially here at the Coalition, is a time of rebirth and inspiration. And what are we up to in the coming year? At the top of the list is program development.

How does any program come to be at the Coalition? More often than not, we glean the best ideas from you, our program participants. Your willingness to share your thoughts is essential to how we think about new offerings.

Prior to developing any new program, I ask the following questions:
1. Does this program fit our mission? (See mission at left.)
2. Who and how many people would benefit from such a program? High attendance is not always a criterion, but program popularity is important to potential funders. Let’s face it, developing a program that few attend is not ideal for anyone, including participants.
3. Is the program planning team and Coalition staff on board? Are stakeholders represented? To answer this, we use focus groups, a demographically diverse group of survivors assembled to participate in a guided discussion about a potential program before we consider proceeding.
4. How does it fit with our strategic plan?
5. Are requests for this type of program repeated in current feedback mechanisms? This would suggest support from stakeholders, which translates to high enrollment.
6. Does another nonprofit group in the community currently offer a similar - or identical - program? Not wanting to undermine the efforts of other groups, we support collaborations whenever possible.

Currently, the Coalition is developing a program that would address concerns expressed by some who take aromatase inhibitors following active treatment for breast cancer (surgery, chemotherapy and/or radiation). Aromatase inhibitors stop the production of estrogen in postmenopausal women by blocking the enzyme aromatase, which turns androgen (a precursor to estrogen) into estrogen in the body. As a result, less estrogen is available to stimulate the growth of hormone-receptor-positive breast cancer cells. And that’s a wonderful thing! These drugs include Aromasin (exemestane), Arimidex (anastrozole) and Femara (letrozole). Though not always, aromatase inhibitors can cause joint pain or stiffness, sometimes resulting in a desire to stop taking the drug. And some may find their activity level diminished or impaired, which, in turn, can lead to weight gain; a discouraging development.

We asked the question: how might survivors effectively cope with these side effects without additional medications? Based on our own experiences over the years, we have identified some effective strategies. Unfortunately, finding hard evidence that these strategies work has proved challenging. But we listened to you. We heard you. And now we are taking action.

“Perseverance is a great element of success. If you only knock long enough and loud enough at the gate, you are sure to wake up somebody.”
~ Henry Wadsworth Longfellow

Do you have a program idea? This is how it begins. Never forget that we are here for you. »
Carol Holtz-Martin - wife, daughter, sister, friend of many, and pastor of a Baptist congregation - went for her annual screening mammogram in April of 2014. Well familiar with this yearly ritual, Carol was also acquainted with the experience of being called back afterward for further imaging. As a woman with dense, cystic breasts, she experienced these frequent call-backs as merely bothersome; to that point, they had revealed only benign conditions. So it was a slightly annoyed Carol who returned to the imaging center that early spring day for more testing. But hours later, she emerged shaken. Interspersed with long waiting periods, multiple images had been taken and a biopsy was conducted. With the results forthcoming, Carol felt ill at ease with the whole experience.

Carol's social worker friend was also a friend of the Coalition. “Call them,” she urged as she handed over the phone number and, before long, Carol found herself talking with Jean Sobraske, the Program Coordinator at the time. Jean listened compassionately and scheduled a Breast Cancer 101 session. Soon after this session, and two weeks after her diagnosis, Carol attended her first Brown Bag lunch. Noting the tremendous learning curve in coming to understand everything she needed to move forward with her diagnosis, Carol shared that “I felt like I had just walked into graduate school with my kindergarten diploma.” She realized just how much her diagnosis and the resulting emotional turmoil had affected her family when, upon her return home from Brown Bag, her husband asked “Can they meet every day?”

After weeks of anxious waiting, Carol awoke on the morning of her surgery feeling strangely calm and peaceful. She surprised herself when she picked up a lipstick and wrote on her mirror an admonition from a close friend of many years, as only this type of friend can offer: Suck it up, princess. “It made me laugh,” Carol recalls. A colorful butterfly sat in her driveway as she prepared to leave for the hospital, and as her husband maneuvered the car to avoid hitting it, Carol felt a deepening sense of awe at the beauty and fragility of life. Friends gathered at the hospital to pray before Carol was taken to surgery, and her surgeon joined them.

“I felt like I had just walked into graduate school with my kindergarten diploma.”
~Carol Holtz-Martin at Brown Bag
The Coalition’s Advocacy Committee stands out as a strong and robust model of how legislative advocacy can be done.

Statewide, we are credited for having a major impact on the passage of the Compassionate Care Act, New York’s law to allow providers to prescribe medical marijuana under controlled circumstances. Work continues to ensure that the CCA is implemented quickly and with the broadest possible scope.

On the national front, the National Breast Cancer Coalition (NBCC) agenda stands with four items:

1. **The Accelerating the End of Breast Cancer Act (AEBC)** (H.R. 1197, S. 746): the legislative component of NBCC’s Deadline 2020® campaign, with the goal that by January 1, 2020, we will know how to end breast cancer. (www.breastcancerdeadline2020.org)
2. **$150 Million for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for FY2017**: an innovative and efficient medical research model that has produced extraordinary results, funding must be re-appropriated every year. http://cdmrp.army.mil/bcrp/
3. **Guaranteed Access to Quality Care for All**: identifying and advocating for the implementation of laws to ensure access to evidence-based health care.
4. **Ensuring the Participation of Educated Patient Advocates**: training and empowering patient advocates to have a “seat at the table” in all levels of health care decision making.

Other legislation has also attracted our attention, including:

- **CARERS Act of 2015**: The Compassionate Access, Research Expansion, and Respect States Act – (S.683) would reclassify cannabis from a Schedule I to Schedule II drug and amend enforcement provisions for cannabidiol use, allowing researchers to move forward and opening other possibilities for medical cannabis use.
- **Frank Lautenberg Chemical Safety Act** (S.697): this would regulate known endocrine disrupting chemicals.
- **The Safe and Accurate Food Labeling Act** (H.R. 1599): dubbed the DARK Act (Deny Americans the Right to Know), this bill, already passed by the House, preempts state and local authority to label and regulate genetically engineered foods.

**Join us at an Advocacy Committee meeting to learn more!**

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**Advocacy Chair’s Update**

**What We’ve Been Following**

In February, the Advocacy Committee held a movie night and screened *Happygram: The Movie*. Director Julie Marron’s first feature length documentary, Happygram is the culmination of several years of research into the issue of informed consent in medicine, particularly within the area of cancer screening. The subject of the film is, specifically, mammograms. It explores questions surrounding the number of times abnormalities are not spotted on mammograms due to dense breast tissue. The film was one of the top documentaries of 2015 and can currently be seen on Vimeo.

After months of waiting, the medical marijuana dispensary in Rochester has finally opened its doors for business. Columbia Care opened in late January 2016 at the Eastman Business Park on Ridge Road. It is currently offering limited medical marijuana products with the plan to expand their offerings soon. While this is undoubtedly a good thing for many patients in the Upstate New York area, there are still hurdles to be overcome. For example, a list of physicians who have completed the New York State Health Department education requirement needed to prescribe medical cannabis is available to physicians; however, it is not available to the public. This is hindering the ability of some eligible patients to access the medication. A list of conditions that qualify a patient for medical marijuana, along with other helpful information, can be found on the Compassionate Care New York and New York State Department of Health websites: www.compassionatecareny.org, www.health.ny.gov/regulations/medical_marijuana

Members of the Advocacy Committee have been following various environmental agencies to explore some of the issues they are working on and zero in on those that may impact breast cancer survivors and the work we do at the Coalition. We have come across a couple of smartphone apps that help consumers avoid exposure to toxic chemicals found in many household and personal products.

- **Detox Me: Created by the Silent Spring Institute**, this app offers detailed information regarding many household and personal products.

*Continued on page 13*
Although the Lymphedema Awareness Month of March is past, any time is a good time to learn about this misunderstood and often misdiagnosed condition. It is estimated by the Lymphatic Education & Research Network (LE&RN) that up to 10 million Americans live with lymphedema and other lymphatic diseases. Many live with the disease for months, years or even decades before they get a proper diagnosis and treatment.

Lymphedema happens when lymph fluid, which carries away protein-rich cellular waste via lymphatic vessels and is filtered through lymph nodes, gets blocked. Over time, the affected part of the body swells with this stagnant fluid. If left untreated, there can be discomfort and pain, disfigurement, loss of mobility, and the risk of cellulitis, an infection that can cause life-threatening complications if left untreated.

There are two types of lymphedema. Primary lymphedema occurs when people are born with a faulty lymphatic system. They may have swelling at birth, or during childhood, or later in their lives. Secondary lymphedema is caused by surgery or injury. Lymph nodes or vessels may be removed or damaged during surgery or radiation as part of cancer treatment. Trauma to the lymph system can also be caused by an accident or non-cancer surgery.

To date, there is no known cure for lymphedema. Still, there is a lot of good news.

There is treatment that lets people manage their lymphedema so they can live healthy and active lives. Known as complete decongestive therapy, or CDT, this gold standard of treatment is a combination of manual lymph drainage (a special type of massage that helps drain fluid from the affected part of the body) along with wearing compression garments and/or bandaging the affected body part to reduce swelling. Vigilant skin care to minimize the risk of infection and exercise to help circulate lymph fluid and increase range of mobility are helpful strategies for those at risk for lymphedema, and for overall good health.

In the Rochester area we are fortunate to have several certified therapists who can effectively administer CDT and guide you to a self-maintenance routine.

There are many resources available to educate people and medical professionals about lymphedema: what it is; who is at risk; how it can be treated and managed; and what can be done to promote research, better and more affordable treatment, and hopefully, a cure.

In the Rochester area we are fortunate to have several certified therapists who can effectively administer CDT and guide you to a self-maintenance routine.

Lymphedema can be scary and isolating. But bolstering yourself with knowledge and taking steps to find treatment and support will make you feel less alone and more confident about managing the condition so that you can live your life to the fullest. ✓

Karen Miltner is a 3 1/2-year endometrial cancer survivor who facilitates the Lymphedema Awareness Network at the Breast Cancer Coalition on the second Wednesday of the month at 5:30pm. All are welcome.
Living With Advanced Breast Cancer

Angela Martin
-By Pat Battaglia

In 2010, at the age of 34, Angela Martin was diagnosed with breast cancer. Angie (to those who have the good fortune to know her personally) quickly became a familiar and much-loved figure in the Coalition’s survivor community. She and another young survivor, Kathy Cook, met in the hospital while recuperating from surgeries done on the same day (read this fascinating story in the Summer 2011 issue of our newsletter*) and the pair went on to represent the Coalition at the 2012 Conference for Young Women, a national event for those diagnosed with breast cancer. They wrote about their experiences in our Summer 2012 issue, and have since attended the annual event on their own.

In November of 2015, Angie postponed a 5-year follow-up visit with her oncologist due to an upper respiratory infection. When symptoms worsened, she went to an urgent care facility, where a chest x-ray was ordered. Nodules were seen on the film and Angie was referred to a pulmonary specialist. “I was kind of in shock,” she notes, and returned home to send her husband a text: “Hey, if you can come home early, it would be great. Don’t call, just come home.” Upon his quick return home, he bolstered Angie’s spirits with the hope that maybe this wasn’t cancer at all.

An avid snowmobiler, Angie went out that weekend and bought herself a new snowmobile. “I caught my wind in my moment of shock,” she says with a smile.

When further testing revealed that the cancer had indeed returned, affecting Angie’s lungs and brain, her husband, extended family members both local and in Virginia, and her health care providers rallied alongside this spirited young woman. And the urgent care doctor whose suspicions were, unfortunately, confirmed, has shed his health-care-provider role and become a caring, knowledgeable advocate. “It was a good point of contact,” Angie reflects.

Chemotherapy began in early December, and after two treatments, was halted temporarily for radiation to the brain. Angie learned she was a candidate to participate in a clinical trial of a new type of brain radiation in which the hippocampus - the area associated with memory, among other things - is spared. She willingly signed on to this study and underwent two weeks of daily treatments. “I’m a very firm believer that you have to be your own advocate,” Angie avows, and when her first treatment produced troubling side effects, she spoke up. She and her medical team determined that steroids might alleviate her symptoms, and Angie took the medication with each subsequent treatment. “From there on out, [radiation] was smooth sailing,” she recalls.

With radiation behind her, Angie resumed chemotherapy and returned to her job, which involves frequent traveling. She can also be found riding the trails on her snowmobile whenever she’s able and the weather permits. Her husband, her family, and her faith sustain her, and she has found new friendships and camaraderie among the members of our Common Ground support group for those living with metastatic breast and gynecological cancers.

Among so many other life lessons learned along the way, Angie emphasizes that “It’s okay to say no and put a period after it.” Pursuing her passions has taken on new meaning for Angie, and in prioritizing her own life wishes and goals, she has found herself unapologetically refusing to take on things that might stand in her way.

A spirited, intelligent self-advocate long before cancer complicated her life’s journey, Angie carries all of her strengths in her walk with advanced breast cancer and has inspired many. It’s an understatement of epic proportions to say that cancer picked the wrong girl in Angie’s case. But it’s unequivocally true. With a period after it.

*All back issues are archived at our website: www.bccr.org
Dr. Wakenda Tyler is an Assistant Professor in the University of Rochester Medical Center’s Orthopaedic Oncology, Metabolic Bone Disease, and Adult Reconstruction Department whose goal is to provide compassionate surgical care to cancer patients with metastases to the bone. She graciously agreed to answer some questions for our publication.

**Pat:** What drew you to orthopaedic oncology?

**Dr. Tyler:** When I started medical school, I knew I wanted to do something that would involve caring for patients with cancer. This stems from an experience I had in college when a close friend and mentor passed away from breast cancer. I didn't know much about orthopaedic surgery when I first started medical school, but when I was exposed to it as a surgical field in my second year, I was quite fascinated. As an athlete myself, I was drawn to trying to understand the mechanics and anatomy of the musculoskeletal system. When a mentor introduced me to orthopaedic oncology, I realized I could combine my love of the musculoskeletal system, surgical interest, and desire to care for patients with cancer all in one. I was set on my course from that point forward.

**Pat:** What types of advanced breast cancer patients do you typically see?

**Dr. Tyler:** As an orthopaedic oncologist, I play several roles in patients with breast cancer. In many cases, patients are sent to me after being diagnosed because an incidental small benign "lesion" is found in the bones during routine imaging. Often, the medical oncologist will count on me to verify that the lesion is not related to the cancer diagnosis. Unfortunately, my other role is when patients are diagnosed with metastatic disease that has spread to bone. In those instances, it is my job to make sure that the integrity of the bones has not been compromised by the cancer and if so, I will either recommend radiation or surgical stabilization of the bone. I perform the surgery in those instances.

**Pat:** What should patients facing bone stabilization surgery know beforehand?

**Dr. Tyler:** I only recommend surgery when it is absolutely necessary because problems such as wound infections, nerve damage, and surgical pain can occur. Having said that, the vast majority of patients do not have complications and recover from their surgeries within a few weeks. In most cases, patients return to full function and sometimes better function (because of better pain control and bone stability) within six weeks.

**Pat:** Are there any new developments in orthopaedic surgery on the horizon for those with bone metastases?

**Dr. Tyler:** The major developments are in our ability to perform more minimally invasive surgeries that can stabilize bones. This allows patients to start ambulating right after surgery. The other major help is the use of bisphosphonates (like Zolendronic acid) and RankL inhibitors (like denosumab), because these agents can reduce the likelihood of someone developing pain from a metastatic lesion, or of a fracture occurring, which ultimately means fewer patients needing surgery. I like my job, but that is the ultimate goal of many of things we do for patients with metastatic breast cancer.

**Pat:** We hear you, Dr. Tyler, and we also hope to be able to close our doors at the Coalition one day because we're no longer needed. Until then, we're grateful for the high level of expertise available in our area thanks to compassionate providers like you.
Among a plethora of information to process after a breast cancer diagnosis is knowing the hormone receptor status of the cancer. Gleaned from the pathology report, this may seem confusing to those hearing it for the first time, but it impacts the treatment decisions that lie ahead.

Hormone receptors are specialized proteins found on and within cells. Specific hormones bind to their corresponding receptors, and are then able to direct cell growth and reproduction. About seventy-five percent of breast cancer tumors contain abnormally large numbers of receptors for estrogen and or progesterone, and are thus labeled as estrogen receptor and/or progesterone receptor positive. In these cases, the naturally occurring hormones fuel tumor growth. Hormonal therapies to treat this common cancer subtype effectively limit the amount of estrogen available to cells, reducing the risk of recurrence in early stage cancers and impeding the growth of advanced cancer. This is not to be confused with hormone replacement therapy, which is sometimes prescribed to alleviate the signs of menopause.

Ninety five percent of estrogen in premenopausal women is produced in the ovaries. Reducing or eliminating ovarian function for these women can be accomplished medically, surgically, or with radiation. The most commonly prescribed medication for this purpose is a five or ten-year course of Tamoxifen, a selective estrogen receptor modulator (SERM) that binds to estrogen receptors, blocking the action of the hormone on them.

After menopause, a smaller but still significant amount of estrogen is produced through the action of an enzyme called aromatase, which converts androgens (hormonal precursors) into estrogen. A class of drugs known as aromatase inhibitors (AIs) hinders this process. AIs do not stop the ovaries from producing estrogen, so they are ineffective for premenopausal women.

The three AIs currently in use are Arimidex (generic name anastrozole), Aromasin ( exemestane), and Femara (letrozole). Each is available as a pill taken once daily for five to ten years, depending on individual circumstances.

AIs lower recurrence rates and improve disease-free survival rates in menopausal women more effectively than Tamoxifen, but with a different side effect profile. While Tamoxifen users show a slight increase in the rate of uterine cancer and deep vein thrombosis, those on AI therapy experience the effects of estrogen deprivation, including a higher rate of musculo-skeletal side effects. Body aches and joint pain have been shown to be more common in those taking AIs, affecting up to 50% of patients on the medication.

Personal Experiences Vary

Maria Mendicino, a breast cancer survivor since 2013, has been taking Femara for well over two years. When joint stiffness occurred in her hands, she consulted a physical therapist, and her pain improved in about a month. Other side effects - hot flashes, decreasing bone density, and increasing cholesterol levels - have been a concern, but Maria soldiers on. “I am thankful to have something which could prevent a recurrence of breast cancer,” she shares. “To me, cancer is worse than what I have so far experienced.”

AI-induced arthralgia is considered to be the top reason for a high rate of noncompliance (not taking the drug as often as prescribed or stopping it altogether) among those taking the medication. Noncompliance rates have been estimated from 13-22% in different studies, climbing higher with the passage of time. Another study found that only 50-68% of women were adherent to their AI at three years.

The causes of AI-induced arthralgia aren’t well known and there is no established treatment. But that is not to say that there is no treatment, and researchers are investigating ways to mitigate the pain. Among them are some local researchers. Karen Mustian, Ph.D., M.P.H., of the University of Rochester Medical Center (URMC), investigated the effects of her specially created YOCAS (Yoga for Cancer Survivors) program on cancer patients, releasing the results in 2010. She found program participants experienced relief of many of the symptoms and side effects of cancer treatment such as pain, fatigue, sleep quality, and overall quality of life. At a recent Coalition Evening Seminar, Dr. Mustian reported that her URMC colleague, Luke Peppone, Ph.D., recently used her data to focus on those in the YOCAS study taking AIs. He found that musculoskeletal symptoms decreased in severity for this group, concluding that further study is needed to confirm and expand on his findings.

Aromatase inhibitors, like many other drugs, come with a list of side effects, some common, others rare. In-depth discussion between patient and doctor can facilitate informed decision-making, determining which medication might be...
Betsy Palozzi felt her 2014 diagnosis of endometrial cancer was a wake-up call. After undergoing a full hysterectomy and five rounds of radiation, she learned there was no evidence of disease and gratefully moved forward. A year later, pain that at first seemed to be rooted in a viral infection did not go away. Betsy’s oncologist ordered a CT scan that revealed a tumor in her groin muscle; one that, on biopsy, proved to be a metastasis of the endometrial cancer.

Betsy and her husband, Mike, were devastated. As she began to fall into the depths of depression, her primary care doctor offered two options: begin antidepressant therapy or attend the Common Ground networking and support group at the Coalition. Betsy chose the latter. “I love the support group,” she affirms, and frequently graces its members with her presence.

What does one gain from fellow survivors that cannot be duplicated in any other way? Why, despite the irreplaceable love and support of family and friends, do those in the midst of life-altering circumstances seek the company of others similarly challenged? The reasons are as varied as the individuals involved. Some may need to witness what coping looks like in the words and actions of another human being. Others might need practical tips for everyday living. Most need the empathetic listening ears of others who “get it”. Betsy shares that “In the group, we laugh and cry. Our talks aren’t always medical, but still, I’ve learned more in that group than from anyone else.” The universal takeaway for Common Ground members is that life still holds meaning, wonder, and joy.

After Betsy’s second diagnosis, the pace picked up. She began a course of aromatase inhibitors in the hope of shrinking her estrogen receptor positive tumor. But cancer can be maddeningly unpredictable; the tumor grew. Betsy’s oncologist recommended chemotherapy in the hope of shrinking the mass to an operable size. This strategy worked. Although the side effects of chemo proved to be debilitating for Betsy and the therapy was cut short, the tumor is operable and her surgery is forthcoming.

Betsy takes one day at a time as she awaits her procedure. Despite lingering neuropathy from the chemo, she takes a walk every day with Mike, who sold his business and retired early so he could walk through this with his wife – literally and figuratively. It helps.

Still, some days are better than others. “If you have to give yourself a down day, do it,” Betsy advises, acknowledging all her emotions. She continues to be a regular at Common Ground, observing that “You can’t really do it alone.”

~ Albert Camus
Our Programs at the Breast Cancer Coalition of Rochester... **all FREE of charge!**

**BC 101**
These one-to-one sessions assist the newly diagnosed in managing the complex tasks and emotions of a breast cancer diagnosis, empowering them to be self-advocates as they proceed through treatment, recovery, and survivorship. Our professional facilitators provide a safe, comfortable atmosphere where information can be absorbed and assimilated while each individual formulates a personal strategy for making informed decisions.

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

**Thursday Night Breast Cancer Support Group**
This discussion-based group, led by Peg DeBaise, LMFT, meets on the 1st and 3rd Thursday of the month from 5:30-7:00pm. This group is perfect for those who are newly diagnosed with breast cancer, or for those within the first two years following the end of treatment. No registration is required.

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

**Book Club**
If a traditional support group isn’t for you but you still like the idea of participating in a supportive community following a breast or gynecologic cancer diagnosis, join our Book Club, led by Pamela Emigh-Murphy, Carol Moldt, Jill Richards, Angelique Stevens or Karen VanMeenen, which meets on the 4th Thursday of the month, from 6:00-8:00pm. Prior sign-up is encouraged. Call us or visit us at www.bccr.org for details and latest book selections.

**Common Ground: Living with Metastatic Cancer Discussion Group**
For those living with metastatic breast or gynecologic cancers, we offer a discussion group on the 1st and 3rd Thursdays of the month at noon. Led by Peg DeBaise, LMFT, the discussion is topic-based, although all concerns of those present will be addressed. Lunch and beverages are provided so RSVP is needed.

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

**Lymphedema Awareness Network of Rochester**
LANROC provides awareness, education, and peer support for anyone living with lymphedema. Caregivers, lymphedema therapists, medical personnel, and those at risk for developing lymphedema are also welcome. This group, facilitated by Karen Miltner, meets from 5:30 to 7:00pm on the second Wednesday of each month.
For information or to register, please call the Coalition at 585-473-8177 or e-mail info@bccr.org

Peer Advocates Lending Support: PALS

In this peer mentoring program, individual breast cancer survivors reach out to those who are new to the disease, providing the reassurance of one-to-one contact with someone who’s “been there”, helping them connect with needed resources, and instilling confidence during a difficult time. Please call to learn how to be enrolled in the program after your own diagnosis, or if you would like to become involved as a mentor.

See page 12 for PALS Program updates.

Young Survivor Soiree

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

The next soiree will be Friday, June 3. Please call to be added to the attendee list.

Voices & Vision: A Writing Workshop

This well-loved group gives people with breast or gynecologic cancer an opportunity to explore and express their feelings through writing. Led by professional instructors from local colleges, Elizabeth Johnston, Pamela Emigh Murphy, Angelique Stevens and Karen VanMeenen, these workshops run in five week cycles on Tuesday evenings. Seating is limited, and advance registration is required.

The Healing Arts Initiative

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

Gentle Yoga

Now offered on Wednesday afternoons in six week sessions throughout the year. Qi Gong is facilitated by certified instructor, Raphaela McCormack. This class is limited to 14 survivors of breast or gynecologic cancer. Advance registration is required.

Ongoing Healing Arts Sessions

Courses run in four-week sessions and are open to 14 survivors of breast or gynecologic cancer. Advance registration is required.

Saturdays:

Gentle Yoga with Raksha Elmer
Nia Movement with Jane Pagano
Fluid Motion with Tracey Boccia
Tai Chi with Nancy Gillespie

Wednesdays:

Mindfulness & Meditation with Siobhan LeGros

Thursdays:

Mindfulness & Meditation with Estalyn Walcoff

Please visit www.bccr.org for the 2016 Healing Arts Program Schedule and Registration Guidelines.

Expansion of the Healing Arts Initiative was made possible by grants from The Greater Rochester Health Foundation and Excellus Blue Cross Blue Shield.
Margaret Supinski had a great idea: she would gather a group of retired friends to provide volunteer services for a local organization. But which organization to choose? She put her question to Patti Cataldi; as our Board Chair, Patti knew right where to direct her. She introduced Margaret to Holly Anderson, and thus began a warm and oh-so-helpful relationship between the spirited group of women and the Coalition.

One morning a month, these women lend their capable hands in performing essential tasks that help our organization run smoothly. From stuffing envelopes and preparing group mailings to inventorying ARTrageous Affair materials, they are happy and enthusiastic helpers, and enjoy catching up with each other in the process. The frequent laughter arising from this diligent group is infectious. It’s hard NOT to smile when they’re here!

They are: Margaret Supinski (the “Ringleader”), Dee McCreary, Donna Stendardo, Debbie McDivitt, Margy Riemer, Mary Willoughby

Margaret is the common thread in this group of friends, neighbors, and former co-workers at Alling & Cory; some of these friendships date back more than forty years. Margaret and Donna (the cousin of Sylvia Cappilino, one of our Founding Mothers) attended the Rochester Institute of Technology together. Margaret and Debbie worked together at Alling & Cory. Although all are retired, Mary and Margy are employed part time in addition to their volunteer work. Dee, sadly, lost her own mother to breast cancer.

Crowded to-do lists can seem overwhelming. But once a month, in walk Margaret and her intrepid group who willingly, cheerfully, and efficiently complete the task at hand before heading out to lunch together. As the women reinforce their longtime connections, we breathe a sigh of relief – and smile – whenever they grace us with their presence.

Thank you, kindhearted ladies, for all you do! ☺️

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### A Commitment to Each Other and to Their Community

- By Pat Battaglia

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**PALS Project**

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**In It For the Long Haul**

Since 2008, our Peer Advocates Lending Support (PALS) Program has offered the support of a trained peer mentor to those who are newly diagnosed with breast cancer, in active treatment for the disease, or dealing with its aftermath. Beginning that first year and for every year since, we have held annual mentor training sessions. Each “graduating class” has added richness and depth to the range of personal experiences represented by our mentors, ensuring that those in need have access to a one-to-one connection with someone who truly “gets it”; one who has faced similar fears, questions, and decisions.

At the close of our latest training session, which was held this past February, we welcomed eighteen new PALS Mentors to our program. Half of these were from the regional area, representing places from Lyons, NY to Batavia, NY and many points in between. With the addition of this new group, we are not only able to offer mentors who represent a broad range of experience, we are better able to serve women and men over a wide geographic area. Because there are many factors that go into making a PALS match, we can’t guarantee that everyone will receive a mentor who lives nearby. But we are working toward that ideal. A local mentor-mentee connection provides more opportunities for the all-important face-to-face meeting that rounds out the experience and enables a truly personal connection.

Co-facilitated by Holly Anderson, Peg DeBaise LMFT, Jennifer Gaylord, Tracy Brown, and me, our latest mentor training covered a lot of ground. From learning how PALS connections work, to the basics of breast cancer, to ways of offering meaningful support, the session was chock-full of information, sharing, and role-playing exercises. This training has evolved through the years so that, after spending the better part of a day with us, new mentors can leave with a solid grounding in what it truly means to walk with another person through a life-altering experience.

As so many of our long-time mentors can attest, mentoring is a two-way street. It takes time. It takes commitment. It takes willingness to be the one who reaches out, who checks in, who listens without judgement and

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*PALS - Peer Advocates Lending Support

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Continued on page 13
The Common Denominator

As I look around the room during Brown Bag Lunches, I can’t help but notice the diversity of the women who gather here at the Coalition every Friday at noon. There may be a forty year age difference between individuals attending. We hail from Hilton, Pittsford, Victor, Rochester, Webster, Canandaigua and beyond. We are mothers, grandmothers, ministers, teachers, attorneys, nurses, social workers, stay at home moms, or perhaps retired. But we share a common denominator. Our lives have each been indelibly altered by a breast or gynecological cancer diagnosis. It’s unlikely our paths would have crossed under any other circumstances, yet it is this common denominator that brings us to together.

By far our most popular support group at the Coalition, Brown Bag Friday is a haven for the newly diagnosed and the 20 year cancer survivor alike. This non-traditional, drop-in gathering for networking and mutual support is open to women - and to men faced with male breast cancer - at any point along the spectrum of diagnosis, treatment, and beyond. Each of us seeks support in different ways and at different times. Whether it’s lending an ear during a particularly challenging time or sharing a laugh over a funny experience, the empathy and caring at these weekly gatherings is palpable. First time Brown Baggers almost always leave saying, “I’m so glad I came!”

The Coalition’s goal is to meet the needs of every person who reaches out to us. We are here with you every step of the way on the journey through breast cancer, and Brown Bag is an important part of fulfilling that mission. If you have never experienced the warmth and power of Brown Bag Friday, please join us any Friday at noon. Bring your lunch, bring your questions; we’ll provide a beverage, dessert, and unparalleled support! We are here for you!

PALS Update continued

offers the lessons learned during your own walk with breast cancer. The payoff comes when you know you have touched another life for the better. Although this kind of satisfaction isn’t a reason one chooses to mentor, it is a wonderful side benefit.

We welcome our latest trainees; the newest members of this growing, compassionate group who continue to remind those facing breast cancer that they are not alone.

Email pat@bccr.org to learn more about PALS.

Advocacy Chair’s Update continued

products such as floor cleaners, lotions, shampoos and many other items. It provides a list of ingredients to look for on the labels and explains what they are. Learn more at www.silentspring.org/detoxme/

• Skin Deep: The Environmental Working Group has an app that puts all the information in their online Skin Deep Cosmetics Database at your fingertips, providing a helpful barcode scanner you can use while shopping to get the lowdown on the products you are considering. Check www.ewg.org/skindeep/app/ for more information.

If the above issues - or any other issues significant to those affected by breast cancer - interest you, please join us at the Coalition on the first Wednesday of any month from 4:30 to 5:30 as the Advocacy Committee meets to talk things over and figure out ways to take meaningful action!

“Our who bring sunshine to the lives of others cannot keep it from themselves.” ~James Matthew Barrie
Food Storage: Five Alternatives to Plastic

Plastic is ubiquitous in food storage. Lightweight, inexpensive, and effective, it is the go-to option for most, whether at the manufacturing level for packaging, in grocery stores, or in the home. But some question our reliance on plastics, citing concerns about the amount of waste it generates as well as the safety of plastics themselves.

Plastics are made from petroleum, a non-renewable resource. While recycling programs exist in many communities, the National Resources Defense Council estimates that only about 7% of plastic is recycled annually.¹

Health concerns arise during the manufacture, use, and disposal of plastics. Dioxins, which are toxic at low levels and known endocrine disruptors, end up in the air and waterways when most plastics are manufactured and incinerated. Phthalates, softening agents that make plastics flexible and give plastic wrap its cling, interfere with the production of male hormones in animal studies and are suspected of having the same effect on humans. Bisphenol-A (BPA), invented in the 1930’s during a search for synthetic estrogens, is another endocrine disruptor often used in can linings and polycarbonate bottles. These types of chemicals, and many others, can leach onto foods that come into contact with plastics.¹

Plastic takes a heavy environmental toll and can increase exposures to harmful chemicals. However, many are finding that it isn’t hard to replace some – or all – of the plastic food storage options often considered indispensable. For some great tips, check this blog by author Beth Terry: myplasticfreelife.com or the website lifewithoutplastic.com. Once you get started, you may come up with your own ingenious, plastic-free ideas!

1. Glass – See-through and easy to clean, glass does not alter the flavor or color of foods, and can serve the dual purpose of storage and serving container. It’s easy and inexpensive to repurpose glass jars in which other foods have been packaged. Canning jars can be purchased in many sizes, and some are freezer safe.² Heatproof glass containers with snap-on plastic lids are another great choice; just be sure the food does not come into contact with the lid. Or look for those with BPA free lids.

2. Stainless Steel – Containers of many shapes and sizes are available in stainless steel. Lightweight and durable, they’re a greater initial investment than plastic or glass, but will last for years.

3. Cloth – Washable food wraps and bags, available in an array of fabrics and sizes, are suitable for many different uses and can easily be made by hand for those talented individuals who are so inclined. In some, cotton is treated with beeswax to make it waterproof and able to form an airtight seal.

4. Silicone suction lids – Available from a number of outlets, these flexible, reusable lids form an airtight seal over your own glass or ceramic bowls, quickly turning them into storage containers.

5. Paper and Foil: Wax paper, parchment paper, and aluminum foil work well for wrapping items such as meats, fish, cheeses, baked goods, and lunchbox items. Foil is the most airtight of these options and best for the freezer, although an inner layer of paper provides moisture absorption and another layer of protection.³ These single-use items add to our landfill burden, but have low toxicity.

¹ www.nrdc.org/living/shoppingwise/food-storage-containers.asp
² For more information: blog.fillmorecontainer.com/index.php/2013/06/13/freezing-in-canning-jars-101
³ www.foodservicewarehouse.com/blog/parchment-vs-wax-paper-vs-aluminum-foil
Orange and Cucumber Salad with Spring Greens

Ingredients

- 1/2 English (hothouse) cucumber thinly sliced
- 3-4 small oranges (such as clementines), peeled and sectioned
- 2 big handfuls young arugula leaves
- 1 baby bok choy, thinly sliced
- 1/2 bunch watercress leaves
- 1 cup green sprouts (such as pea shoots)
- Toasted pumpkin seeds (pepitas) or sunflower seeds, as desired
- Juice of 1/2 orange
- Juice of 1/2 lemon
- 1 teaspoon each lemon and orange zest, or more to taste, optional (but highly recommended)
- 1 to 2 tablespoons extra-virgin olive oil
- Salt and freshly ground pepper to taste

For Serving (optional)

- Try adding sliced kalamata olives, feta cheese or topping with grilled chicken, salmon or tofu

• Combine all the ingredients in a serving bowl. Toss together and serve.

Makes 4-6 servings.

Adapted from Number2Pencil

EWG’s Dietary Guidelines:
For Your Health and the Environment

• Eat more vegetables and fruits. Avoid pesticides when you can. The overwhelming majority of Americans don’t eat enough vegetables and fruits. People can’t always find or afford organic food. EWG’s Shopper’s Guide to Pesticides in Produce is an easy-to-use list of conventionally grown fruits and vegetables that tend to test low for pesticide residues. EWG’s Dirty Dozen list details conventional produce that routinely test high for pesticides. EWG advises shoppers to buy organic versions of those items when possible.

• Eat less meat, especially red and processed meat. Red and processed meats are believed to cause cancer and heart disease, and their production is bad for the environment. The American Institute for Cancer Research recommends eating no more than 18 ounces of red meats weekly – the equivalent of six hamburgers – and avoiding processed meats. Use EWG’s Meat Eater’s Guide for Climate Change and Health to find healthy, low-carbon protein alternatives.

• Skip sodas and sugary or salty foods. EWG’s interactive Food Scores database and app helps shoppers find foods low in sodium and added sugars. Adults should limit sugar to six to 12 teaspoons a day. Children should consume even less. A single canned soft drink contains 10 teaspoons of sugar. Drink more water instead, filtered is best. Use EWG’s Water Filter Guide to find the right filter for your water and budget. Limit salt, especially if you have high blood pressure.

• Eat healthy and sustainable seafood. Many Americans would benefit from eating more seafood rich in healthy omega-3 fatty acids, which can lower blood cholesterol levels and reduce the risk of heart disease. Pregnant women and children should steer clear of seafood with high mercury levels and should limit consumption of canned tuna. Use EWG’s Good Seafood Guide to find fish and seafood richest in omega-3s, lowest in mercury contamination and sustainably caught.

• Beware of processed foods with harmful additives. The federal Food and Drug Administration allows more than 10,000 chemical additives in food. Some of these substances are linked to serious disorders; others haven’t been studied adequately. EWG’s Dirty Dozen Guide to Food Additives describes some of the most worrisome additives and gives tips on how you can avoid them. EWG’s interactive Food Scores database can steer you away from the more than 22,000 foods that contain artery-clogging trans fat, a prime culprit in the nation’s epidemic of heart disease.

Reproduced with permission.
Celebrating Our Valued Volunteers

Our appreciation for all you do grows and grows!

On March 16, 2016, we hosted our annual Volunteer Reception, a time to honor and say “thank you” to those who have generously donated their time and talents to help us in so many ways. There are many opportunities for volunteering throughout the year. For more information on volunteering, call or email us: 585-473-8177 or cindy@bccr.org. We have something for everyone!
Pledge Sheet

You may also register and fundraise online at bccr.org!

Ask your friends, neighbors, relatives, co-workers and others to sponsor you! Complete this form and collect the pledge money when pledges are made. Checks must be made payable to Breast Cancer Coalition of Rochester and all check numbers must be recorded in the column below.

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Women only ☐ 5K Runner ☐ Walker ☐ Female ☐ Male ☐ I am unable to participate, but please accept my donation of $  

I have read and fully understand the liability waiver on the reverse side.

Signature

First Name

Last Name

Address

City

State

Zip

Phone

E-mail

Age on May 8, 2016

Are you a breast cancer survivor? ☐ Yes ☐ No

Raffle to win a Trek 7.2 FX Road Bike ☐ $5 for 1 ticket ☐ $20 for 10 tickets ☐ Other amount:

☐ Cash ☐ Check (Please make payable to Breast Cancer Coalition of Rochester.) ☐ American Express

☐ Mastecard ☐ Visa Number Expires Amount Charged $  

Name on Card

Credit Card Signature

Date

FOR OFFICE USE ONLY

Registration $ _____

Pledges $ _____

Raffle $ _____

Total $ _____

Cash $ _____

Checks $ _____

Charge $ _____

Verified By ______

Entered in Database ☐

Bib # ______

Volunteers with spirit Connie, Betty & Ayanna

You may also register and fundraise online at bccr.org!
Registration & Information

The Pink Ribbon Run is the premier "women-only" race in Greater Rochester. Women, of all ages and abilities are welcome to participate in the 5k road race. Our course is certified to be accurate by the USATF #NY13102KL.

The Family Fitness Walk (2.3 or 3.6 mile options) is open to all men, women and children, walkers, strollers, joggers and fitness enthusiasts.

All participants must read and sign the attached liability waiver.

When
7:15 AM Registration
9:00 AM Family Fitness Walk Start Time
9:30 AM 5k Race Start Time

Where
Genesee Valley Park @ Roundhouse Pavilion.
Shuttle Parking Available - Marketplace Mall - North Lot at Jefferson Rd. & Hylan Dr. (between Macy's & Penney's).
Parking also available adjacent to the Park on Moore Rd. look for signs.
Handicapped Parking ONLY in Genesee Valley Park.
Please view and print maps of the Race, the Walk and all parking locations online @ www.bccr.org

Prizes $300 to overall winner and a $200 bonus to Course Record Breaker. Additional prizes for age groups, survivors and fundraisers. Visit bccr.org for more information.

Per USATF guidelines, gun time will be used for all prizes and net time will be provided as a courtesy to runners.

Raffle to win a Trek 7.2 FX Road Bike (donated by Towpath Bike).

Cost
$20 All pre-registrations. $30 Day-of registrations. Fees are waived for those raising $50 or more. Form on reverse side must be filled out and signed by all participants.

Registration/Pre-register and fundraise online at bccr.org
Packet Raise $1,000+ to receive a Pink Fitbit Flex.
Pickup Create your own fundraising page, it's safe and secure!

Pre-register by mail. Send your form and checks to:
Breast Cancer Coalition of Rochester
1048 University Ave., Rochester, NY 14607.

Pre-register and pick up your packet in person on May 4, 5, 6, 7.

Breast Cancer Coalition
1048 University Avenue, Rochester.
Wednesday 5/4 Thursday 5/5 Friday 5/6 Saturday 5/7
8 AM - 7PM 8 AM - 7PM 8 AM - 7PM 8AM - 12NOON

Day of Registration and packet pick up begins at 7:15AM, Genesee Valley Park @ Roundhouse Pavillion.

Event T-Shirt to the first 3500 registrants at packet pick up.

Pledge Sheet
Ask your friends, neighbors, relatives, co-workers and others to sponsor you! Complete this form and collect the pledge money when pledges are made.

Checks must be made payable to Breast Cancer Coalition of Rochester and all check numbers must be recorded in the column below.

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Liability Waiver

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 running a road race is potentially a hazardous activity. I assume all risks associated with running/walking 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 Run Women's 5K and Family Fitness Walk. 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, 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 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 in the fitness walk. 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.

All participants must read and fully understand the above waiver and sign on the reverse side.

How did you hear about this race?  TV  Radio  Print Ad  Direct Mail  Other:

☐ Please send me more information about Breast Cancer Coalition and other program events  ☐ Please contact me about volunteer opportunities
Regional Outreach Director’s Update

Since September 2015, I’ve driven through my share of gently rolling hills in the Finger Lakes region of Central and Western New York. For the most part, Mother Nature has been kind. The travel has been good.

It’s exciting to reach deeper into the counties surrounding Monroe. I’ve been fortunate to connect with survivors and their supporters who want to help us increase the support, education, and connections between — and for — breast cancer survivors living in our Upstate New York region.

This effort has extended beyond introducing ourselves to human service agencies and programs — although that continues. Our outreach to the medical community includes meeting with health care providers and their staffs, sharing information that they can, in turn, share with patients who need our support.

We’ve invited regional breast cancer survivors to become PALS mentors so that we can build a stronger network of support. In fact, half of the most recent group of peer mentor trainees were from outside Monroe County. Those who could not make the last training are eager to enroll in the next.

Our first regional evening educational seminars were held in March. Registered dietitian Christina Ganzon, Finger Lakes Health, presented Healthy Choices - Breast Cancer Survivors & Nutrition in Geneva. Dr. Nayana R. Kamath, a medical oncologist for Wilmot - Batavia, discussed the role of chemotherapy before and after surgery at our Batavia event. Both seminars offered learning opportunities and encouraged building connections among regional survivors.

The Coalition introduced one of our Healing Arts programs to Dansville area breast cancer and gynecologic cancer survivors, who were invited to enroll in a 6-week pilot session of Gentle Yoga led by Kate Drake, RYT/OTR. The class filled quickly and we even began a waiting list!

As we travel these winding roads and climb new mountains as part of our regional outreach, there is plenty of room for fellow travelers. If you would like to join us, we welcome your support. Volunteer at a regional event or help us deliver Voices of the Ribbon in counties outside of Monroe. Call us! Your help will allow us to reach more regional breast cancer survivors.

So grab your backpack and pick up your walking stick! Someday, together, we’ll look back at what an incredible climb to the top this has been. New survivors will join in along the way. We’ll scale the mountain and we’ll reach the summit. And the view? It will be spectacular.

Please call (585) 473-8177 x310 or e-mail tracy@bccr.org for more information.

Outreach Coordinators’ Update

Reflecting on my Outreach goals for 2016, it is clear I cannot accomplish them alone. In some cases, I need volunteers to help me. In others, I need businesses, clubs, communities, and faith communities to let me help them.

The most vital aspect of my job is to let people know about the valuable, local, and no-cost services of the Coalition; this is my passion and commitment. To accomplish this fundamental goal, I represent the Coalition in the following settings:

Community Festivals

We expect to have a presence at about eight festivals this year. Each involves eight-to-ten-hour days and several shifts of volunteers per day. I need your help! Can you work for a few hours on a weekend day?

Faith Community Initiatives

Can I help you? The Coalition provides information about screening and assistance programs, our support services, other available resources, healthy lifestyle choices, and ways to establish support within your own community.

Neighborhood Health and Wellness Activities

Localized efforts bring community resources to people where they are. In some cases, residents may be socially or economically isolated from this valuable information. Is your gym, club, or neighborhood youth, senior, nutrition or health center hosting such an event? We may be able to attend.

Employer-based Health Events

Is your business interested in encouraging healthier lifestyle choices for your employees? We offer information on a variety of healthy living strategies. Call to arrange a presentation for your staff.

Community Fundraisers

Our independent, local organization relies on the generosity of area groups who choose to donate their charitable dollars to us. Be an ambassador! Remind people of the value of keeping their donor dollars local to support local cancer survivors. Volunteer as our representative at an event to thank generous folks personally.

To accomplish my goals - the Coalition’s goals - I NEED YOU. I need your time, your enthusiasm, your eyes, your ears, your connections, your ideas, your vision. Help your Coalition make sure that no one faces breast cancer alone.
“The care I received was unbelievable; phenomenal,” Carol gratefully acknowledges. Surgery went well, and she recovered quickly. As she was preparing to return home, the surgeon asked Carol if she wanted to see what was under her bandages. “I can’t look,” she answered. “Would it help if I held your hand?” her kind doctor replied. So, holding tightly to her surgeon’s hand, Carol watched as her bandages were removed. “It’s not so bad” she said, and left the hospital with a fledgling sense of acceptance of her newly re-formed and healing body.

A cherished friend made the trip to Rochester from Boston to stay with Carol for a week after her surgery. “She babied me, made beautiful meals, and reminded me to breathe deeply when I became tense,” Carol remembers.

When she received her pathology report, Carol learned that her cancer had been removed entirely with no remaining evidence of disease. Neither chemotherapy nor radiation were called for in her case. As her cancer was found to be sensitive to estrogen and progesterone, a five-year course of hormonal therapy was begun to reduce the already low risk of recurrence. It was the best possible outcome she could have hoped for.

“Through this all, I’m struck by the power of presence; of doing what needs to be done, and of the meaning of deep friendship,” Carol observes. In taking command of the things that were hers to control while letting go of the rest, and gradually widening her circle of support in her own time - from family to close friends to trusted health care providers to her congregation and to newfound friends at the Coalition – Carol came to trust what she terms “grace upon grace”; the assurance that the help and support she needed would be there when she needed them.

To others just setting foot on an uncertain path after a breast cancer diagnosis, Carol offers words of gentle, yet hard-won wisdom: “You can do this – it is within you. Seek resources. You are strong, you are creative, and you absolutely will find your way. But don’t do it alone.” She continues, “Don’t be afraid to set boundaries between what you need and what you don’t need. Ask for whatever you need and say no without apologies. It may seem like a wilderness. But you will get through this, one hour or one day at a time.”

Thank you, Carol for your presence, your mindfulness, your sagacity, empathy, and humor - and all that makes you YOU! Your star shines brightly in our survivor community.

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**A Personal Journey continued**

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**Lymphedema continued**

mother of two and a runner with primary lymphedema shares her successes, challenges, and helpful tips.

**Lymphedema Awareness Network of Rochester**

For those in the Rochester area living with lymphedema, please come to a meeting of the Lymphedema Awareness Network of Rochester (LANROC). These gatherings are all about education and support. In odd-numbered months we have a peer support meeting in which helpful information and personal experiences are shared. On even months, we invite a professional to speak about a particular lymphedema-related topic. Check page 10 of this issue for more information.

LANROC has a Facebook Group Page that anyone is invited to join. Check us out to find stories about lymphedema in the news and stay up to date with what’s happening at LANROC meetings.

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**Aromatase Inhibitors continued**

worth taking for an individual. The advantage of taking these medications is a significantly reduced risk of the cancer returning, or in the case of metastatic disease, of prolonging life.

Still, quality of life matters. Switching from one aromatase inhibitor to another may help when the side effects are intolerable. Rarely, a more difficult decision must be made. During the nearly two years that Dennise Webster took Femara, she suffered from progressively worse muscle, bone, and joint pain that landed her in the offices of a rheumatologist, a neurologist, and her oncologist. When months of testing did not reveal a cause for her symptoms, Dennise chose to stop her medication. Her symptoms improved, and Dennise's oncologist recommended Aromasin, but the pattern repeated itself. Fully aware of the benefit of the medication, Dennise made a difficult decision – she has stopped hormonal therapy. “My husband and I both agree at this point in our lives I need quality, and I will take my chances,” she says, while acknowledging that it is a heavy load to bear.

It is part of our mission at the Coalition to empower survivors to achieve the best possible quality of life. We are working to build a program for those experiencing AI-induced arthralgia; we hope to offer education, support, and non-medical coping strategies. To that end, we are listening to ALL the stories. Because each survivor speaks their truth. And each one matters.

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1. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2878260/
3. http://meetinglibrary.asco.org/content/157032-174
4. http://annonc.oxfordjournals.org/content/early/2013/03/06/annonc.mdt037.full
A Tribute to Carol Henretta  - By Christine Hall

We in the Common Ground group have all had time to think about Carol over the last several months. First, our concern was centered around her unexplained symptoms, then it was when she wasn’t feeling well and finally, when she spent her final days at home with her family.

There is sadness and a deep feeling of loss, yet at the same time there is so much joy in having known her. As I struggle to find peace, my mind keeps coming back to this, “Carol is such a gift; everything about her is a gift.”

So many of us have been on the receiving end of a holiday card from Carol, or a table runner, or another handmade gift she created. Her thoughtfulness was incredible, but her best gifts were her humor, compassion, and wisdom.

During one of our group meetings, Carol was visibly upset and said that she didn’t belong in this group. She said felt different than the rest of us because she hadn’t endured the same treatments that the rest of us had. I looked at her, the woman who helped make Common Ground so special, and I wished I had a super power that would show her how incredibly special she is, especially to this group of heroes. And in that very moment, I knew more than ever that we all belong here.

We each have our own story, our own purpose, our own cancer. But cancer can’t take away what we feel in our hearts, and that is a deep love for Carol and an appreciation for each other and each day we have on this earth.

Carol’s smile will be missed.
Carol’s laugh will be missed.
Carol’s perfect nails, hair and holiday outfits will be missed.
Carol’s guidance will be missed.
Carol’s empathy will be missed.
Carol’s friendship will be missed.

Day in and day out as Carol touched the lives of her family, friends, and colleagues, she offered very sound advice: “Sometimes you need to take one day at a time, sometimes you need to take a half day at a time, sometimes you even need to take things one hour at a time.”

Carol and I were “yoga buddies”. We’d always try to stand across from each other during our Tuesday morning classes. She said it helped her to watch me when she couldn’t hear our instructor. Little did she know, it helped me as well. She was a symbol of strength and kindness that brought me great comfort and joy. I will continue to practice yoga in the spot where I was helpful to her and I will continue to have the hope that she always encouraged.

Namaste my dear friend Carol, Namaste.

Friends Remembered...

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

Pat Bonino
Carol Henretta
Lana Hoffere
Kathy Mangione
Stephanie Scism

Tributes Welcomed

Would you like to write about someone you have lost to breast cancer? We welcome submissions from friends and family members and are particularly interested in stories about how they touched and changed your lives.

Please send your submission (300-500 words) with a digital photograph to Pat Battaglia, Voices of the Ribbon Newsletter Editor, at pat@bccr.org.

We would be happy to honor your loved ones.
Our Fundraising Friends

**Flocking and Other Festivities**

For the second year, seven local Legacy Senior Communities chose to raise fun and funds for the Breast Cancer Coalition in October. Open House events at each locale featured entertainment, activities, and tours. Legacy’s largest location at Clover Blossom once again led the charge in a lively and good-natured competition of individual communities and their energetic Lifestyle Directors.

One of the most successful and eye-catching events at Clover Blossom was the successful Flamingo Flocking. Residents in all living settings could purchase $5 flocks of dazzling pink birds to festoon their yards or, in the case of apartments, the doors of residents. For a mere $1 additional contribution, “flockers” could maintain anonymity. Those with a flocking aversion could purchase “insurance” against flocking for just $3. Local winery offering tastings, cookie sales, and an auction all set to the Big Band sounds of the Eastside Swingtet rounded out the celebration at Clover Blossom.

Park Crescent location in Greece had a live chain saw carving demo and subsequent raffle, a bonsai demonstration and raffle, a visit from “Reverend Mother” Phyl Contestible, and super successful chili cook off.

Other Legacy locations holding their own events included Parklands (Chili), Cranberry Landing (Irondequoit), Willow Pond and Village Wood (Penfield), and Erie Station (Henrietta).

We are so honored to be the beneficiaries of the enthusiastic, giving residents and staff of these life-filled communities and thrilled to accept their generous gift of $5025.78

**The Power of Pink**

Eastview Mall’s Brighton Accessories store took part in their national organization’s Power of Pink Campaign to raise funds for local breast cancer support organizations by selecting our Coalition. Assistant Store Managing Partner Lauren Henry and her crew acted as Coalition Ambassadors for the month of October.

Aficionados of the Brighton line eagerly anticipate the annual release of a limited edition Power of Pink Bracelet, and this year they were treated to three releases over a seven week period. Ten dollars from each sale at the Eastview location was given to the Coalition in recognition of the strength and power of women facing the challenge of breast cancer.

Thanks to the enthusiastic and caring staff at the store for putting their hearts and minds to work for the Coalition! The campaign raised $731 for the benefit of Rochester area breast cancer survivors.

**Pink Ribbon Blend**

The Coffee Connection created a special Breast Cancer Blend for the Coalition and introduced it at our Holiday Open House raising $72. We look forward to offering this delicious raspberry blend at area festivals this summer.

**A (BRA) Dazzling Affair**

With the guidance and vision of Femfessionals Rochester President Cheryl Mantia and the connections, talent, and vision of many other members, the first annual Femfessionals BRA Dazzle event was a dazzling, festive success in every way.

Weeks of publicity, which had been subject to (at least!) daily updates, were deftly managed and marketed by Michelle’s Michelle Ames, a member.

Greeting guests on the “pink carpet” was a larger-than-life size, exquisitely detailed balloon bra created by Arigami. It provided the perfect backdrop for arrival photos taken by Immagine Photography.

Area celebrity men including a newscaster, two drag queens, a retired hockey star, and everyone’s favorite “Uncle Phil” gamely modeled area artists’ bra creations, strutting proudly to the light and sound talent of CMI Communications. Emcees Scott and Sandy from the Buzz welcomed models to the runway at the Radisson Hotel Rochester Riverside, which served an exceptional meal in an elegant setting.

In keeping with the artistic focus of the show, centerpieces by Rockcastle Florist were stunning and creative.

Proudly and eloquently representing the Breast Cancer Coalition was young survivor Kathy Cook. The compelling story and voice of this beautiful breast cancer warrior powerfully reminded all WHY these monumental efforts to support the work of the Coalition are so vital.

With exhausted satisfaction, the organization presented us with a generous donation of $4890. WE are honored and grateful indeed.

**Super Good Sports**

Gift donations to honor a survivor friend or family member are especially touching. Recently we received one such unexpected gift of $300 to honor our dear friend Kathy Simpson from the Akron, New York JV Field Hockey Team. Thank you, Akron; that’s a very lovely thing to do.

**Pink Ribbon Blend**

The Coffee Connection created a special Breast Cancer Blend for the Coalition and introduced it at our Holiday Open House raising $72. We look forward to offering this delicious raspberry blend at area festivals this summer.
Giving In Style

- The elegant rooftop space at the Strathallen Hotel was the setting for the 2015 Morgan Stanley Fashion Show. This private annual event featured fashions from Panache Vintage & Consignment modeled by a few of the firm’s employees. The models were styled by Michael Avery & Company, and carried flowers from Stacy K Floral. Scrumptious light fare, music by Go Sound Systems, and a stunning view of Rochester made this a truly special evening. Morgan Stanley was pleased to present Executive Director Holly Anderson with a check for $1500.

- Shear Ego International School of Hair Design hosted a Pink Party open house with Rochester Woman Magazine at the Titus Avenue location. Enthusiastic students form the school provided manicures, haircuts, brow waxing, and make up application for a nominal fee, which was donated to the Coalition. The party also featured wine tasting, food samples, and vendor tables. The party raised a much appreciated $472.

We Might As Well Dance

Kimmie Reap of Penfield wanted to offer support to breast cancer research locally, so she held a Dance for Breast Cancer in October. Her donation of $327.75 will help fund our annual local research grant this Spring.

Another Successful Launch

Our friends at Rochester Woman Magazine hold monthly launch parties at area hot spots to unveil the latest issue. Each features refreshments and often includes auctions or activities to benefit a local “cause” October’s “Think Pink” launch party on the Strathallen Rooftop was a delightful occasion and resulted in a donation of $250 to the Coalition.

One Person’s Idea

Triano’s Meat Market & Deli

Friend of the Coalition

Lisa Cerra undertook a fundraising in cooperation with a family member’s business, Triano’s Meat Market. Her infectious enthusiasm inspired the business to offer a meat package for raffle which proved to be a very popular offering! Lisa contributed a generous $559, and acted as a wonderful ambassador for the Coalition in the process.

Chili for Charity

With some 30 batches of every possible variety of chili, all the fixin’s, grilled ‘dogs and delectable homemade desserts, the Xerox Community Involvement Program once again presented Chili n Dog Day to benefit local charities offering support to those dealing with cancer. This much-anticipated lunchtime chili party also offers an incredible array of handmade raffle baskets for every hobby and interest. This year’s event raised $2500 for the Breast Cancer Coalition.

Quiet Giving

Sometimes we receive proceeds from unknown events or collections. Perhaps they are in honor of a loved friend or colleague? We accept these gifts gratefully!

- In a quiet example of local giving, we received an unexpected gift of $97 from the Churchville – Chili Bus Drivers Association.
- Juniors at Aquinas Institute sent an unexpected gift of $100.87.
- Heritage Christian Services surprised us with a check for $265.
- Thank you Creative Bookmarks for your gift of $48.

Canes For Our Cause

Delicate twisted glass cane pink ribbon ornaments, lovingly created in a special limited edition offering was the holiday offering of More Fire Glass Studio of Rochester for the benefit of our Coalition. These handcrafted works of art and tribute were sold in the studio in November and December. The Coalition received a donation of $315 and is able to offer a few remaining ornaments for sale in our store. Stop by to purchase one of these lovely gifts!

More than Good Grooming

Celebrating their move into a stunning new space, Brighton’s Mens’ Room Barber Lounge and Spa dedicated the proceeds of the grand opening celebration and a multitude of raffles to two local charities. Music, tastings of coffee, wine, beer and spirits, foods and live music filled a giant tent on a crisp October night. We thank owners Craig and Rebecca Webster for your commitment to making Rochester the best community possible and for your kind donation of $2500.

Igniting Youthful Spirit

For the second year, the young gymnasts and cheerleaders of Ignite Cheer Tumbling celebrated a Tumble-a-Thon to raise money for the Breast Cancer Coalition. Friends and family were the cheerleaders for this event, having pledged a per-skill amount for each successfully demonstrated skill. Their high energy antics were given to the Coalition and totaled $661!
Our Fundraising Friends

FUEL FEET They Are the Movement

It would be hard to think of a local business that cares more about the health of our community than Fleet Feet Sports and its sister Yellow Jacket Racing. Several annual October activities have once again resulted in generous support for the Coalition. This year’s most appreciated contribution is $3100. A big thanks to Fleet Feet and the hundreds of walkers and runners who made this happen.

Fueling good works

- The good folks of the Ridge Culver Professional Firefighter’s Association work hard to make our community the best possible place to live and work. In addition to educational and recreational programs, they also support a variety of other agencies doing good works, and the Coalition is proud to be among them. Thanks, Ridge Culver, for this year’s donation of $450 to support local research and programming!
- The Laurelton Volunteer Fire Association combined efforts with Stitchworks to create Breast Cancer Awareness T-shirts, raising $118 for our Coalition.

It Went Swimmingly!

The young ladies at Spencerport High School created a host of fun activities to enliven their October 10 Swim invitational. Flaming pink flamingos greeted five teams and scores of enthusiastic supporters who enjoyed pizza, swim cap, and T-shirt sales. 150 cardstock pink ribbon cards were completed with touching messages of hope and love and eventually covered the walls of the pool area. This lively day of wet fun raised $1742!

Breast Reconstruction Awareness Day

In recognition of national Breast reconstruction Awareness Day on October 21, Vega Plastic Surgery and Medspa hosted an informational session in the form of a presentation and panel discussion as well as a fashion show featuring local women who have chosen reconstruction after mastectomy. In the comfortable and fun setting of Artisan Works, these women shared their pride, self-confidence, and a wealth of information about the reconstruction process to a curious and admiring audience. A small admission and the auction proceeds from several beautiful donated pieces of art were given to the Coalition. Thanks to Vega Plastic Surgery for an informative and festive event and a donation of $1034.

Learning More Than the Three Rs

- The mission of the Citizens of the World Club (COW!) of Pittsford Sutherland School is to educate, fundraise and volunteer in order to relieve local and world problems. The focus of October was breast cancer, and in addition to hosting speakers and creating educational posters they conceived a community fundraising event that featured face and painting. For a $1 donation, students could be “decorated”. The students raised $182.22 and learned much about this disease.
- Midlakes High School staff enjoyed the opportunity to kick back and dress down on Fridays in October, raising $75 for the Coalition.
- Students at Siena Catholic Academy selected the Breast Cancer Coalition to receive their 2015 donation of $192. It’s great to see young people contributing so generously to the community!

The Beauty of Pink

- In October our Neighborhood of the Arts friends at Artistic Designs Hair Salon offered a way for clients to honor survivors and warriors in their own lives with pink tribute ribbons. Donations were accepted and rewarded with salon discounts, and soon the walls filled with these tributes. These simple acts of recognition and remembrance raised $800 to support the programs of the Breast Cancer Coalition. Thanks, Jodi and team!
- Clients of Park Avenue’s Maxim Salon sported pink hair extensions in October in a visible show of support for the programs we offer to area survivors. For a donation that was given to the Coalition, customers were also offered special pricing on other services. They dubbed their October campaign “Show Your Strength”, and raised $558.67!

Pumped For the Cause

- Rochester Athletic Club put the collective muscle of its membership to work on October 24 in a “Triathalon of Classes” at three of their area locations. Clubs at Stoneridge, Perinton, and Pittsford held 30 minute class samplers. Their efforts raised a collective and impressive $1727.22.
- Gold’s Gym in Webster put the strength and energy of their client athletes to good work for us in October. A series of good spirited challenges and special classes and T-shirts paid off in increased muscle, good feelings, and a donation of $810.

Thanks, Neighbors!

In a wonderful example of local support, we have received a gift of $1650 from the Get-It-Straight Foundation. Dr. Terry Giangreco, orthodontist with the practice of the same name, offered this donation “with heartfelt gratitude for all that the Coalition does to fight breast cancer.” Dr. G, we couldn’t do it without this kind of support.
The name of the individual honored or remembered is shown in **bold** type.
The Breast Cancer Coalition thanks donors for these gifts made since our last listing.
(Donations made after December 31st will be included in the summer newsletter.)
*We apologize for any errors and/or omissions on our donor pages. Please notify us if a correction is in order.*

### In Honor of:

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<tr>
<th>All Survivors</th>
<th>Eileen Goldman</th>
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<td>Lisa Larkin</td>
<td><strong>Clients, Colleagues, Family &amp; Friends</strong></td>
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*Donations ending December 31, 2015*
In Memory of:

George Adler
Linda & Richard Cooper

Genevieve Agostinelli
Mafalda Agostinelli

Mary Antetomaso
Margie Micca

Wayne C. Anthony
Barbara Rafoth

Jacque Ater
Kathie Finks
Nancy Gadziala, MD

Anna Bazan
Cobblestone Captial Advisors

Augusta Berardicurti
Margaret Cress

Linda Betters
Anonymous

Cathy Bishop
Susie Smith
Robin Vavrina

BCCR members who lost their battle with breast cancer
Sylvia Cappellino

Judy Buchanan
Ray Buchanan

Patrick Butler, Sr.
CAEP
Dale H & Evelyn B. Clark
Mary Graham
Nancy Gravitz
Thomas Raffa
Page Simpson

Kimberly "Kym" Cardamone
Dolores Brooker

Ginny Coco
Modern Nature Bodyworks - Carrie Gaynor

Dorothy Cooley
Brenda Grammatico

Bernice Cornell
Linda & Richard Cooper

Darala Crowell-Tobey
Beverly Crowell

Miriam Davis
Linda & Dick Cooper

Arlene Diorio
Mary Cunningham

Geraldine Dunlap
Sue Van Slyke

Margaret Dyer
Cathy & Mike Kauffman

Kim Facteau
Christine & Robert Baker

Esther Flynn
Mary Ann & Robert Henley
Lois, James & Erin Murphy
Florence Smith

Lisa Fox
Thursday Night Swing-in-Dance Community

Eileen Gagner
Laima Gallo

Eugene Goodreau
Maysie Goodreau

Christine Goodwine
Rosa Piccirillo

Frank Grego
Matilda & Richard Panke

Arlyn Grossman
Robert Grossman

Ethel Hall
Stacy Murch

Pat Haralambides
Anne & Jim Townsend

Irene Henn
Peggy Hoff

Jean & Leon Herritt
Sandy Herritt-Rosenthal

Anne Jackie
Kris Hunt & Dee Miller

Joan Kasprovic
Barbara Anderson

Wendi Klafehn
Sue Sharp

Andrea Krinsky
Louise Cerrone

Lisa Kubby
Judy Emerson & Woody Packard

Ruth Lawlor
Mary & John Knowles

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Sue Weisler

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Pat Mandina
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Connie Zeller

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Michelle Mann & Stephen Atterbury

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Jennie Viggiani

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James McDonald

Molly Mehalak
Anonymous

Kim Miller
Dee Miller & Kris Hunt

Marilyn Mortillaro
Dolores Brooker

Betty Morrison
Kelly DeMay

Tina Navarre
Kelley Ann Buicci

Marilyn Nuffer
Bonny Geitlinger

Irene Oyer
Carol & Paul Bartlett
Patricia & Richard Bates
Brenda Barkley / Mildred McNall
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Bonnie & Jim Brunswick
Tammy Charles
Stephanie Coddington
Diane & Robert Davison
Pete & Jerry Gath
Rosemary & Larry Gleason
Greater Rochester Visitors Association
Lynda Hally & Bill White
Ruth & Philip Harvey
Pat McCormick
Mary & Jerry Seeldo
Barbara Thompson
Ray & Julie Vincent
Windy Hill Gang
Emily Wojcik - Cub Scout Pack 67
Women of the Moose

Laurie Pask
Arthur Hengerer, MD
Ellen Pfeiffer

Maureen Philbin
Kathleen & Thomas Philbin

JoAnn Popovich
Alisa Cook

Kathleen Parker-Raeside
Shirley & Richard Parker
Mark Raeside

Bea Rapowitz
Bertram Rapowitz

Christine Riesenberger
Sandra Abbott
Connie & Bill Belz
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Cally & Chris CHilas
Marlene & Louis Cook III
Luisa & Glenn Cooke
Armand D'Alfonso
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September, when the Request for Proposals (RFP) is posted on our website www.bccr.org under the research tab.

The proposals received in 2015 came from Cornell University, The University of Rochester Medical Center, Upstate Medical Center University and Roswell Cancer Institute. They were distributed to participating Research Advisory Board members, a team comprised of breast cancer survivor advocates as well as medical and research professionals.

In February of this year, the participating Advisory Board members met for Review Day to discuss the proposals, finalize scores, and make their recommendations. The projects were evaluated on scientific merit and adherence to Coalition goals of innovation, approach, impact on breast cancer, and the ability to generate data for further research.

Executive Director, Holly Anderson, presented the Advisory Board’s recommendations to the Coalition’s Board of Directors for a final decision regarding funding for the recommended proposals. This process culminated in a Research Award Ceremony, where the grant recipients were introduced, presented the first half of the award funds, and spoke about their work to the public. In August, Drs. Schimenti and Evans will submit progress reports to the Coalition and receive the second half of their grant funding.

Since 2003, the Coalition’s Research Initiative has given more than $630,000 to regional researchers. The 2015-2016 application cycle is the fourth time since 2003 when two award recipients were chosen for funding. These grants, unusual for a nonprofit, grassroots organization, focus on breast cancer cause, prevention, prevention of metastasis, and cure; they are an integral part of the Coalition’s continuing efforts to eradicate breast cancer.

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Join Me In Making a Planned Gift to the Coalition!

My name is Laura Wood and I’m a long-time breast cancer survivor.

I’ve decided to name the Coalition in my will to help ensure that all breast cancer patients have access to the same high level of support I had so many years ago.

I invite you to consider doing the same when making your financial or estate plans. I can’t think of a better legacy than to help others who are touched by a diagnosis of breast cancer.

For more information about how you can do this, just call the Coalition at 585-473-8177, and ask to speak to Deb Allen, their new Director of Development. They’ll be happy to answer any questions you might have.

Until we end breast cancer once and for all, your generosity is deeply appreciated.