11th Annual Terri Schmitt Legislative Reception

Moving Forward and Pushing Harder

2014 marked the eleventh year of the Annual Terri Schmitt Legislative Reception. This year’s event was held on August 13th. To open the night, the chairperson of our Advocacy Committee, Marianne Sargent, spoke of the journey the committee has taken over the last fourteen months. This includes the addition of several new members, showing them the ropes, and learning together that “As citizens we can make a difference.” The committee traveled to Albany to meet with our legislators and finally watch New York become the twenty-third state to pass medical marijuana legislation.

The reception this year was well attended by elected officials and their representatives, as well as advocates, survivors and many of Terri’s family members. Held in honor of former Rush Town Supervisor Terri Schmitt, a beloved figure in the early days of the Coalition, this annual event is an evening where members of the community are able to speak with their government representatives about many topics, including current healthcare issues such as the Compassionate Care Act, and the Breast Cancer Deadline 2020 initiative.

Dan Deckman with daughter Sophie and Holly Anderson

12th Annual Tee’d Off at Breast Cancer Golf Tournament: Delayed But Not Denied

Dark skies and torrential rain greeted the few teams who showed up hoping to tee off early at Brook-Lea Country Club on July 28 for the 12th year of our annual golf tournament. With several holes already under water, the decision was made to cancel the event. When Brook-Lea Country Club offered us a “rain date,” we gratefully accepted their generosity, and the golfers who returned to the rescheduled tournament on August 18 were blessed with a mild, sunny day.

This potential disaster turned out to be a highly successful event.

Ready to tee off!
VOICES of the Ribbon
The Newsletter of the Breast Cancer Coalition of Rochester
Our Mission is to provide support to those touched by a diagnosis of breast cancer, to make access to information and care a priority through education and advocacy, and to empower women and men to participate fully in decisions relating to breast cancer.

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We’re MOVING! . Back Cover

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When the Coalition incorporated in 1997, the vision of this emerging organization revolved around three arms: education and support for women and men diagnosed with breast cancer as well as the people who love and care for them; advocating for legislation that is in the best interests of those affected by this disease; and finding ways to empower research that has the potential to lead us toward an end to breast cancer. All the developments you see in this organization today – the groups, seminars, and events that have taken place in the lovely office space we have occupied since 2002 – are directed toward fulfilling this original vision.

We’ve come a long way since 1997.

We still have far to go.

2014 is proving to be an exciting year for the Coalition. WE ARE MOVING AT THE END OF THE YEAR. Yes. It’s true. Though we have loved our current home of twelve years, parking has become a serious challenge. But rest assured. As one door closes, another opens. Look for our familiar Horse-on-Parade mascot grazing in front of our new home just a block away, still in our beloved Neighborhood of the Arts at 1048 University Avenue.

Your trust, your work, your drive, your consistency, your generosity have made the Breast Cancer Coalition of Rochester everything it is today. From a small group of concerned women talking around a kitchen table to the powerhouse of hundreds of advocates, thousands of program participants, and leaders for common sense - you have been the seeds of change.

With this issue of Voices of the Ribbon comes an invitation to make a gift to assist with this growth and change. Right here. Right now. With this issue comes an envelope*. Already this year, we have been able to serve hundreds of program participants through Breast Cancer 101, Brown Bag Fridays, PALS Project, Evening Seminars, Healing Arts Initiative, the 11th Annual Advanced Breast Cancer Seminar and a variety of support programs. We also opened our doors to women facing diagnoses of gynecological cancers, using our successful support and education models to help them understand and cope with their diagnoses. We are moving forward in a new location because our commitment to our mission includes making sure those who need us can access us in the most efficient, comfortable manner. Have you benefitted from any of our programs, advocacy efforts, research initiative or other services in any way?

The Coalition’s ability to meet the needs in our community is because of your consistent, driven generosity. You have grown this organization from the ground up, helping men and women cope with and learn about their breast cancer diagnosis. We could never accomplish so much without such a dedicated group of supporters. Thank you for your gifts in the past, and thank you for considering a gift to the Breast Cancer Coalition of Rochester this year. Your support means so much.
On a late Friday afternoon in early December of 2001, a stunned Gloria Morgan walked out of the imaging center and into the darkening, deserted parking lot. She had spent four hours inside the building undergoing one test after another – a mammogram, ultrasound, biopsy – and although the conclusive results were still a few days away, she knew in her heart of hearts that life would never feel quite the same. And within those few days, it was confirmed: the lump Gloria had found during her monthly self-exam was, indeed, breast cancer. At age 44, one year into a separation and with three teenage daughters to consider, Gloria wasn’t prepared for this journey.

But being proactive is nothing new to her. During a college health class, the eighteen-year-old Gloria learned how to do a breast self-exam. “It was something that penetrated the very fiber of my being,” she recalls, and has faithfully continued the practice monthly ever since. In late 2001, when she found the lump “in a place that was very awkward – right at the bra line”, she waited to be sure it wasn’t due to normal monthly changes before she took action.

A week later, the lump was still there. A call to her OB/GYN resulted in the appointment at the imaging center which had turned into a marathon. “I called my mom and cried,” Gloria remembers, and took extra comfort in attending services at her church that Sunday. She was at work on Monday when her OB/GYN called and said, “Gloria, I’ve got your report.”

“You’re calling me at my job? Aren’t you seeing patients?” Gloria replied. “But I’m concerned,” he answered. “How are you?” “I love my OB/GYN,” Gloria confides. This kind doctor delivered the bad news and steered her into the office of a surgeon, who, on reviewing the pathology report, recommended a lumpectomy. When Gloria shared the news of her upcoming surgery with her daughters, the youngest, age 12, gave voice to her fear. “Are you going to die?” Mother and daughter were both in tears, but Gloria maintained her presence of mind. “Well, I’m going to die one day,” she answered, “but I’m not going to die from this.”

Gloria had finished her Christmas shopping uncharacteristically early that year. “I love being in the stores a week before Christmas,” she says with a smile. But that particular year, she had bought gifts and tucked them away in her office and at a friend’s house during October and November; she was ready to celebrate the season before her diagnosis came. “It was almost like I knew something,” she muses. On December 21, just after the classes she taught had ended for the holidays, Gloria underwent surgery to remove her tumor. Afterward, her doctor shared that the entire mass was as self-contained as if it were in a “zip-lock bag” and had not invaded the surrounding tissue or spread to any lymph nodes.

Whatever it was that had driven her to shop early that year, Gloria felt a sense of relief as she recovered from her surgery.

Under her mother’s care, with the support of her daughters, and with meals provided by caring co-workers, Gloria quickly recovered. Soon it was time to schedule appointments with a radiation oncologist and medical oncologist. While still on holiday break from her teaching, the decision was made to begin radiation therapy. A five-year course of tamoxifen, a useful drug in cases of hormone-driven breast cancer, was also recommended. Gloria willingly began radiation treatments, but after reading about possible side effects of tamoxifen, hesitated at the idea of taking it until her general practitioner explained the survival advantage it would provide her. She warily began a five-year course of the medication. “Some of the side effects I didn’t enjoy,” Gloria recalls about radiation and tamoxifen. “But I realized what I had to do. I had the best of treatment.”

When classes resumed in late January, Gloria reduced her teaching schedule to four hours a day. “My colleagues and my department chair...
In June of 2014, the New York State Legislature passed a law allowing healthcare providers to recommend the medical use of cannabis under carefully controlled circumstances. On August 27, the Monroe Community College Little Theater was the site of a community forum on this new legislation. Hosted by the Coalition and community co-sponsors Compassionate Care NY, Naides Oncology Rowing, US Too Prostate Cancer Education and Support, and the Student Nurses Association at Monroe Community College, this informative event took the place of our usual Wednesday evening seminar. The turnout was gratifying and those in attendance engaged in an in-depth discussion about what this new law means to New Yorkers, along with the frustrations at delays in seeing medical marijuana reach the hands of patients in need.

With our Director Holly Anderson to moderate the discussion, the speakers represented a diverse range of backgrounds and experiences. Luke Peppone, Ph.D., of the University of Rochester Medical Center, spoke of marijuana use throughout history and provided background on its current classification as a Class 1 controlled substance; one considered to have no currently accepted medical use and a high potential for abuse. His is among the voices disputing this contention. There are major difficulties in conducting research on cannabis in the US because of its classification, but Dr. Peppone pointed to research from other countries demonstrating its benefits and relative safety. There is more that needs to be known about the medical properties of cannabis, and lifting its stigma can open the door to further research.

Marianne Sargent, our Advocacy Committee Chair, spoke of the arduous journey that she and other NY State advocates have taken and continue to take in pursuing the legalization of medical marijuana. She told of the ongoing struggle to facilitate access to this medication for qualifying patients in the face of delays as the process for obtaining medical cannabis is under construction in this state. Those in the greatest need, such as children with intractable seizure disorders, are the most vulnerable and have the most to lose as the clock ticks on.

Julie Netherland, Ph.D., the Deputy State Director for the New York Policy Office of the Drug Policy Alliance, explained the details of the Compassionate Care Act (CCA), the medical cannabis law that advocates worked so tirelessly to see enacted. Although the legislation went through so many revisions that it is no longer considered to be the CCA, Dr. Netherland and others are working to improve this new law, including facilitating access to medical marijuana for the most vulnerable patients.

Sue Nill Kidera, a stage IV colon cancer survivor and CCA advocate, spoke powerfully of her need to make her personal medical decisions based on the best evidence. Patients like Sue who will be in treatment for the rest of their lives need good strategies for combatting the side effects of treatment. Medical cannabis can offer relief from such symptoms as nausea and pain, greatly increasing the quality of life for cancer patients, among others.

Patrick Fisher, the local Chapter Leader of Us Too, the International Prostate Cancer Education and Support Network, spoke of the positive effect medical cannabis can have for those dealing with the effects of prostate cancer treatment.

State Senators Ted O’Brien (55th District) and Joe Robach (56th District) rounded out the discussion by expressing their support of the CCA. Daunting hurdles have been overcome by lawmakers in seeing the NYS law enacted, and obstacles still remain. Foremost on the minds of many is the wait period for a distribution system to be set up. The state has fourteen months remaining to develop a workable system, but many patients cannot wait that long. So we at the Coalition forge on, alongside other advocates, scientists and lawmakers, working toward swift implementation of this new law.

We are grateful to those who took the time to be with us on a late August evening to sort through complex issues.
Our guest speaker of the night was Terri’s son, Tom Deckman. Tom spoke of his mother and the fighting spirit and determination she showed by not only enduring a breast cancer diagnosis, but by going through it while in office. He recalled his mother’s resolve to always move forward and always push harder. Although Tom thought he would feel awkward giving a speech in a place that he had never been, he didn’t. He could see why his mother and so many others who have walked through the doors of the Coalition find solace. He asked those present to please fight so that we can find the cause of breast cancer and put an end to it. He asked all the elected officials in attendance to “Please push harder.” I am sure Terri was listening and beaming with pride as her son spoke in her honor.

There were many elected officials in attendance this year, including those from federal, state, county, city and other local levels. Members of the advocacy committee, survivors, family and friends of BCCR were able to speak with their representatives about the work of the Coalition and how each of them has benefited from this organization. It was a wonderful evening filled with great conversation, delicious food and even better people.

The Advocacy committee meets the first Thursday of the month at 4:00 pm and is always looking for new members. If you are interested about learning more, please contact the Coalition at 585-473-8177. We would love to have you join us.
An Interview with Jonathan Friedberg, M.D., M.M.Sc.
- By Pat Battaglia

Jonathan W. Friedberg, M.D., M.M.Sc., is Director of the James P. Wilmot Cancer Institute, and Chief of Hematology/Oncology at the University of Rochester. In May of 2014, UR Medicine announced the creation of the Wilmot Cancer Institute. This new organizational structure encompasses all clinical and research programs in cancer at the University, and includes a growing network of satellite locations throughout the region. Dr. Friedberg recently took the time to address the concerns of patients and how they will be affected by this new Institution.

Q: What does the newly reorganized Wilmot Cancer Institute mean for cancer patients in general, and breast cancer patients in particular?

Dr. Friedberg: The concept of the Institute led from a variety of factors. The first is on the research side. We’ve spent two years in discussions to come up with our strategic plan for research. What we recognized, along with most of the other major research institutions, is that science is now a team sport. We put together large research teams in several focus areas. We think that’s going to put us in the most competitive position to get grants and also to do the best science. That team concept is better exemplified by an institute than a center because many investigators may not be in this building. They’re all throughout the medical center.

The other thing that led to the institute was our regional strategy. The Wilmot Cancer Center not long ago was a building down the street, and more recently, this building. In a short period of time, we now have seven locations from Geneva to Brockport. At each of these locations, medical records are completely integrated. There is the opportunity for clinical trial participation. Social workers from the hospital are available. We’re able to provide charity care that wasn’t possible before. Patients treated at any of these locations can be served by our survivorship program and incorporated into other types of services like nutrition support.

Why do this? Cancer care has become far more complex in this era than ever before. There’s no disease other than breast cancer that better exemplifies this. Before you even get treatment, the number of physicians involved in your care is substantial. It’s very hard to duplicate that kind of infrastructure outside of a large hospital facility.

This building is still called the Wilmot Cancer Center. But the institute is our brand of care. It’s about what we offer; this integrated multidisciplinary academic base of care with a focus on research and clinical trials.

Q: The Comprehensive Breast Care Center at Pluta has recently come under the wing of the Institute. What changes, if any, can clients of the Center expect?

Dr. Friedberg: Basically, I view this as a merger of two institutions, both of which had long standing histories of outstanding care of breast cancer. We saw that a lot of the patient population at the Pluta Cancer Center has breast cancer. Our Comprehensive Breast Center here had a dedicated space, but there were some issues with the space. We saw an opportunity to build a new, better, integrated breast center by having everything physically located under one roof. In May, we moved all of our breast cancer operations from here to Pluta.

What that means is that there’s a critical mass of all the different disciplines out there now. The breast tumor boards happen at Pluta. The Highland Breast Imaging program has been based out there. It’s enhanced convenience for the patient.

Q: A change in a familiar health care setting can be unsettling to patients. How do you handle the worries of patients who are concerned about the potential pitfalls of the new system?

Dr. Friedberg: That’s a very important question. I’ve given that a lot of thought and intention. I can’t claim that there hasn’t been any anxiety over this; there has been. I think what’s most comforting to many is that, for

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the vast majority, their physician hasn’t changed. In fact, most of the nursing teams haven’t changed either. We picked up our breast center here en masse — secretaries and everything — and moved it to Pluta, so there are a lot of familiar faces there.

One of the special things about Pluta was the feeling of a smaller, intimate environment. The staff at Pluta felt it was very important to try to maintain that feel. They embraced our being there to bring in things like clinical trials and enhanced services. But with added volume, the feel of their infusion room is different; the scheduling might be a little more cumbersome. We’ve paid a lot of attention to that and we’re really working to try to preserve the good things at Pluta. It’s outside of a hospital, outside of a medical center; you walk in there and it has a different feel. Physically, it hasn’t changed.

We have ideas of further expansion of some of Pluta’s ancillary and complementary services. They’ve had long standing interest in things like yoga, massage, tai chi, and cooking classes. We have proposals under way that we’re hoping to be able to officially speak to soon. And I think that the team at Pluta is very excited about that.

**Q:** Are there any advantages of having the Wilmot Cancer Institute in the Rochester area that might extend to all area cancer patients, whether or not they receive their care at the Institute?

**Dr. Friedberg:** I’d like to think there is a halo effect of having such a large center in the area; that all patients benefit through interactions that we have with our colleagues in other systems.

**Q:** What are the long term goals of the Institute in terms of patient care?

**Dr. Friedberg:** I see us as expanding our regional footprint. It’s very important to have a large population that you’re treating to be able to have that expertise close to home.

The other clinical goal of the Institute is to offer unique services. For the breast cancer population, our survivorship program is a great example of that, where in a short period of time, we’ve become recognized nationally as having a program that has all the tools and resources that patients are now expecting to provide a road map for care after treatment is finished.

Closer to home, we’re looking to collaborate with community based organizations like yours. We don’t have the bandwidth in our survivorship program, and we shouldn’t compete. If you have support groups that are very successful, we don’t need to duplicate that. What we’d like to try to do is form partnerships where we work together to do something that hasn’t been done. And that kind of community engagement becomes more and more possible when you’re thinking regionally.

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Look for interviews with leaders of Lipson and Interlakes Cancer Centers in an upcoming issue.
During October, a month dedicated to breast cancer awareness, one day - October 13 - is set aside to promote awareness of metastatic breast cancer. While the shelves of stores are peppered with products displaying pink ribbons and the mantra of early detection is promulgated throughout the media, the 155,000 Americans living with advanced disease can claim one day to spread the word about a condition they will live with for the rest of their lives. Is one day enough?

Is one day long enough to share the stories of courage, grit, hope, and joy that abound among those who share this life-long condition? Is it long enough to spread awareness that despite the ongoing interruptions of this devastating diagnosis, meaningful, productive lives are lived and hopes continue to be realized?

We at the Coalition don’t think so. That is why we hold gatherings throughout the calendar year devoted to those who live with breast cancer each and every day. We call these twice-monthly events “Common Ground” for a reason. There are as many variables with a late-stage breast cancer diagnosis as there are in early-stage disease, and although the particular features of each person’s walk with advanced breast cancer may be very different, we find time and again through sharing stories in a safe, confidential setting that, in the words of Maya Angelou, “We are more alike than we are different.”

Those who attend these informal, come-as-you-are meetings share lunch, share their stories, and share themselves. They reach out to each other, offering listening ears and empathetic hearts in non-judgmental companionship on an unchosen, but all too real journey. And the imprint they have on our survivor community as a whole is unmistakable. They put a real, very human face on metastatic breast cancer and add much to the collective wisdom of this remarkable organization.

We still acknowledge those living with advanced breast cancer on October 13 and celebrate those who continue to forge onward while holding those who are no longer with us close to our hearts. And when the day has come and gone we’ll keep on doing that.

Because, when all is said and done, we truly are more alike than we are different.
HER2/neu Positive Metastatic Breast Cancer: Researchers Test a New Combination of Drugs -By Pat Battaglia

Results of a double-blind, randomized, phase III clinical trial conducted at 204 centers in 25 countries were released recently. Investigators from the CLEOPATRA (CLinical Evaluation Of Pertuzumab And TRAstuzumab) trial in North America, Europe, and Asia randomly assigned 808 patients with HER2/neu positive metastatic breast cancer who had not received previous chemotherapy or biological treatment for their metastatic disease to two arms of the study: 402 received Perjeta (pertuzumab), Herceptin (trastuzumab), and docetaxel, while 406 received the same regimen with a placebo to replace pertuzumab.

Patients who received Herceptin plus Perjeta had a median survival of 56.5 months compared with 40.8 months for patients treated with Herceptin alone. No new safety issues emerged during the long-term follow-up in the trial, including cardiac toxicity, according to a recent presentation at the European Society of Medical Oncology (ESMO) meeting in Madrid.

The 15.7-month difference in overall survival translated into a 32% reduction in the survival hazard for the Perjeta arm of the study.

In the United States, Perjeta costs about $5,900 a month and Herceptin about $5,300 a month. Perjeta is priced lower than some other new cancer medicines because it has to be used with Herceptin.

HER2/neu positive diagnoses represent approximately 20-30 percent of all breast cancer diagnoses.* Although this new treatment regimen could represent a substantial improvement on the standard of care for metastatic breast cancer patients whose tumors test positive for HER2/neu overexpression, the results of this study have been published as an abstract and presented at a conference, and are considered to be preliminary until published in a peer-reviewed journal.

The study was supported by Roche, which manufactures Perjeta, and Genentech, manufacturer of Herceptin. Employees of both companies were among the co-authors.

For more information:

October’s designation as National Breast Cancer Awareness Month has been imprinted on our collective psyche in this country. Although about 30 percent of those diagnosed with breast cancer will, at some point, experience the spread of the disease to distant sites within the body – locations outside of the breast – known as metastatic breast cancer (MBC), there is just one day during October dedicated to this group. This has occurred thanks to the efforts of the Metastatic Breast Cancer Network (MBCN).

In the summer of 2009, nine members of MBCN traveled to Washington, D.C., to lobby with congressional members to designate their chosen day in October as National Metastatic Breast Cancer Awareness Day. Meanwhile, advocates throughout the country called their Senators and Representatives to urge their support for this measure. On October 13 that year, the MBCN received word that their efforts had succeeded. Both Houses of Congress had unanimously passed a resolution to set aside one day each year to highlight the stories and needs of those facing MBC.

There are many ways to observe this day, whether you are facing this diagnosis yourself, someone you

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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 coping with the diagnosis.

**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 regrowth...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: Carol Moldt, Jill Richards, Angelique Stevens and Karen VanMeenen which meets on the 4th Thursday of the month, from 6:00-8:00pm. Prior sign-up is required. Call us to reserve your seat, learn the next book selection, or to suggest a book.

**Common Ground:**
**Living with Metastatic Breast or GYN Cancers**
For those living with metastatic breast or gynecologic cancers, we offer a support gathering 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. Bring your lunch, bring your questions, and we will provide beverages, dessert, and compassionate listening ears. No RSVP is needed.

**The 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 Millner, meets from 5:30 to 7:00pm on the second Wednesday of each month.
Peer Advocates Lending Support: PALS SM

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 13 for PALS Program updates.

Voices & Vision:
A Writing Workshop for People with Breast Cancer
This well-loved group gives people with breast or gynecologic cancer an opportunity to explore and express their feelings through writing. Led by professional instructors: Elizabeth Johnston, Pamela Emigh Murphy, Angelique Stevens and Karen VanMeenen, these workshops run in five week cycles on Tuesday evenings. Seating is limited, and advance registration is required.

Gentle Yoga
On Monday evenings, you can find women stretched out on our floor doing Gentle Yoga taught by Susan Meynadasy, a registered yoga trainer. These popular sessions run in six week cycles, and the class is limited to 14 survivors of breast or gynecologic cancer. Advance registration is required.

The Healing Arts Initiative
Offering instruction in practices such as Fluid Motion facilitated by Tracey Boccia, Gentle Yoga facilitated by Raksha Elmer and Susan Meynadasy, Qi Gong facilitated by Raphaela McCormick, Tai Chi facilitated by Nancy Gillespie, and Nia Movement facilitated by Jane Pagano, this initiative is an opportunity to learn a new modality or become reacquainted with one that may have fallen by the wayside. Classes run in four-week sessions on Saturday mornings throughout the year and are limited to 14 survivors of breast or gynecologic cancer. Advance registration is required.

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 in early 2015. Please call to be added to the invitation list.

Photo sources: www.freeimages.com
The Power of Brown Bag Friday

Brown Bag Friday is a networking group held at the Coalition at noon every Friday; rain, shine, sleet, snow or hail. Without a doubt, it is our most popular program. When informally surveying program participants and survivors, an overwhelmingly majority mention that coming to Brown Bag Friday was one of the best decisions they ever made. How’s that for a powerful message?

For someone who is newly diagnosed, listening to and learning from other survivors is an enlightening experience. Women currently in different phases of treatment or recovery gather around the table, indulge in scrumptious treats, and share their breast cancer stories. Some women who are many months or years out of active treatment also attend weekly Brown Bag Friday sessions to stay connected to the Coalition, continue to network, and provide support to those who are newly diagnosed. Anyone who has received a diagnosis of breast cancer is welcome to attend the group on any given Friday;

no RSVP is needed. Those who attend for the first time typically walk away exclaiming, “I am so glad I came!”

Each session starts off with a particular question based on a topic of interest to breast cancer survivors. Recent discussions have ranged from communicating with your medical team, to body image, to grappling with emotions. The topics vary widely and there is always time to talk about the individual concerns of those at the table, even if that means veering far from the chosen topic of the day. In sharing your story and listening to others, it can be very empowering to recognize how the breast cancer experience of someone else can be similar in some ways to your own.

We at the Coalition hope that through the connections forged at the Brown Bag table, women will continue on their journeys feeling informed and strengthened by a group of those who are overcoming, or have overcome, similar obstacles.

Program Coordinator’s Update

Laura Albert

“If you’re brave enough to say goodbye, life will reward you with a hello.”

- by Paulo Coelho

To learn more about our support programs and the information available at BCCR, please contact Laura at 585-473-8177 or laura@bccr.org

Are you on our mailing list?

Is your e-mail address and/or phone number a part of our listing? Please send us your information for our mailing list so that we can offer e-mail news as well as print news. Send your information (full address or just your other details) to Laura Albert at laura@bccr.org

Thanks!

“We should notice that we are already supported at every moment. There is the earth below our feet and there is the air, filling our lungs and emptying them. We should begin from this when we need support.”

-Natalie Goldberg (Writing Down the Bones)
Since 2008, the PALS Program has been providing one-to-one support for those facing a breast cancer diagnosis. The experience of someone who has lived through the shock, uncertainty, and difficult learning curve of breast cancer can provide hope to someone just making their first tentative steps on a similar path. Those who have received the support of a PALS mentor have been extremely grateful for their connection with someone in a similar situation. But not all who take part in this program have been diagnosed with breast cancer.

A small segment of the population inherits specific genetic mutations that can put them at risk for developing breast and gynecological cancers. Based on a family or personal history of breast cancer, along with discussions with physicians and genetic counselors, some people opt to be tested for the BRCA1 and BRCA2 mutations, which account for about 25% of hereditary breast cancers.* (The National Institute of Health estimates the percentage of hereditary breast cancer to be between five and ten percent of all diagnoses.**) After in-depth discussions with doctors and family members, in addition to a good deal of soul-searching, some women who have learned they carry one of the BRCA mutations make the wrenching decision to undergo a prophylactic bilateral mastectomy – to have both breasts removed even though no cancer is currently present – rather than face the uncertainty of a heightened risk of developing cancer. They may also, depending on the circumstances and risks, opt for a hysterectomy as well.

These decisions are very individual and never taken lightly. Navigating the emotional aftermath of such a choice can be overwhelming. Consequently, the PALS Program is open to those who are considering prophylactic surgery due to their BRCA status, in addition to those who have been diagnosed with breast cancer.

PALS is a well-established program, and our trained mentors represent a wide range of experience. If you have been diagnosed with breast cancer or been found to carry one of the BRCA mutations, consider calling the Coalition. We’re here to complement the support of family and friends by providing voices of experience, and we’ll extend a helping hand to steady you as you forge your own path.

* * http://ghr.nlm.nih.gov/condition/breast-cancer

“Thousands of candles can be lighted from a single candle and the life of the candle will not be shortened. Happiness never decreases by being shared.”
-Buddha

Up-Hill
- By Christina Rossetti

Does the road wind up-hill all the way?
Yes, to the very end.
Will the day’s journey take the whole long day?
From morn to night, my friend.

But is there for the night a resting-place?
A roof for when the slow, dark hours begin.
May not the darkness hide it from my face?
You cannot miss that inn.

Shall I meet other wayfarers at night?
Those who have gone before.
Then must I knock, or call when just in sight?
They will not keep you waiting at that door.

Shall I find comfort, travel-sore and weak?
Of labour you shall find the sum.
Will there be beds for me and all who seek?
Yea, beds for all who come.

Enjoy the Breast Cancer Coalition Library

http://www.freeimages.com
Ten Tips for Storing Summer’s Bounty in the Fall Kitchen

By Pat Battaglia

The cool weather is upon us. Fruits and vegetables that have grown all summer are now available in the form of delicious fall vegetables. Bins in farmers markets and grocery stores are full, and the variety of colors, textures, and tastes is seemingly endless. Greens such as arugula, kale, and spinach are still in good supply. Also available are broccoli, cauliflower, cabbage, eggplant, potatoes, sweet potatoes, onions, and much more. And of course, there is the abundant variety of squashes that herald Autumn’s arrival. Fresh apples from local orchards are another harbinger of the season.

Once you’re home from the market or grocery, or if you’re bringing in the harvest from your own garden, storing your produce carefully will ensure that it remains at peak flavor and nutrition until you’re ready to enjoy it.

To keep your produce fresh and flavorful:

1. Store fruits and vegetables separately. Fruits give off ethylene, a gas that can prematurely ripen vegetables and lead to faster spoilage. Bananas in particular ripen very quickly and cause any nearby produce to ripen quickly as well.
2. Remove all ties and rubber bands, and trim away any parts that may be beginning to spoil before placing in bags or containers.
3. Allow air flow by puncturing your storage bags or using ventilated containers if you have them.
4. Pack items loosely in the refrigerator. Produce keeps longer with a little “breathing room”.
5. Store tomatoes at room temperature with the stems facing downward. This protects the stem area from moisture loss and the entry of molds.
6. Root vegetables such as potatoes, onions, garlic, and fresh ginger do not need to be refrigerated. Store in a cool, dark, dry space.
7. Carrots and parsnips, on the other hand, need to be kept cold and will keep for two weeks to a month if properly stored in the refrigerator. The trick is to prevent condensation from forming around them. Remove any greens if they’re still attached, wrap them in cotton or paper towels, and place them in ventilated bags.
8. Fresh herbs are wonderful, but leftovers can deteriorate quickly. Freeze chopped herbs in an ice cube tray with olive oil or water poured over them. The individual cubes are recipe ready!
9. Thin-skinned winter squashes such as delicata and spaghetti squashes will last a month or two after harvest. Hubbard and buttercup squashes and pie pumpkins will last up to four months, while the thick-skinned buttercups and cushaws may last until Spring. Store squashes in a cool, dark, dry place.
10. Keep apples in the crisper drawer of your refrigerator, in perforated bags. Remove any with signs of rot. That “one bad apple” won’t spoil the whole bunch if it’s removed promptly.

For more information:
http://www.gardening.cornell.edu/factsheets/vegetables/storage.pdf
http://www.organicgardening.com/cook/harvesting-and-storing-squash
These two recipes feature those versatile, plentiful Fall staples, squash and apples.

### Apple Ginger Crisp

**Ingredients**

**Apple Filling**
- 6 green apples, sliced but not peeled
- 1 T. lemon juice
- 2 T. unbleached all-purpose flour
- 1 1-inch piece fresh, peeled ginger root, finely chopped
- 2 tsps. ground cinnamon
- 1 tsp. ground cardamom
- 1/8 tsp. fine sea salt
- 1/3 cup frozen apple juice concentrate, thawed to liquid

**Topping**
- 1 cup whole wheat pastry flour
- 1/4 cup (1/2 stick) melted butter
- 1/4 cup pure maple syrup
- 1/4 tsp. grated nutmeg
- 1/4 cup slivered almonds

- Preheat oven to 350 degrees.
- For apple filling, toss apples with lemon juice. Stir in flour, ginger, cinnamon, cardamom, salt and apple juice concentrate. Spread in an oiled 9x13-inch baking dish. Set aside.
- For topping, stir together flour, butter, syrup, nutmeg and almonds. Crumble topping over apple mixture, pressing it down gently.
- Bake for 45 to 50 minutes or until apples are bubbling and tender.
- 8 servings

*From Whole Foods: http://www.wholefoodsmarket.com/recipe/apple-ginger-crisp*

### Spaghetti Squash with Pine Nuts, Sage, and Romano

**Ingredients**

- 1 spaghetti squash, halved lengthwise and seeded
- 1/4 cup toasted pine nuts
- 1/4 cup grated Pecorino Romano cheese
- 2 T. chopped fresh sage (or 1 tsp. dried)
- 2 tsps. butter, melted
- salt and pepper to taste

- Preheat oven to 375 degrees.
- Place the squash, cut side down, in a large baking dish.
- Bake in the preheated oven for 50 minutes.
- Separate strands of squash with a fork, scrape from the rind, and place in a bowl. Add the pine nuts, cheese, sage, butter, salt, and pepper; toss to combine.
- Serve immediately.
- 4 servings


### Cooking Spaghetti Squash

*Method:* Just get in there and cut it in half (lengthwise) or quarters. You don’t want to cut it up too small unless you want short strands. Scrape out the seeds and pulp as you would with any squash or pumpkin. Bake rind side up about 30 to 40 minutes at 375 F. Microwave 6 to 8 minutes (let stand for a few minutes afterwards) Then you can separate the strands by running a fork through in the "from stem to stern" direction.
Many teams regrouped and spirits were high, both on the course and at the dinner that followed, where raffle prizes were handed out and stories exchanged. None of this would have been possible without the tireless efforts of the planning committee, headed by Sean Patton and Lee Cordero, and joined by Sylvia Cappellino, Rick Dougherty, Cindy Dykes, Kay Kolb, Charlot and Remo Rossi, Susie Smith and Connie Zeller. Special thanks to them and the volunteers and staff who assisted at the event: Natalie Brueckner, Cheryl Deyle, Marcy Lazio, Lori Meath, Betty Podlesh, Julie Shaw, and Brenda Tartaglia.

We hope you will join us when we return to Brook Lea Country Club on Monday, July 27, 2015, for the 13th annual “Tee’d Off At Breast Cancer” Golf Tournament!

<table>
<thead>
<tr>
<th>TOURNAMENT RESULTS</th>
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<tr>
<td><strong>1st Place Men's Flight</strong></td>
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<tr>
<td>Wynn Bowman</td>
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<td>Chris Lake</td>
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<td>D. Spampananto</td>
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<td>Joshua Stubbe</td>
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<td><strong>1st Place Women's Flight</strong></td>
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<td><strong>1st Place Mixed Flight</strong></td>
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<td>Sam Burgess</td>
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<td>Phyllis Haberer</td>
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<td><strong>Long Drive Women</strong></td>
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<td>Amy Hagler</td>
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<td><strong>Long Drive Men</strong></td>
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<td>Ben Carlson</td>
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Fore!

*Event photos taken by Ria Tafani*
Breast Cancer Golf Tournament

Golfing in memory of Sheri

Marcy Lazio, Connie Zeller and Betty Podlesh providing refreshments

Striking a pose!
Our Generous Donors

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Big Oak Driving Range & Golf Shop
Bill Gray's Restaurants
Breast Cancer Coalition of Rochester
Sylvia Cappellino
Cole Real Estate
Jackie Colicchio
Country Club Liquor Mart
Eagle Cleaners
Eastway Liquor
Gallea's Tropical Greenhouse
Genesee Valley Pennysaver
Georgetown Liquor
Grinnell's Restaurant
Hedonist Chocolates and Ice Cream
Invesco
Izzo Golf
Kay Kolb
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Kathy Macbeth
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Mercedes-Benz of Rochester
Monroe Golf Club, Jim Mrva
Oppenheimer Funds
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Anne Smith
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Tony D's Coal Fired Pizza
Wambach Garden Center
Wild Wood Country Club
Windsor Cottage
Carolyn Yaekel

Special thanks to Robin Vavrina for the beautiful centerpieces!

Our Generous Sponsors

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Pink Tee Sponsors - $1,000
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Dick Warner • Wonder Windows

Recognition Sponsors - $125
Walter J. Deck, DMD, PC • Prudential Retirement • Upstate Niagara Cooperative, Inc.
Outreach Coordinators’ Update

We often speak of our promise to “keep it local” when thanking our donors for monetary gifts. We are proud to let people know that the money they work so hard to raise for us will indeed be used for programs to serve Rochester area women and their families. We are especially proud of our research initiative, and know that our grants, though modest, provide the “seed money” for promising (often young) Rochester area researchers.

This year, we were the beneficiaries of another Rochester based organization who decided to “keep it local”. We were awarded a grant through the Pollution Prevention Institute at RIT (P2I) to fund two Interns. Asia Wang, a U of R Sophomore in Public Health, and Victoria Koukoulas, recent U of R graduate, spent their summer work experience with us to complete a community survey and atlas of nail salons and to offer education to at-risk women of childbearing age about reducing chemical exposures in daily life and work.

The information gained through the work of the interns on this project is a true gift not only to the Breast Cancer Coalition of Rochester, but the entire community. The face to face contact with area nail salon owners and employees was a time intensive effort that we could not have accomplished without this grant. The addition of these two amazing young women to our staff for the summer allowed us to reach out to less-served neighborhoods, and gave us a core of information to share with women of childbearing age and their daughters.

It is our hope, and that of the Pollution Prevention Institute, that sharing practical, clear information to reduce exposure to known endocrine disrupters, pesticides, and other harmful chemicals will empower the next generation of women to better protect themselves and their daughters.

Karen Ashbaugh quietly entered the scene at the Coalition after she was diagnosed with breast cancer. Following her interests in integrative medicine and clinical research, she participated in a clinical trial investigating the effects of curcumin on patients undergoing radiation therapy. When her treatment was finished, she sought volunteer opportunities at the Coalition and has proven her willingness to help whenever and wherever she is needed, taking on leadership roles with characteristically understated strength.

Karen stepped in to lead the ARTrageous Affair’s Registration and Checkout Committee at a time when Patti Cataldi, Chair of the Coalition’s Board and Co-Chair of the ARTrageous event, was struggling to find someone to fill that role. “This is no small task,” says Patti. “She organizes and orchestrates the army of volunteers who come to the Gala, making sure that each guest has the best experience possible that evening.” Karen has also recruited her son, Max, to help with the event.

An eloquent, thoughtful speaker, Karen has shared her concerns with legislators on issues important to those affected by breast cancer, rising in the pre-dawn hours to catch the bus to Albany with other Coalition advocates on our annual Advocacy Day. This savvy advocate has also represented the Coalition at community events.

When our freshly polished Research Initiative took flight again in 2012, Holly Anderson’s thoughts turned to Karen when considering potential candidates for the new committee. Karen jumped at the chance. Her interest in research, piqued by her clinical trial participation, led this IBM executive to manipulate her busy schedule to accommodate Research Committee meetings and events. As a Survivor/Advocate Reviewer, Karen has carefully read, reviewed, evaluated, and scored proposals submitted to the Outreach arm of your Breast Cancer Coalition.

As we incorporate this “new” information into what we offer at health fairs and community events, volunteers have the opportunity to become ambassadors for prevention.

Volunteer SPOTLIGHT

Karen Ashbaugh

-Karen Ashbaugh

Continued on page 23

-In every community, there is work to be done. In every nation, there are wounds to heal. In every heart, there is the power to do it.”

-Marianne Williamson

Lori Meath

Continued on page 23
“Breast Cancer Exosomes, Novel Intermediaries in Psychosocial Stress-Induced Tumor Pathogenesis.”

Current data indicate that metastasis is responsible for approximately 90% of fatalities in breast cancer patients. Recent work from University of Rochester (U of R) laboratories and others has demonstrated that psychosocial stress can increase tumor growth, angiogenesis, and metastasis. Cancer patients can experience significant stress and depression which often correlates with poor survival.

Mr. Dawes’s proposal tested the novel hypothesis that a newly-identified extracellular vesicle population, circulating exosomes, plays a mechanistic role in driving stress-induced tumor progression. These exosomes carry various pro-tumor molecules, including protein and RNA, capable of eliciting a shift to metastasis. In his September midterm report, Mr.

On June 30th and July 15th respectively, the Research Committee hosted final presentations from 2012–2013 Coalition grant recipients Ashwani Sood, PhD from Roswell Park Cancer Institute and Ryan Dawes, PhD candidate at University of Rochester Medicine. The sessions were fairly well attended and summaries of their presentations are included below.

In addition, on September 11, 2014, the Research Committee traveled to Roswell Park in Buffalo to visit the laboratory of Gokul Das, PhD. Dr. Das gave an extremely informative tour and presentation. Committee members came away with a greater understanding of his research. We also met the graduate student and post-doctoral candidate members of his research team. Meeting us and putting a "face" to the research, as it were, is beneficial to them and is a part of the Research Committee’s “outreach/researcher interface” mission. A similar committee visit to the laboratories of Helene McMurray, PhD and Mark Noble, PhD is planned for October 23, 2014.
A Tribute to Lisa Fox

Lisa Fox, who left us on July 18th, was a valued participant in many groups at the Coalition. She brought with her a charming smile and great attitude. While cancer robbed her of energy, she was determined to do one meaningful thing each day. She was radiant when she talked about dancing and valued the support of her friends in the Rochester dance community. She was a social worker at Rochester General Hospital and was always more than willing to help fellow members of the Common Ground support group with questions about how to navigate the healthcare system. Lisa is survived by her daughter Shara and was proud of the young woman she is becoming. A kind, spirited, fun-loving person, Lisa taught us the value of living in the present. We would like to remember her with the words that were shared on her memory card:

I’d like the memory of me to be a happy one,
I’d like to leave an afterglow of smiles when life is done.
I’d like to leave an echo whispering softly down the ways, of happy times and laughing times and bright and sunny days.
I’d like the tears of those who grieve, to dry before the sun
Of happy memories that I leave when life is done.

Oh Lisa, thank you for entering our lives...and leaving happy memories.

High Flight

Oh! I have slipped the surly bonds of earth,
And danced the skies on laughter-silvered wings;
Sunward I’ve climbed, and joined the tumbling mirth
Of sun-split clouds, --and done a hundred things
You have not dreamed of --Wheeled and soared and swung
High in the sunlit silence. Hov’ring there
I’ve chased the shouting wind along, and flung
My eager craft through footless halls of air...
Up, up the long, delirious, burning blue
I’ve topped the wind-swept heights with easy grace
Where never lark or even eagle flew --
And, while with silent lifting mind I’ve trod
The high untrampled sanctity of space,
Put out my hand, and touched the face of God.

- John Gillespie Magee, Jr

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.

Jacque Shatzel Ater
Mary Coniff
Anna Conte
Lisa Fox
Jane & Larry Glazer
William "Bill" Martel
Ann Mowher
Sheri Schwartz

The Breast Cancer Coalition celebrates the lives of longtime friends and supporters Jane & Larry Glazer.

We join a grieving community in mourning their untimely passing.

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@bcr.org.

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

Aaand They’re Off!

A gorgeous late Summer evening greeted guests who once again enjoyed a sumptuous buffet dinner, live harness racing, and a bit of gaming at Batavia Downs. For the 4th year, supporters of the Coalition joined our dedicated friends Melisande and Richard Bianchi as they hosted another exciting event at the newly remodeled Batavia facility. Bills Hall of Famer Thurman Thomas was on hand to welcome guests, pour a few drinks and have photos taken with happy fans. A great evening of fun resulted in a wonderful gift to the Breast Cancer Coalition of Rochester of $7000!

The Coalition’s Laura Albert with Thurman Thomas

Charmed By Charity

Charmed by Charity is a national program of the popular Alex and Ani line of jewelry.

Among other items, the stores offer “stacking” bracelets which are designed to be combined to create a “story” of each wearer’s passions and inspiration. Local non profits or individuals are able to “host” an evening of shopping and refreshments at an Alex and Ani store to benefit a favorite charity. A portion of these evening’s proceeds are then given to the charity. On May 15 a party was hosted by Kelly Grover which lead to a much-appreciated gift of $556.95.

OPA!

Rochester’s iconic Greek Festival celebrated its philanthropy program’s fifteenth year on May 30. The Coalition was one of the first recipients of a generous donation from the program in 2003. Each year, the Festival committee selects one local non-profit agency to be featured and given $5000 for that year. The program is unique, though, in that each year, any agency that has been previously been chosen is given an additional gift of $1000. The ongoing generosity and local commitment of this festival community is inspiring. Thanks, Greek Fest!

Strollin’ Seniors

Westwood Commons is a Senior Living Community that strives to make each resident part of a vital, active community. On August 15, this active group held a “mini marathon”. Residents collected pledges from sponsors within the community and in their own families. Each resident simply completed any distance they found comfortable and were cheered on by onlookers. This marathon resulted in some tired but proud residents who were thrilled to donate $305 to our Coalition.

Snip, Snip

Master Hair Stylist Joe Chesbro is a Rochester treasure. Since 2008 he has offered his artistic wizardry at Rocky Greco’s salon in Pittsford. Clients wait happily for an appointment with the Master, and are never disappointed. To honor the health struggle of several clients, Joe recently held a haircutting event from which a portion of the proceeds was directed to the Breast Cancer Coalition of Rochester. We thank Joe and his clients for a gift of $200.

A Swinging Success

Lisa Fox was a spirited member of a “swinging” group of Swing Dancers who regularly meet for fun and exercise. Lisa was also a beloved member of our Coalition, lost recently to this dreaded disease, breast cancer.

To honor the memory of this amazing and much-missed woman, Take a Swing at Breast Cancer Dance was held at Taylor’s Night Club on September 26. Coordinator James Manning and his crew hosted a great party that included a silent auction.

It was an evening that would have thrilled Lisa, and she would be touched to know that “her party” resulted in a generous gift of $1785, to the Coalition. This gift assures that her gentle and joyful spirit will serve many others facing the challenge of breast cancer.

We miss you, Lisa!

Snip, Snip

Master Hair Stylist Joe Chesbro is a Rochester treasure. Since 2008 he has offered his artistic wizardry at Rocky Greco’s salon in Pittsford. Clients wait happily for an appointment with the Master, and are never disappointed. To honor the health struggle of several clients, Joe recently held a haircutting event from which a portion of the proceeds was directed to the Breast Cancer Coalition of Rochester. We thank Joe and his clients for a gift of $200.
**Wegman’s Card Winner**

Our presence at the annual Park Avenue Fest would not be the same without the Wegmans Gift card raffle. It seems there are few who would not jump at the chance to win a $250 spree through Wegmans aisles. This year’s lucky winner was booth visitor Anne Ivers of Rochester. Congratulations, Anne! And thanks for stopping by our booth to chat.

**Volunteer Spotlight continued**

the Coalition for funding, in addition to attending all-day panel review sessions. She has also accompanied other committee members on field trips to funded researchers’ laboratories, technical presentations, and much more. Quite literally willing to go the extra mile, Karen was the official chauffeur for Matthew Allen, Vet. MD, PhD on two occasions when he flew in from Ohio to serve on the review panel. As the daughter of a veterinarian, Karen especially enjoyed talking with him about his practice and research; surely an unexpected bonus for her.

As Patti Cataldi so aptly states, “[Karen] has proven herself as an unflappable, unassuming, steady leader.” And so we shine this month’s volunteer spotlight on this smart, compassionate woman with a “can-do” attitude. Thank you, Karen!

**Putting in a Pinch**

Golfers are a hardy bunch, and frequently dodge rain, animals, misdirected golf balls, and stiff breezes in pursuit of their “art”. The lady golfers are Blue Heron Hills demonstrated their determination and resourcefulness on a soggy event day by moving their putting contest indoors! With a square of indoor carpet green and the metal half of a drink shaker serving as the somewhat-elusive hole, the laughter more than made up for the dismal day and a good time was had by all.

Thank you, ladies, for a gift of $105 representing monies donated for chances to win a door prize. The spirit of this group, many of whom have been touched by breast cancer, is part of the gift they share.

**Boomers Fail to Dampen Spirits**

Feisty thunder storms did not deter the ladies of the Midvale Country Club on June 24 at Midvale Country Club. They simply waited. And then out onto the wet course they filed when the lightening departed. Armies of pink-clad golfers spread out across the beautiful Midvale course only to be driven back in a half hour later. Still not thwarted, they headed out again! All of this “down time” gave players more chances to bid on an incredible variety of raffle items donated by area businesses and individuals. Dinner was delayed, but the tournament was completed. The happy, if somewhat damp golfers ultimately raised $6040 to support the Coalition. The dynamic duo of Marcy Lazio and Betty Podlesh are to be congratulated again for a spirited and successful event. (PS This writer had a great time!)

**Outreach Update continued**

information. How would YOU like to become familiar with this material? Written communications? A training session? Give it some consideration and send an email with your thoughts to me at lori@bccr.org.

We could not have taken this next step in our Outreach effort without the help of the P2I and their commitment to “keeping it local”!

**Wegman’s Card Winner**

Our presence at the annual Park Avenue Fest would not be the same without the Wegmans Gift card raffle. It seems there are few who would not jump at the chance to win a $250 spree through Wegmans aisles. This year’s lucky winner was booth visitor Anne Ivers of Rochester. Congratulations, Anne! And thanks for stopping by our booth to chat.

**Sharing Wedding Joy with Mom**

Sarita Lanning was a mom lost to breast cancer when her sweet daughter Jenn was just thirteen years old. Jenn Lanning has given her time and talents to the Breast Cancer Coalition as a volunteer to honor her Mom for many years.

In planning for her wedding this Summer, Jenn wanted to carry on the practice of bringing her memory of her mom into all that she does. With her fiancée, Jenn decided to make a donation as a “wedding gift” to the Coalition in lieu of wedding favors for the guest tables.

No doubt Sarita’s presence was felt by many on that special day, and as guests were thanked in her honor, the love of a daughter on her wedding day for her cherished mother was shared.

Jenn, Mom would be proud! And may you share a long and happy life with your new husband.
Donations ending June 30, 2014

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

In Honor of:

Mary Carafos
Theresa & Daniel Eckert
Frank & Norma Riedman

Phyllis Connelly
Louise Cerrone

Judy Cummings
Amy Williams

Lisa Fox
Thursday Night Swing-In-Dance Community

Corinne Heh
Dawn Lindboom

Colleen Joseph
Theresa Perry
Mary & David Webster

Joanie Morse
Marie Hoover
Judith Wade

Margaret Nichols 90th Birthday
Judith Rhodes

Olga Russell
Kathleen Russell

Jamie Scripps
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Susie Smith
Robin Vavrina

Tiffany Stapleton
Linda Braun

Suzanne Unell
Alice & John Stout

Dennise Webster
Robin Pulver

Tina Woodruff
Ashlee McLoughlin

In Memory of:

Harold Abrahamson
Luann Pero
Gail Wilder

Susan Ames
Barbara Natalie

Glenn Berna
Janet & Gary Comfort
LaDonna Court
Linda Makowski
Ruth Ostrander
Karen Panosian

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Marcia & Jack Sherman

Caroline Mirrione
Gia Allen

Kelly Sargent
Sandy & Dave Kolupski

Janet Stager
Thursday Night Swing-In-Dance Community

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Jacqueline & Richard Whistler

Kenneth Wood
Joyce Prosser
Eric & Kelly Schmidt & family

Founder’s Circle $5,000 +
Midvale Country Club - Golf Tournament

Visionary Circle $1,000-$4,999
ACL Associates - Teed Off at Breast Cancer - Pink Tee Sponsor
Aladdin’s Natural Eatery
American Century Investments - Teed Off at Breast Cancer - Pink Tee Sponsor
Annunciation Greek Orthodox Church
Bonadio Group - ARTageous Affair - Bronze Ribbon Sponsor
Canandaigua Knights U19 Girls Hockey - Our Blood, Our Sweat, & Cancer’s Tears Tournament

In Honor of:

Mary Carafos
Theresa & Daniel Eckert
Frank & Norma Riedman

Phyllis Connelly
Louise Cerrone

Judy Cummings
Amy Williams

Lisa Fox
Thursday Night Swing-In-Dance Community

Corinne Heh
Dawn Lindboom

Colleen Joseph
Theresa Perry
Mary & David Webster

Joanie Morse
Marie Hoover
Judith Wade

Margaret Nichols 90th Birthday
Judith Rhodes

Olga Russell
Kathleen Russell

Jamie Scripps
Diane Ripple

Michelle Shayne, MD
Carol Giffi

Teresa & Paul Skiba
Marilyn Casaceli

Kathy Smith Gorman
Delroise & Terry Weis

Susie Smith
Robin Vavrina

Tiffany Stapleton
Linda Braun

Suzanne Unell
Alice & John Stout

Dennise Webster
Robin Pulver

Tina Woodruff
Ashlee McLoughlin

In Memory of:

Harold Abrahamson
Luann Pero
Gail Wilder

Susan Ames
Barbara Natalie

Glenn Berna
Janet & Gary Comfort
LaDonna Court
Linda Makowski
Ruth Ostrander
Karen Panosian

Edith Jane Betlem
Joanne Hammond

Mary Ann Borrelli
Andrea Borrelli

Judy Buchanan
Christina Bell
Debbie, Bell
Kevin Bell
Ray Buchanan
Carol Button

Alberta DeReu
Michelle Adriangian

Santo Farina
Rachel Brady
Laurie & John Brooks
Mary Buckley
Janet Prinzivalli

Loretta Garland
Gail & Darnell Garland

Dale Griffin
Joyce & Carl Lompo

Sara Jane Kimber
Judy & Jo Baran
Alan Braun
Barbara Harvey
Daniel Hunt
Charles Manzella
Pamela & Joseph Manzella
Patricia Smith
V.J. Stanley, Inc.

Phyllis Maynard
Diane Ripple

Connie McIntyre
Marcia & Jack Sherman

Caroline Mirrione
Gia Allen

Kelly Sargent
Sandy & Dave Kolupski

Janet Stager
Thursday Night Swing-In-Dance Community

Robert Swift
Scarlet Artruc
James Derrenbacher
Hazel & Robert Durthoy
Eunice & Donald Gerould
Livonia Middle School
Lynn & Paul Maginn
Debbie & Sam Piperni
Mary Lou & Harold Roenser
Sheila & Steve Ryan
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Donna Thiele-Cleaver
Melisande & Richard Bianchi
Phyllis Connelly
Joanne Hammond

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Lori & Randy Cook
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Kathleen Eno
Kathy MacBeth-Clark
Jan & Larry Telle
Jacqueline & Richard Whistler

Kenneth Wood
Joyce Prosser
Eric & Kelly Schmidt & family

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Bonadio Group - ARTageous Affair - Bronze Ribbon Sponsor
Canandaigua Knights U19 Girls Hockey - Our Blood, Our Sweat, & Cancer’s Tears Tournament
Century Mold - Tee’d Off at Breast Cancer - Eagle Tee Sponsor
The Duke Company - Tee’d Off at Breast Cancer - Pink Tee Sponsor
Elizabeth Wende Breast Care
Fidelity Charitable Gift Fund - Dr. Weide W. Young, EWBC
Harter Secrest & Emery - ARTrageous Affair - Bronze Ribbon Sponsor
Konar Properties - ARTrageous Affair - Bronze Ribbon Sponsor
Madonna OB/GYN/Invision Health - Tee’d Off at Breast Cancer - Pink Tee Sponsor
The Maplewood Nursing Home - ARTrageous Affair - Bronze Ribbon Sponsor
RGHS - Lipson Cancer Center - ARTrageous Affair - Silver Ribbon Sponsor
Pluta Cancer Center Foundation - ARTrageous Affair - Bronze Ribbon Sponsor
RockcastleFlorist - Pink Ribbon Run & Walk - Bronze Sponsor
Shapiro, DiCaro & Barak - Tee’d Off at Breast Cancer - Pink Tee Sponsor
Standard Insurance Company - Tee’d Off at Breast Cancer - Pink Tee Sponsor
T. Rowe Price Retirement Plan Services, Inc. - Tee’d Off at Breast Cancer - Cart Sponsor
The Zeller Corporation - Tee’d Off at Breast Cancer - Pink Tee Sponsor

Advocate’s Circle $500-$999
Alex and Ani + Energy
Melisande & Richard Bianchi - ARTrageous Affair - Pink Ribbon Sponsor
BNP Paribas - Tee’d Off at Breast Cancer - Green Tee Sponsor
Canandaigua National Bank & Trust - Tee’d Off at Breast Cancer - Green Tee Sponsor
Elmwood Dental Group - ARTrageous Affair - Pink Ribbon Sponsor
Growing In Voices
Johnson & Johnson Match
Laura Koenig
Monroe Community College AAWCC - Pink the Atrium & Pink the PAC
Radiation Oncology at Lipson Cancer Center - ARTrageous Affair - Pink Ribbon Sponsor
Ristorante Lucano
Williamson Apple Blossom

Pink Ribbon Circle $100-$499
Holly Anderson
Scott Adair
Joe Chesbro
Carole Cilano & John Short
Karen Dee Dries

Domenico DiLucia
Duke Company - Annual Open House
Barbara Erbland
Extra Credit, Inc.
Louise French
Ben Gioseffi
GrandeVille Senior Living Community of Greece
Growing in Voices Foundation
Deb Henretta & Sean Murray
Jacquelyn Howitt, MD
Cathryn Kwit
Lincoln Financial Group - Tee’d Off at Breast Cancer - Hole Sponsor
Kathy MacBeth
Mason Marketing, LLC - Tee’d Off at Breast Cancer - Hole Sponsor
Paula Martin
Molye Chevrolet - October Pink Ribbons
Mary Jo Provenzano
Prudential Financial - Tee’d Off at Breast Cancer - Hole & Recognition Sponsor
Restoration Church of God
Shirley Taccone
Thursday Night Swing-In-Dance Community
Turner Engineering, PC - Tee’d Off at Breast Cancer - Hole Sponsor
VMD-MT Security - Corporate
VMD-MT Security - Employee Action Committee/Sunshine Club
Chris Wagner - St. Joseph’s Neighborhood Center, Inc.
Susan Waugh
Joyce W Orih
Wonder Windows - Tee’d Off at Breast Cancer - Hole Sponsor

Friend’s Circle $50-$999
Elaine Costello
Marla Hamilton
Peggy Leverenz
Mary Jo Meteyer
Perter Perkins
Jean Rudai
Patricia Scheiber
Kimberly Stolp
Nancy Vanzetta
Connie Ventura

Contributor’s Circle $1-$49
Pam Allison
Mary Ann Asam
Bernadette Bruno
Tania Chen
David Crawford
Elaine & Sam Cumbo
Mary Gilligan
Bernadine Gordon
Theodora Gunn
Dianne Hebbrecht
Doreen Holmes
Karen Moulton
Nicky Olenwik
Lori Jeanne Peloquin

Pittsford Picture Framing
Nancy Slyver
Carol & John Toscano
Janice Wilson

Gifts in Kind:
Mallory Dixon
Patricia Ewing
Howard Jones
Junior Girlscout Troop 60599
Karen Miltner
Karen Nolan
Carol Platt
Sheila Povoski-Butler
Andrea Reynolds
Charlene Sudore

United Way Donors continued
Tashanda Thomas
Ted Thompson
Jacqueline
Tramontana
Valerie Trenchard
Bayley Tripp
Laurie Tschudi
Willie Mae Tucker
Lisa Tydings
Deborah Urts-Zealson
Maureen Valentine
Shawna Valentino
Sheryl Valentino
Andrew Valerioti
Laina Valerioti
Yaritza Vazquez
Kim Vent
Robby Villa
Kellirae Vonglis
Nicole Wahl
Lisa Warney
Lisa Wasson

Mark Watts
Karen Wells
Kathryn Whelan
William White
Amy Wilkin
Alexander Williams
Janet Williams
Marcia Williams
Rachel Williamson
Kathryn Willison
Carol Willnow
Eleshia Wilson
Toya Wilson
Amy Winterberger
Kelly Wise
Harry Wood
Joan Wood
Ashleykay Yaniga
Lisa Yankevich
Diane Yankloski
Annmarie Young
Karen Zuber-Roberts

“The little unremembered acts of kindness and love are the best parts of a person’s life.”

-William Wordsworth
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THE COALITION’S CURRENT WISH LIST

- A cure for breast cancer
- Books about breast cancer for women, men, children, families (2010 or later)
- Books about endometrial, ovarian, cervical, fallopian, or other GYN cancers (2010 or later)
- Books about prostate or testicular cancers (2010 or later)
- Copy paper, white
- Foam core (new)
- Gift cards: Wegmans, Tops, DiBella’s, Staples, Target, Barnes & Noble, Michaels, pizza, etc.
- Paper products: napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam products)
- Tablecloths 70x90 and 70x108 (white, sage green, pink)
- Vacuum cleaner (new, upright)
- Folding 6 or 8 foot table, lightweight
- Batteries, D and AA

The following items are needed specifically for PALS Paks: (all items must be new)

- Hand knit caps
- Scarves or bandanas
- Fleece throws/blankets
- Journals
- Note cards
- Satin sleep masks (lavender or unscented only)
- Thank you cards
- Foam ear plugs
- Lanyards (preferably plain)

The Coalition’s current wish list includes a variety of items that can be purchased or donated to support the cause. The list includes items such as books about different types of cancer, paper products, gift cards, and home essentials like tablecloths and vacuum cleaners. Each item on the list is important in different ways, whether it’s for practical use, emotional support, or simply to show appreciation for the work the Coalition is doing.

Metastatic Awareness continued

know and love is, or if you have not been so affected but want to lend your support. You might begin by arming yourself with knowledge about MBC. The Coalition is a good place to start, as is the MBCN (www.mbcn.org). You might make a donation to the Coalition in honor or memory of those facing MBC, or any individual you may know. Donations to our Research Program, which focuses of halting the metastatic spread of breast cancer as one of its two objectives (the other is finding a cause for the disease in the first place) would be gratefully received, or you might sponsor a Common Ground lunch group. If you know someone affected by this disease, call them, or better yet, take them out to lunch. Offer a listening ear to someone with MBC and you may be surprised to hear the voice of a vibrant, active person who, while facing an overwhelming diagnosis with courage and determination, is living life to the fullest and defining her/himself as much more than a diagnosis. Find that “common ground” even if your own journey is very different.

However you choose to recognize October 13, it is your chance to do something meaningful for those facing a frustratingly incomprehensible disease. Even if these words reach you after the day has passed, there are 364 other days when you can make a difference for someone, or make a contribution to a worthy cause, or to add to your working knowledge of MBC. As often as it has been said, it remains undeniably true: knowledge is, indeed, power.

The 14th Annual
October 22, 2014
7:00 – 9:00 pm
FREE!

The evening will begin with a short candlelit walk through the Artwalk district, followed by reflective readings, tributes and music at the Coalition, 840 University Avenue.

Lives Touched, Lives Celebrated
Music... Reflections... Tributes... Song...
How to Avoid Pinkwashing

Store shelves are brimming with pink items during the month of October. It can be very confusing to decide what, if anything, to buy. How do you tell if the money you spend will go to any meaningful cause?

Breast Cancer Action, the self-described watchdog of the breast cancer movement, has coined the term “pinkwashing” to describe the promotion of a pink ribbon product by a company that claims to care about breast cancer but does not contribute much, if any of the profit from that product to breast cancer-related causes. In addition, many pink-ribbon products, such as perfumes containing known carcinogens, have been linked to the disease itself.

To help consumers sort through the plethora of pink ribbon products and make informed purchasing decisions, Breast Cancer Action’s Think Before You Pink campaign urges everyone to ask these critical questions before buying pink:

1. Does any money from this purchase go to support breast cancer programs? How much?
2. What organization will get the money? What will they do with the funds, and how do these programs turn the tide of the breast cancer epidemic?
3. Is there a “cap” on the amount the company will donate? Has this maximum donation already been met? Can you tell?
4. Does this purchase put you or someone you love at risk for exposure to toxins linked to breast cancer? What is the company doing to ensure that its products are not contributing to the breast cancer epidemic?

Source: Breast Cancer Action. For more information, go to www.thinkbeforeyoupink.org.

If you have doubts about your pink ribbon purchase after reviewing these critical questions:

1. Take action to demand pink ribbon products don’t contain chemicals linked to breast cancer.
2. Write a letter asking the company to be transparent about its donations.
3. Consider giving directly to a breast cancer organization whose work you believe is most essential to addressing the breast cancer epidemic.
structured my teaching schedule so that I would come in, I would teach, and I would leave,” she recalls, giving this grateful warrior some much needed rest as the ongoing radiation therapy began to drain her energy reserves. With a co-worker to give her rides to treatment, other co-workers and friends to provide meals, and her mother and daughters to sustain her, Gloria completed her radiation treatments. Her long course of tamoxifen eventually ended.

Her life’s journey, detoured by breast cancer, has not been derailed. As the current Director of Educational Opportunity Center, Gloria has forged ahead in her education career, and openly shares her breast cancer story with others. “Because of my transparency,” she says, “I got phone calls from people; people from my church, someone that knew someone that heard about it.” Stories have been shared; people have made appointments for mammograms and begun doing breast self-exams after hearing of Gloria’s story. She has accompanied people to appointments and shared her experience with others who have been diagnosed with breast cancer. All of this has come as something of a surprise to Gloria – a welcome surprise – because many within the African American community tend to guard personal information carefully. As well they should; as we all should, at least most of the time. But there are times when it is in our best interests to reach out to others, when the circle of trust must expand in order to receive the information and support needed to move forward. If not, in Gloria’s words, “You don’t get that support system that is so needed. [Her emphasis]”

Participating in a group setting is only one way to receive that support, Gloria counsels. “You can go to lectures.” The Coalition offers a safe, supportive, confidential community of survivors; those who have faced a breast cancer diagnosis or are still dealing with it and are willing to extend a helping hand to others similarly diagnosed. Much of this support is provided outside a traditional group setting. Still, there are concerns about the safety of sharing personal information among new acquaintances. History, unfortunately, gives us examples of times when this has backfired on people of color. Trust of health care providers, or those representing any other establishment or institution, is an ongoing issue. There are other concerns about the consequences of having a cancer diagnosis on record when one wants to apply for a job or obtain life insurance. But Gloria is very frank in asserting that the biggest issue is trust. Her answer to those who express these reservations in regard to health care providers is simple: “In order for them to treat you correctly, you’ve got to tell the whole story.”

Gloria has her own thoughts on this matter. “What’s the solution? In my opinion, I think the answer begins with education. Knowledge is power. And the people who educate them have to be people that they trust, who potentially look like them, in order for them to ‘get it’. And that’s my two cents, for what it’s worth.”

She continues, “I think people need to understand that when it comes to health, you’ve been given this body and it’s only for one time. I had to come to this conclusion; I had to understand that I have a responsibility to take care of this body. If I don’t do it, no one else will. I’m responsible for that, and hopefully I can impact and help others.”

In sharing her journey so openly, Gloria has boldly opened a door into a world of possibilities, not all of which can be known ahead of time. Others facing similar dilemmas have found her because of her openness, and she has shared the insights gained through hard experience. The challenges of her community are obvious to her. More clear are the human struggles and stories needing to find a voice in a culture that is still learning how to hear them. No matter what our background is, we all have the obligation to listen to these voices, to heed them, and to learn from them; to learn how best to offer a helping hand when needed and to empower those in a position to help when we can’t. It will take a huge leap of faith on both sides of the culture chasm, and in making that leap, to cross that chasm and find the ties that bind us into one complete human story. Because none of us can do this alone. We all need each other.

As the saying goes, a journey of a thousand miles begins with a single step. Gloria has stepped fearlessly into a place of openly sharing of a deeply personal story. Her voice is one of compassion and truth, and through her commitment to telling her story without reservation, she is making a difference for those whose voices need to be heard. ☯
Upcoming Events & Programs at the Coalition

Wednesday, October 22, 2014
Lives Touched, Lives Celebrated
7:00pm

Wednesday, January 21, 2015
Ribbon Cutting & Open House
Stay Tuned!

Board of Directors:

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Susan Meynadasy

Outreach Coordinator
Lori Meath

Newsletter
Pat Battaglia & Susan Meynadasy

PALS Coordinator
Pat Battaglia

Questions? Contact the Coalition at (585) 473-8177
Volunteer Information form

Name
Address
Phone Work/Cell
E-mail
☐ I am a breast cancer survivor

I am interested in learning more about (check all that apply)

PROGRAMS:
☐ Advocacy Committee
☐ Research Committee
☐ PALS (Peer Advocates Lending Support) Mentor
☐ Annual Advanced Breast Cancer Seminar

REPRESENTING THE BREAST CANCER COALITION AT:
☐ Health Fairs
☐ Festivals
☐ Public Speaking (Churches, Schools, Community Groups)

FUNDRAISERS:
☐ Pink Ribbon Run & Family Fitness Walk
☐ “Tee’d Off” at Breast Cancer Golf Tournament
☐ ARTrageous Affair Gala
☐ Community Event Fundraisers

OTHER:
☐ I am bi-lingual in ____________________________

☐ I am a deaf interpreter
☐ I am able to deliver newsletters (Quarterly)
I am available: ☐ Days ☐ Evenings ☐ Weekends

Other ways I would like to volunteer: ____________________________
_________________________________________________
_________________________________________________

Take Action!

Become a Supporter of the Breast Cancer Coalition of Rochester by making a gift today!
Your donation will ensure that you will receive a subscription and invitation to all general meetings, educational forums, and special events. Additionally, you will help support our goal of creating an active voice in the Greater Rochester Region in the fight against breast cancer through advocacy, education, and support.

Name
Address
City State Zip
Phone
E-mail
☐ I am a breast cancer survivor

☐ $500 Founder’s Circle
☐ $1000 Visionary Circle
☐ $500 Advocate’s Circle
☐ $100 Pink Ribbon Circle
☐ $50 Friend’s Circle
☐ $25 Contributor’s Circle
☐ $ Other

☐ I am not able to make a donation at this time but would like to be on your mailing list.

I would like to make a gift of $
In ☐ Honor of
☐ Memory of

Please send notification of my gift to: (name and address)

Payment Choice
☐ Check, Money Order ☐ Visa/Master Card/AmEx
Amount Enclosed $ 

Credit Card No.
Expiration
Signature
Name on Card

Breast Cancer Coalition of Rochester
840 University Avenue Rochester, New York 14607
(585) 473-8177; www.bccr.org
Voices of the Ribbon is published quarterly by the Breast Cancer Coalition of Rochester for the purpose of providing encouragement and inspiration to those facing a breast cancer diagnosis, their supporters, and care providers. In addition, it is intended to impart accurate, science-based information to enlighten and empower its readership.

“The great thing in this world is not so much where we stand, as in what direction we are moving.” - Oliver Wendell Holmes

AND WE'RE MOVING!

Stay tuned for news about the Breast Cancer Coalition's new home!