PINK RIBBON RUN & FAMILY FITNESS WALK  Mother’s Day 2015 -by Cindy Dykes

On May 10th, Mother’s Day dawned with the promise of an unseasonably warm, sunny day as hundreds of volunteers and thousands of runners, walkers and supporters gathered at Genesee Valley Park, for the 14th Annual Pink Ribbon Run and Family Fitness Walk. The perfect weather conditions drew a large crowd of enthusiastic participants and supporters to cheer them on.

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Thank you to our friends at Clark Mayflower Moving & Storage for the smooth move!

Late last year, when the time came to pack up our beloved former location and move down the street to our new, expanded facility, Clark Moving and Storage came to our rescue. Arranged by co-owner Kathy Macbeth, a survivor and member of the Coalition’s Board of Directors, two Clark Moving trucks and a cheerful, efficient team showed up on a cold winter day to do the heavy hauling. For weeks prior, staff members had carefully packed boxes provided by Clark. Boxes, office furniture, and all our assorted belongings were quickly transported and carefully placed in the new space; an enormous task we simply could not have done ourselves. Thank you Clark Moving!
From my desk, I look through the window and see blue skies and sunlight peeking through a tree fully leafed in lush, glorious green splendor thanks to all the rain this season. *Thanks to all the rain this season.* I can hear the groans.

Gratitude comes in many forms, as so many of you know. A diagnosis of cancer often changes the way we think about the beauty of our world, our shared experiences, our beloved families and friends, our generous neighbors, that pesky coworker, that annoying driver, that rude receptionist. Cancer changes our perspective in a blink of an eye.

“Gratitude can transform common days into thanksgivings, turn routine jobs into joy, and change ordinary opportunities into blessings.”
- William Arthur Ward

In our new home, I find myself counting many blessings.

First, there is parking, the lack of which was the most cited frustration listed in program evaluations at our former location. Your honesty helped shape our priorities as we sought our new home. Please notice the parking spots reserved for guests and clients of the Breast Cancer Coalition and use them first when visiting.

We have wonderful leaders. Though I am the most visible leader, our behind-the-scenes Board of Directors makes our existence possible. These volunteers complete their tasks after returning home from full time jobs, around busy family schedules, or while preparing meals; often working well into the wee hours. Three Board members will soon leave their positions, but each has committed to staying involved. Exiting are Marianne Sargent (Advocacy Chair), Kathy Macbeth (Community Friends Chair) and Tom McJury (Facilities Chair). Thank you for all you have done through the years.

All our volunteers are our lifeblood. They go above and beyond in countless ways, and many have become our greatest leaders.

Few readers have not met or interacted with our kind, dedicated staff. Each has extensive duties, yet none ever hesitates to take on “just one additional little thing”. Always available to lend an ear or a helping hand, they care deeply for our visitors and for each other. They have learned to smile through tears. And they return each day ready to face whatever challenge is presented. This month, we said goodbye to Alison Currie, our Research Administrator, who leaves our Breast Cancer Research Initiative in tip top shape and, true to her nature, has committed to staying involved as a Research Committee member.

Finally, and most importantly, I am grateful for you. You are the reason we come through our doors every day; you are the reason the doors open at all. Though many of you enter for the first time in crisis, you quickly begin to navigate this tough terrain. We watch you make sense of metaphorical tree roots, twisted paths, rocks and boulders, cliff edges and murky tree lines. We watch you bushwhack your way through cancer and thrive in the aftermath of fear. We watch you survive. You inspire us to do our best, to honor our mission, to celebrate everything. Even the rain. ✭
On August 13, 2013, I was diagnosed with Stage IIIa Triple Negative Breast Cancer (TNBC). Suddenly, I had joined “the club” of women who attended Coalition groups I had facilitated: Voices and Vision and the RISE I and RISE II groups. It’s a club no one aspires to join. But the members were a sisterhood of support that helped me get through treatment.

2013 was a busy year for me and Kay, my partner of fifteen years. In April, we travelled to China to meet my newborn grandson. While there, I felt a lump that was different from others I’d felt in the past. I quickly put any suspicion out of my head. We don’t travel internationally every year, but when Kay was diagnosed with early stage Alzheimer’s disease in the fall of 2012, we quickly signed up for a trip to Israel and Palestine with a group from Colgate Rochester Crozer Divinity School, which we had both attended. Fortunately, Kay’s diagnosis was removed, and in June, we gratefully traveled to Israel and Palestine. We were married a month after our return.

Because of all this activity, I procrastinated for five months in getting my mammogram. Now it was time for my screening, which turned out to be much more. My diagnosis came three weeks after our wedding.

Like many who receive a cancer diagnosis, that moment is firmly etched in my brain. Little did I know that this journey would be wrapped in such compassion and support. It all began with an amazingly kind radiologist telling me she was quite sure the images on the ultrasound were cancer. I remember sitting in the dressing room between the ultrasound and the first biopsy, texting Holly Anderson, a long time dear friend, with my news. Holly and I are part of group of women who have Monroe Community College in common. (I clearly recall the somber and holy moment we gathered on Holly’s desk 16 years ago to shave her head after she started chemo.) Her response after my diagnosis kept me grounded. Holly met with Kay and me, which helped prepare us for the journey ahead. We were not alone.

We quickly assembled my health care team and I got all the necessary scans. Our choice of surgeon was a double blessing because of his wonderful nurse practitioner and their team. We met with an oncologist, who we immediately liked and trusted, and who patiently answered all my questions, even providing copies of research studies on occasion. My team not only provided information, but the kind of information that recognizes the emotions involved while empowering us to make our own decisions.

I’m still absorbing the TNBC diagnosis. This sub-type lacks the three most common receptors known to fuel most breast cancer growth: estrogen, progesterone, and the HER-2/neu gene. Many therapies target one of those receptors, so in the absence of these treatment options, triple negative disease often requires more aggressive chemotherapy. Although the 20 year survival rate is similar to other types of breast cancer, the risk of recurrence in the first 3-5 years is higher, and drops sharply after five years. True to the TNBC profile, my tumor was small and aggressive, having spread to several lymph nodes. One of my nodes was actually larger than the tumor! That little node was working hard to protect me.

Since my cancer was stage III and grade 3, the recommendation was for five months of neoadjuvant chemotherapy, followed by surgery. My infusion nurse showed wisdom and compassion beyond her years. The whole infusion team was terrific! Afterward, given the option of a mastectomy or lumpectomy with axillary node dissection (in which all the nodes in the area were removed), I chose to trust my team in believing that the second option was more than sufficient.

The surgical pathology report showed a complete response – no evidence of cancer! Then came radiation therapy, and I was so impressed with my radiation oncologist for cramming all my stats onto a 3x5 index card, and her easy, down-to-earth manner. The radiation team cheered me on as I completed each treatment. I also met with an integrative medicine doctor who, after running a battery of blood tests, advised me on diet and supplements. Getting acupuncture on a consistent basis was already part of my life and my accupuncturist insisted on treating me within two days after every chemo treatment. We were able to work out a financial arrangement to make that feasible. In addition, I took advantage of free massages at my cancer treatment center.

My care team would not be complete without mentioning my PCP, who is no longer practicing. She knew me well, and
On Monday May 11th, with the lilacs in full bloom, we were visited by the compassionate Senator Kirsten Gillibrand, who came to talk about her CARERS (Compassionate Access, Research Expansion, and Respect States), Act 2015. The CARERS Act 2015 would:

- Expand research opportunities on medical marijuana.
- Allow doctors to recommend medical marijuana to Veterans.
- Allow states to import cannabidiol (CBD), a recognized treatment for epilepsy and seizure disorders.
- Permit banking for registered marijuana dispensaries, offering the financial security.
- Remove marijuana from Schedule I and reclassify it as a Schedule II controlled substance, recognizing it as a drug with accepted medical use.
- Recognize states’ responsibility to set medical marijuana policy and eliminate potential federal prosecution, a fear of many parents of children with disorders that can be treated successfully with cannabis derivatives.

While at the Coalition, Sen. Gillibrand met personally with patients and their families who desperately need medical marijuana. During the press conference, the Senator advocated for the passing of her bill in powerful words. As she stated, “We need to change our laws.” She went on to say, “I’m urging congress to support the CARERS Act” and “I’m simply asking congress to take care of American families.” She also stated that “This is a case of ideology versus scientific research,” and “Some of our kids have one hundred seizures a day, and with medical marijuana, it would decrease them to one to two weekly.”

After her speech, Senator Gillibrand introduced Christine

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A Talk with Alex Solky, M.D.
-By Pat Battaglia

The son of two local physicians, Dr. Alexander Solky received his medical degree and completed his residency at the University of Rochester School of Medicine and Dentistry. With an extensive family history of various cancers, it was natural for him to receive Board Certification in medical oncology. He is currently President of Interlakes Oncology and Hematology, PC, an oncology and hematology practice with five offices from Geneva to Brockport. In 2013, Interlakes became affiliated with the University of Rochester’s Wilmot Cancer Institute. Dr. Solky kindly took time from his busy schedule to meet with me recently for a conversation.

Pat: Interlakes Oncology’s focus is on compassionate care. What does that mean for your patients, and for you as an oncologist?

Dr. Solky: The whole idea of compassionate care centers on the fact that it’s extraordinarily difficult to walk into an oncologist’s office. It takes a lot of courage on the part of the patient and for the family. When we have our annual meeting for the staff, one of the things that I’ve said every time since I’ve been President is “No matter how bad a day you’re having, the person who’s in front of you is having a worse day. Be kind and be gentle.” I don’t think anybody’s perfect, but we try. Sometimes there are hard discussions, there are difficult choices that we have to make, but if we’re doing it with kindness and trying to take the whole person into account, not just their cancer, then we hope people are going to feel a little better about the things they have to go through.

There’s so much access to information, but as an oncologist, you’re dealing with a person who comes into their diagnosis with a set of values, a set of beliefs, their own friends that have had different experiences with the medical system; if you forget about that and it’s all about the data, then you haven’t helped.

Pat: You and Holly Anderson have worked together on the ASCO guideline update committee that revised the adjuvant hormonal therapy protocol for those diagnosed with estrogen and progesterone receptor positive breast cancers. What changes were made and why? How do these changes benefit patients?

Dr. Solky: ASCO – the America Society of Clinical Oncology – is the biggest group of oncologists in the world. When you’re a general medical oncologist, you treat all different kinds of cancer. To the great benefit of patients, and to the great fear of doctors, the medicine is changing rapidly. One of the things that the guidelines help doctors do is assimilate huge volumes of data and put it together in a way that is helpful for them to treat patients. At ASCO, there are a number of different groups that put together guidelines for cancer. On each individual guideline panel, they take some of the brightest oncologists who specifically do that type of cancer medicine to review the data along with a patient advocate and one or two general medical oncologists. The goal is for the guidelines to be useful to patients and to general oncologists. The guidelines really help oncologists figure out the best options to present to the patient. Holly and I have actually done three different revisions of the guidelines together.

There have been significant changes in the last decade in terms of how we treat estrogen and progesterone receptor positive breast cancers in women. As the data from very large trials became available, we needed to update the guidelines. For example, the duration of anti-hormonal treatment has been evolving in the last decade. Up until several years ago, five years of anti-hormonal treatment was the standard. There was a big international trial that looked at giving women 5 years of tamoxifen and then 5 years of one of the aromatase inhibitors – femara – and asked whether women did better if they got extended...
Living With Advanced Breast Cancer

Staying True to Myself
- By Christine Hall

In 2012, shortly after celebrating the ten-year anniversary of her original breast cancer diagnosis, Christine Hall learned that her cancer had returned and metastasized to her bones. She recently shared her journey with the attendees of our most recent Advanced Breast Cancer Seminar. Here is a condensed version of her talk that day.

Being true to myself is one of the most important things I have learned in the last two years. It took me a little while to come to that realization, and I can divide it into three phases.

**Early Phase**

When I was first diagnosed I didn’t know what to do. Did I need to know enough about cancer to be able to banter in medical terms with my health care team? Did I need to become a vegetarian? Did I need to start juicing? Did I need to exercise every day? Did I need to be able to understand all the latest developments in research and clinical trials? Did I need to give up my Diet Pepsi? It was overwhelming and disconcerting.

I was figuring out what kind of patient I wanted to be. I was also reading about stage 4 cancers, about metastatic breast cancer, and lots of stories about people “like me.” I was hoping to gain some insight or some nugget of information that might help me feel more at ease. I looked and looked, but it didn’t come and there were a lot of sad stories. And I wondered, and I festered about them. This, too, was overwhelming until I realized, “your cancer is not my cancer. My cancer is not your cancer.”

The fact is that we are all completely different, even those of us that share membership in the advanced breast cancer club. The best I can do is to be true to myself; to focus on the things that I can control and not burn energy on the things that I can’t.

**Middle Phase**

Part of my so-called “middle phase” has to do with the day to day challenges. I had always thought your insurance and employer would take good care of you. To make a long story short, I went on disability, which overpaid me for four months and then my employer let me go. In a 30 minute span I had incurred $2,400.

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additional debt and would be unemployed, without health insurance. I spent the better part of three months trying to figure it out. Phone call after phone call, research, applications, appointments, documentation, it was taxing and stressful – just what I was trying to avoid. The bulk of it is resolved and I now understood what I had previously been so naïve about.

The other part of my middle phase is a bit on the dark side. The diagnosis of advanced breast cancer comes with your own personal black cloud: just like that, your mortality is sitting right in front of you, uninvited. Thoughts about cancer are almost always there. But there are so many other things to think about, and all kinds of thoughts can race through your head in a couple of minutes.

My advice for this is to train your mind to focus on the positive. Continue to control what you can and make a concerted effort to get up every day and find joy in the things and people around you.

**Ongoing**

This is the part where I tell you that I am glad I have cancer. Well, sort of. I have met the most amazing people and have been given great opportunities. I had my 15 minutes of fame with my pathologist from Strong. We were on TV together and had a photoshoot for a magazine article. He also happens to be an amazing, caring man. He is one of my heroes.

And then there is my circle of hope, the very special people that are fighting with me: my doctors and the nurses in the infusion center, my Coalition friends. These are the sort of people that hug you with their heart and

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Research Administrator's Update

Coalition Awards
2014-2015
Grant for Breast Cancer Research
By Alison Currie

On Tuesday, March 24, 2015, the Coalition awarded a $50,000 research grant to Zhenqiang Yao, MD of the Pathology and Laboratory Medicine Department at the University of Rochester Medical Center. The Coalition is committed to supporting and furthering breast cancer research and has prioritized four focus areas: initiation, prevention, prevention of metastasis, and cure. Coalition grant money is intended for use as “seed money” to fund innovative new projects with the potential to yield significant medical breakthroughs. Dr. Yao’s proposal to “Study the Effects of an IAP Inhibitor on Breast Cancer Bone Metastases” aligns perfectly with the Coalition’s priority of prevention of metastasis.

Bone is a common site for the spread (metastasis) of breast cancer. The subsequent tumor growth and bone break-down can result in severe pain and fractures. Spinal cord compression and paralysis can result if metastases occur in the spine. Current approved treatment for bone metastases inhibits bone break-down but does not improve patient survival, as it does not target cancer cells. Dr. Yao has found that treatment with a small molecule compound that degrades “Inhibitor of Apoptosis Proteins” (IAP) causes cell death in certain breast cancer cell lines. In addition, this compound simultaneously prevents bone loss while stimulating bone formation to help repair the affected bone. Dr. Yao will investigate treatment with this compound to kill breast cancer cells, prevent the growth of established bone metastases, and stop the development of new metastases. Dr. Yao is striving to develop an “all-in-one” drug strategy to prevent breast cancer bone metastasis and maintain healthy bone. The Research Committee is looking forward to following Dr. Yao’s work. They have planned a visit his laboratory in October for a progress update and tour. Dr. Yao is required to submit midterm and final research reports. In addition, he will return to the Coalition in the summer of 2016 to give a final presentation on his Coalition funded research.

This month, Alison Currie leaves her Research Administrator position at the Coalition. Alison needs to devote more time to her engineering consulting work and managing the care of an elderly family member. In her spare time (if there is any), she hopes to further pursue her musical, athletic, and artistic interests. The Coalition extends a heartfelt thank you to Alison for all her contributions and dedication to the Research Initiative. We wish her success in all her endeavors! The Coalition welcomes Jennifer Gaylord as the new Research Administrator.

NBCC Lobby Day continued

In the past, New York State has had the co-sponsorship of the entire congressional delegation. As of this writing, both Senator Schumer and Senator Gillibrand have signed on, and members of the House are steadily signing on. Has your representative signed on? Check for updates at Thomas.loc. Please consider calling your House member and thanking him/her if they signed on to co-sponsor HR 1197, ask them to sign if s/he hasn’t, and call both U.S. Senate offices to thank our Senators.

The $150 Million Re-Appropriation for the Department of Defense (DoD) Breast Cancer Research Program (BCRP) for Fiscal Year 2016 is an innovative research model to “eradicate breast cancer by funding … high-impact research through a partnership of scientists and consumers.” Since 1992, over $3 billion have funded research projects whose results include development of the drug Herceptin and other emerging treatments, as well helping develop digital and tomographic screening procedures. With funding levels decreasing, advocates have worked steadily to ensure the continuation of this yearly congressional appropriation. It has now passed the House and will be presented in the Senate.

http://cdmrp.army.mil/brcp/

Advocacy drives research and public policy. In a world of shrinking dollars and growing demands, grassroots calls, emails and visits by citizen advocates can inspire and sustain support, making allies of policy makers who might not otherwise have a connection to the issues that are important to people affected by breast cancer. Be part of the effort!

Rebecca Solomon is the BCCR Team Leader to NBCC.
Kathleen Maxian: An Interview with an Ovarian Cancer Advocate

When Kathleen Maxian’s younger sister was diagnosed with breast cancer at the age of 40, she underwent the genetic testing available to her at the time and was found to be negative for the BRCA gene. It wasn’t until after Kathleen was diagnosed with advanced ovarian cancer in 2009 that her sister’s genetic profile was found to be incomplete. Subsequent testing uncovered a mutation that put both sisters at risk for breast and ovarian cancers. Knowing that her cancer could have been prevented by prophylactic surgery was a difficult burden to bear, but Kathleen faced her diagnosis and treatment head on, becoming a vocal advocate for herself and others in the process. She is the Founder and President of the Western New York Ovarian Cancer Project (WNYOCP), based in the Buffalo area, which empowers area women through education, awareness, and support. (Visit the WNYOCP’s website at www.wnyovariancancerproject.org) Kathleen’s cancer recurred in 2011 and again in 2013; she has been cancer free since that time. She graciously agreed to share her wealth of knowledge with the Coalition community.

Pat: What are some good initial steps a woman newly diagnosed with ovarian cancer might take?

Kathleen: For women in whom ovarian cancer is suspected, it is important that they be seen by a specialist called a gynecologic oncologist. Recent studies have shown that women who have their surgeries done by gynecologic oncologists at high volume hospitals have the best outcomes. Gynecologic oncologists are specialists at diagnosing and treating ovarian cancer, and perform complex surgeries. The surgery for ovarian cancer is called a ‘debulking’, and is considered major abdominal surgery.

Within the past year a new way of treating ovarian cancer has shown to also improve survival. Traditionally, the initial treatment has been surgery first then chemotherapy. Now doctors are using neoadjuvant chemotherapy, followed by debulking surgery, then more chemotherapy. Not all patients would need or be eligible for this approach, but we encourage women to discuss this option with their gynecologic oncologist.

Once diagnosed, it is important for women to learn some basics about their disease. A good place to start is a professionally facilitated support group like those at the Coalition. Studies show that participation in this type of group can help alleviate anxiety as women meet others who are experiencing similar challenges. Groups provide a trusted environment to learn about managing side effects, stress and other treatment options. In 2009, when I first woke up in my hospital bed and learned that I had stage IIIB ovarian cancer, I thought it was a death sentence. I just wanted some hope, and I found it in the support groups I attended. I learned about my disease, slowly, from trusted resources and other women with the disease. I took back control of my life in those groups, and I learned to advocate for myself.

Pat: Breast cancer has many subtypes. Does the same hold true for ovarian cancer? If so, can you give a brief overview of these subtypes?

Kathleen: The most common type is ovarian epithelial cancer. This means that the cancer started in the surface layer covering the ovary. There are various types of epithelial cancer: serous (the most common type), endometrioid, clear cell, mucinous and undifferentiated or unclassified. Some, called primary peritoneal, are found in the abdominal walls and around organs, and are treated similarly to ovarian cancer. Other more rare types are germ cell tumors, which start in the egg, and borderline ovarian cancers, which usually have a low malignant potential.

Treatments are based on the type of ovarian cancer you have. This important information is located on the surgical pathology report. A copy of this report is reviewed with women, typically after their surgery.

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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 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.
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 13 for PALS Program updates.

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
a popular program taught by Susan Meynadasy, a registered yoga trainer, is offered on Monday evenings and Tuesday mornings and afternoons. Limited to 14 survivors of breast or gynecologic cancer, these classes run in six week sessions. Advance registration is required.

Qi Gong
Now offered on Wednesday afternoons in six week sessions throughout the year. Qi Gong is facilitated by certified instructor, Raphaella 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
- Art Therapy with Joyce Kliman

Thursdays: NEW!
- Mindfulness & Meditation with Estalyn Walcoff

The next soiree will be Friday, September 18th. Please call to be added to the attendee list.

Please visit www.bccr.org for the 2015 Healing Arts Program Schedule and Registration Guidelines.
On April 24, we proudly hosted our 12th annual Cindy L. Dertinger Advanced Breast Cancer Seminar: Tools for the Journey, sponsored by M&T Bank and Assemblymember Harry Bronson. Over one hundred survivors, health care providers, family members, and supporters gathered at the Memorial Art Gallery to learn about the latest research in treating metastatic breast cancer.

Living with advanced disease presents its own challenges. Yet, the reality is that women with metastatic breast cancer can live full and meaningful lives. This seminar addressed some strategies to live well with metastatic breast cancer. Moderated by Dr. Marilyn Ling, panelists discussed how to manage various aspects of the disease and side effects of treatment.

First in the lineup was Farhan Imran, M.D., a specialist in hematology and oncology, who spoke on clinical research updates. Dr. Imran touched on the basics of metastatic breast cancer, how treatment decisions are made, and future research targets. Deeanne Bevin, licensed Master Acupuncturist, provided an interactive experience highlighting our bodies’ energy sources. To round out the day’s medical presentations, Aaron Olden, M.D., a palliative care specialist, discussed common complications of metastatic disease. Treatments for those complications include palliative care and complementary therapies. The speaker panel also included two survivors; Mary Jane Weed and Christine Hall shared their deeply meaningful first-person stories on living with advanced breast cancer.

The feedback was overwhelmingly positive and those in the audience appreciated the honest, inspiring speeches from our survivor panelists. It was certainly a great learning experience! If you missed the seminar, mark your calendar for the 13th annual event on Friday, April 8, 2016. We hope to see you next year!

If you or someone you know is living with metastatic disease, local resources are available. I encourage you to contact the Breast Cancer Coalition to attend our discussion group, Common Ground: Living with Metastatic Breast and GYN Cancer. The group gathers on the first and third Thursday of the month at 12:00. Join us for a meaningful opportunity to network with other survivors.

*To read Christine Hall’s words, please turn to page 6. Mary Jane Weed’s words will be included in our next issue.

Networking and Fun: Our Latest Young Survivor Soiree

On Friday, June 5, a crowd of young survivors gathered for an evening of networking and a "do-it-yourself" project. After a round of lively introductions, women crafted flavor-infused balsamic vinegars. A selection of fresh, aromatic herbs such as thyme, mint, and tarragon, were gathered from the Public Market and decoratively placed around the room. As folks leisurely traveled to each table, they created their own jars of vinegar and gathered recipe cards tailored for each flavor.
The 2015 PALS mentor training session has come and gone, and we at the Coalition are thrilled to welcome a new group of peer mentors. We first saw many of these fresh faces to our program when they were newly diagnosed, and witnessing their full-circle healing journeys is an extraordinary experience. Each has found her own way through the emotional upheaval and uncertainty of breast cancer. Each in her own time has reached a place where she is mentally and physically ready to extend a helping hand to others. They and all our PALS mentors are living proof that healing happens, even in the most difficult circumstances.

Many who seek a PALS mentor are newly diagnosed with breast cancer or in the midst of treatment. Others may be facing an unanticipated detour along the way or finding the experience of moving beyond active treatment to be more than they bargained for. There are many scenarios in which women – and men – can benefit from a connection with someone who has had similar experiences. Our new group of mentors broadens the base of experience represented in our group of PALS mentors, helping ensure that those seeking this type of support can be matched with someone whose experience will be truly helpful.

PALS mentors have made a big difference in the lives of hundreds. In taking the initiative to reach out and truly listen without judgement, a mentor can empower someone facing this life-altering diagnosis as s/he come to terms with swirling emotions and an overwhelming amount of information that seems to have been written in a foreign language. The power of the simple presence of someone who has also faced these things and is doing well can never be overestimated.

And very importantly, a mentor provides a safe, confidential listening ear, encouraging those newly diagnosed with breast cancer to explore their emotions, empowering them as they move through their decision-making process.

A PALS mentor can add a crucial element to the circle of support surrounding an individual. Our mentors are a phenomenal group of individuals, each with a unique story and perspective, and we welcome our newest trainees into this fold!

*For more information on PALS, please contact me at pat@bccr.org.

* PALS - Peer Advocates Lending Support

“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”

-Leo Buscaglia

“...When you open yourself to the continually changing, impermanent, dynamic nature of your own being and of reality, you increase your capacity to love and care about other people and your capacity to not be afraid.”

-Pema Chodron
In one of my favorite childhood movies, Mary Poppins sings the refrain, “Just a spoonful of sugar helps the medicine go down.” These days, sugar is still added to children’s medications to make them more palatable, and it’s also added to all kinds of everyday foods we eat, often without our realizing it’s there. Cookies, cakes, and sweets of all sorts are overtly intended to fill our sweet tooth and indulge the inner child in many of us, but sugar is often added to non-dessert items such as pasta sauces, salad dressings and other condiments, breakfast cereals, and flavored yogurt.

Added sugars are present in packaged and processed foods under a variety of names: sugar, sucrose, dextrose, maltose, lactose, and fructose are just a few; if it ends with “ose”, it’s a sugar. There are also corn syrup, high fructose corn syrup, invert sugar, honey, sorbitol, maltodextrin, erythritol, and many others.

How much, if any, of this do we need? How much is too much?

There is little disagreement among experts that the average American daily consumption of about 22 teaspoons of added sugar of is too much, and is a contributing factor to increasing obesity rates.1 While research has shown that consuming added sugar doesn’t directly cause cancer2, obesity is associated with increased risk for many cancers, including postmenopausal breast cancer3, and is implicated in other health issues such as heart disease and type 2 diabetes4.

Our cells require sugar to survive, but our bodies

Continued on next page

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Sweet and Savvy

Mindfully Indulging Your Inner Child

- By Pat Battaglia

Peanut Butter & Pretzel Truffles

A sweet/salty treat with low added sugar

Ingredients

- 1/2 cup crunchy natural peanut butter
- 1/3 cup coarsely crushed salted pretzels
- 1/2-2/3 cup chocolate chips

- To crush the pretzels, place them in a sandwich-size plastic bag and roll a rolling pin over them.
- Combine peanut butter and pretzels in a small bowl.
- Freeze until firm, about 15-20 minutes.
- Roll the peanut butter mixture into balls, using about 1 teaspoon for each.
- Place on a baking sheet lined with parchment or wax paper and freeze until very firm, about 1 hour.
- Melt ½ cup chocolate chips in the microwave or in a double boiler. Roll the frozen balls in melted chocolate. Melt additional chips if needed to coat all the truffles.
- Refrigerate until set, about 30 minutes.
- Store in an airtight container in the refrigerator for up to 2 weeks.

Makes 15-20 truffles
Each truffle contains about 2 grams of added sugar.

Adapted from EatingWell: January/February 2010
do not need added sugar in order to function. Complex carbohydrates such as breads, cereals, and rice, are broken down into sugars during digestion. Healthy foods such as fruits and dairy products contain high levels of naturally occurring sugars in addition to many vital nutrients. For example, one-half cup of unsweetened blueberries contains about 7 to 8 grams of sugar. A typical 1-ounce butter cookie has 6 grams of sugar. But the berries also contain vitamins, minerals, phytonutrients, and fiber, while the cookie is primarily carbohydrates and fat; the so-called “empty calories”. When considering our food choices, sugar content is just one part of a much larger picture.

According to experts at the M.D. Anderson Cancer Center, women should have no more than 25 grams of added sugar per day, which is about six teaspoons. For men, the recommendation is 37 grams, or nine teaspoons. Individual needs may vary, depending on body size, health conditions present, and individual tolerances.

As long as you are able to eat normal volumes of a variety of different foods and maintain a healthy weight, there is little need to count sugar grams. And if, like the children in Mary Poppins, it takes a spoonful of sugar to help the medicine go down – medicine, in this case, being nutrient-dense foods your body needs – then choose wisely and don’t let those spoons full of the sweet stuff add up to more than you need.

With a little understanding and self-observation, you can throw a little sweetness into the mix in whatever form you prefer and indulge your inner child in a healthy manner.

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1. newsinhealth.nih.gov/issue/oct2014/feature1
3. cancer.gov/about-cancer/causes-prevention/risk/obesity/obesity-fact-sheet#q3
4. nhlbi.nih.gov/health/health-topics/topics/obe/risks

**Make Sun Tea**

Harness the power of the sun to make a simple and delicious beverage that will help keep you hydrated on hot summer days. Choose your favorite tea – black, green, or herbal - and place one teabag per pint of water in a clear glass jar with a lid. Leave it out in the full sun to steep for at least an hour, or up to several hours. Sweeten to taste if you like, and you can also add fresh lemon juice or mint leaves to complement the flavor of your tea. Fill a glass with ice, pour in your sun tea, and enjoy!

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**Summer Fun Tip**

**Gazpacho**

**Ingredients**

- 6 large ripe tomatoes, seeded and chopped, or 1-1/2 cups canned plum tomatoes, drained
- 2 red bell peppers, cored, seeded, coarsely chopped
- 2 large cucumbers, peeled, seeded, coarsely chopped
- 1 medium yellow onion, coarsely chopped
- 1 clove garlic
- 1-1/2 cups canned tomato juice
- 1/4 cup red wine vinegar
- 1 tablespoon olive oil
- Pinch of cayenne pepper or a dash of hot sauce
- Salt and freshly ground pepper to taste
- 1/2 cup fresh parsley, chopped

- Place tomatoes, red peppers, cucumbers, onion, and garlic in a food processor or blender in several small batches. Make sure to add enough tomato juice to each batch to keep blades from clogging.
- Process until well mixed, but do not puree completely.
- Combine processed vegetable mixture, vinegar, olive oil, cayenne pepper or hot sauce, salt, and pepper in a large bowl and cover.
- Refrigerate for 4 hours or longer, adjusting seasonings if necessary.
- Ladle soup into soup bowls.
- Garnish with parsley.

Makes 8 servings.
Approximately 64 calories and 2 grams of fat per serving.
*Voices of the Ribbon editor’s note: Look for BPA-free cans or seek bottled varieties of canned Ingredients.

From *Cooking Smart*, a publication of the American Cancer Society, 2009, revised 4/14.
Reprinted by the permission of the American Cancer Society, Inc. www.cancer.org. All rights reserved.
A fun filled glorious celebration on Mother's Day!

Walkers and runners enjoyed the scenic views of the Genesee River and Erie Canal, which provided a beautiful backdrop for the sea of bright pink t-shirts and other colorful accessories donned by women, men, and children. All were drawn together to fight breast cancer and support those who have traveled this road.

As people gathered, they were treated to the lovely voices of the ladies from Vocal Point, an a cappella singing group, and lively warm-up exercises led by fitness instructors from Bounce Aerobics.

Runners took off from Moore Road near Elmwood Avenue through the lower part of the park and finished their 5K race along the canal. Walkers crossed the Genesee River and followed the river trail to two bridge return options that resulted in either a 2.2 mile or 3.6 mile walk as members of the Genesee Rowing Club and Naiades Oncology Rowing group cheered them on from the river below. Walkers were also entertained on both sides of the river by the Flower City Pride Band, members of After Hours Co-Ed A Cappella group, and a drumming group from Brockport.

Organizing an event of this scope is a great undertaking that would not be possible without the hard work and dedication of many volunteers who helped before, during and after the event to ensure everything went smoothly and safely. We want to thank all of our volunteers, especially the Pink Ribbon Committee members who spent many hours planning and fine-tuning this year’s event, led by Debra Bonsignore, Event Director; Bix DeBaise, Race Director; and Benita Aparo, Walk Director. A special shout out to the team leaders who oversee
and organize volunteers in each component of the event: parking, volunteer check-in, registration, walk and race route marshals, finish line, refreshments, t-shirt distribution and raffle tickets.

A big “thank you” goes out to our generous sponsors who make this event possible: premier sponsor Van Bortel Chevrolet/Ford/Subaru; gold sponsors, Wegmans, who provided the refreshments and prizes, WROC Channel 8, WARM-FM 101.3, WFKL-FM 93.3 (Fickle), The ZONE 94.1, Towpath Bike, YPC Media/Bounce Aerobics; and our other valued sponsors, Barefoot Sportswear, Cycle Stop, Inc., Fleet Feet Sports, Rochester Woman Magazine, UR Medicine Imaging, Clark Moving & Storage, Dunkin’ Donuts, Freetime Magazine, Ashby Madison Salon, Biomet, Bonsignore Studio & Spa, Business Web Strategies, Tom and Maria Cook, Marketplace Mall, Rockcastle Florist, Business Web Strategies, Schoen Place Auto, and Skillsoft.

We hope you will join us for this Mother’s Day tradition at the 15th Annual Pink Ribbon Run & Family Fitness Walk on Sunday, May 8, 2016.
THANK YOU... TO OUR GENEROUS RACE SPONSORS! more sponsors pg.20

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Van Bortel
There's nothing we won't do for you!
OUR PREMIER SPONSOR
GOLD SPONSORS

AND TO OUR GENEROUS SIGN SPONSORS ADDING EYE APPEAL ALONG THE WALK ROUTE!

Anonymous Supporter
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Holly Anderson
Benita Aparo
Stephen Atterbury
Pamela Bernstein
Stacey Bershod
Aria Camaione-Lind
James Cappellino
Richard Cataldi

Kathleen Fielder
John Frazier
Paul A. Garsin
Linda Hall & Family
Sharon & Ed Hanchett
Margaret Heberger
Jan Miller
Allan Rayburn
Jean Stowell
Marcy Tiberio

iPad Mini Raffle Winner: Christee Cosner
Christee's husband
Ryan collected her prize

Pink Gift Basket Raffle Winner: Sandi Melos

A few of our dedicated and fantastic volunteers!

Walking in style!
Outreach Coordinators’ Update

“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.”

Lori Meath

Summer Festivals Are Here!

As I write, we are on the other side of our ten day presence at the Lilac Festival. Though Rochester’s spring weather can be a roller coaster (95 degrees on one day, 45 degrees another!) there is no other experience that compares to the pure outreach experience of ten days outdoors at our community’s largest event. We are able to let folks know that we are here and ready to offer education, support and advocacy for themselves or their friends and families should they face the diagnosis of breast or GYN cancer.

I am humbled and always incredibly impressed by the scores of volunteers who are willing to fill shifts to share the message of the Coalition. They sit in scorching sun, driving rain, gusty wind and also under glorious blue skies and with refreshing breezes. They give of their time to speak with passers-by, disseminating information and listening compassionately to the stories people share. To all who answer my calls for help, I thank you. Your personalities, generosity and shared experiences are what make my job such a joy.

As we move forward, one focus of our outreach is to become a presence at more community festivals throughout the summer. While none will compare in size to the hundreds of thousands who visit Highland Park each May, smaller festivals in area towns and villages will give us the opportunity to speak with people less likely to be aware of the Coalition as a resource. We will offer minimal merchandise. Our focus will be on sharing our mission through our general brochure and newsletter as well as describing our myriad program offerings.

Here are some locations where we can be found this summer:

- PRIDE Festival, July 18
- Spencerport Canal Days, July 25-26
- Park Ave. Festival, Aug 1-2
- Brockport Summer Arts Festival, Aug 8-9
- Clarissa Street Reunion, August 15
- Oktoberfest in Irondequoit, Sept. 19
- Palmyra Canal Days, September 19-20
- Hilton Apple Festival, October 3-4

If you have never done so before, please consider sharing a few hours of your time with us at a festival in or near your community. Contact Lori at Lori@bccr.org if you are able to help with this important work.

Volunteer SPOTLIGHT

The Men of the Coalition
- By Pat Battaglia

They lift heavy boxes and cartons. They fetch furniture. They’ve emptied and refilled storage rooms, showed up in parks at 5am, stayed at galas until after midnight, hung heavy frames on walls, sat at booths, provided shuttle service at all hours, run endless errands, and much, much more. They endure slave labor with slave pay: not a nickel. Their work is most often carried out behind the scenes, during the evening hours and on weekends. They are the husbands and sons of our leaders and staff members, cheerfully and efficiently carrying out tasks that might have taken weeks for us to accomplish on our own.

When our new Center opened at the beginning of this year, our guys were on hand to lift, tote, arrange, re-arrange, set up shelving, hang pictures, and take on endless tasks as we took our brand-spanking-new but empty space and turned it into our comfortable and welcoming home. They lightheartedly handled heavy loads and made the work look easy. But we know better.

In the wee hours of the morning, they’ve helped set up our Pink Ribbon Run and Family Fitness Walk on Mother’s Day and stay until the last participants have gone and the area is cleaned. Their pay? Coffee and doughnuts at the volunteer center.

Preparations on the day of our annual ARTrageous Affair begin early in the morning. Clean-up ends at around midnight and continues the next day. It’s a massive undertaking that our guys have handled with aplomb.

Who has ensured our advocates who travel the country arrive on time for their departing flights and have a ride home when they return? You guessed it, our guys.

College-age sons are sometimes MIA while away at school or traveling, but when they’re here, they work

Continued on page 26
Philanthropy

Andrew Carnegie, Henry Ford and George Eastman. What comes to mind when you think of these three figures in our history? All were great business men who were pillars of the industrial age in the nineteenth and twentieth century. They were also some of the greatest philanthropists our country has ever known. More contemporary figures such as Warren Buffet, Tom Golisano, Bill and Melinda Gates, and Oprah Winfrey are sharing their wealth supporting causes such as health care, education, poverty, and clean water.

Here at the Coalition we are so fortunate to have the most important philanthropist as part of our community – YOU! We are grateful for all the support we receive from you. Your donations allow us to do so much. Your contributions help fill PALS packs, secure facilitators for healing arts and support groups, and provide supplies and resources for lots of other programs, outreach, and local research.

You don’t have to have millions of dollars to be a philanthropist. Every dollar helps, and combining many gifts together can have an impact similar to that of a Carnegie or Rockefeller.

Each of us chooses the charities we support for our own reasons. I found these suggestions from personal finance writer, Trent Hamm, author of the blog, The Simple Dollar. His criteria for making charitable gifts are quite interesting:

• Support charities that you feel are most strongly connected to you and/or your family, or are highly local. They provide you the opportunity to directly witness your dollars at work, as well as to donate your time if you so wish.

• These charities tend to be smaller organizations that have an impact in your community, not a part of a large national group.

• These charities also enable you to directly donate time and talent. They are local enough to volunteer directly or work for these groups. This means that you have the clear opportunity to do even more than before – and spend your volunteer time and money working for the same goals.

While one-time large gifts tend to receive the most attention, the gifts that come from a donor year after year, or over a lifetime, can have a big impact on grassroots organizations.

Thank you for your continued support!
A Tribute to Harvey Anderson  - By Zachary Anderson

March 1, 1928 – February 10, 2015

How do we measure the success of a man and the life that he lived? For a man like Harvey, many of us would point to his career in business as President of the Rochester Coca Cola Bottling Co., a business that was family-owned and which ultimately served as a stepping stone for him to become the philanthropist that many of us knew him to be. From serving on the board of the Rochester Press Radio Club and Tennis Club of Rochester, to his work with Rochester Community Baseball, Harvey loved giving back to the community as much as he believed it was his duty to return the kindness and generosity that the people of Rochester had shown his family. The effects of his generosity can still be felt today, as two high school senior athletes have been awarded the Harvey E. Anderson Scholarship each year since its establishment in 1987. Harvey actively supported many local organizations, especially the Breast Cancer Coalition of Rochester even though he had lived in Florida for almost thirty years, proving that although you can take the man out of Rochester, you can’t take Rochester out of the man. Harvey, the father-in-law of our Executive Director Holly Anderson, will long be remembered for his presence in our lives, particularly at ARTrageous Affair where- true to his giving heart- he invested in more art, raffle tickets, Warrior Wall pledges and LIVE auction items than anyone on record. A longtime fixture on the Start-Finish line crew of the Pink Ribbon Run & Walk, this year was a little quieter, a little sadder, without him. Thank you, Harvey, for gracing us all with your time and presence. Irreplaceable, you will long be remembered. ☹️

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@bcrr.org.

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

Good People Giving Back

Our dear friends at Van Bortel Subaru honored the Coalition once again by choosing us to be the “Sixth Charity” locally in the national Share the Love Campaign.

Along with five respected charities in the country, top producing dealerships were given the opportunity to select a local charity to receive $250 for each purchased or leased Subaru during the campaign period from November through January.

Our heartfelt thanks go to Subaru of America, Inc. for offering this opportunity to local dealers, and especially to Rochester’s Kitty Van Bortel and her team for making the donation of $11,860 a terrific gift to start our new year.

The (Tow)path of Community Spirit

The folks at Pittsford’s own Towpath Bike Shop are a group passionate about fitness, and especially about biking. Their unwritten mission is to inspire others to share that passion, and to provide an experience that eliminates any barriers to enjoying the great outdoors.

Owner Scott Likly kept that mission in mind when planning the 4th annual Breast Cancer Ride and Run, held on October 12, 2014. With Team members Jamie Cronkwright and Rob Schuler, Scott designed a day of fun, fitness, and camaraderie to benefit the Coalition.

Mendon Ponds at foggy dawn was the site for a gathering of hundreds of riders, runners, and walkers. Courses were designed to accommodate families as well as seasoned competitive riders, featuring distances of 10, 25, and 50 miles. Multiple rest and refresh stops along the courses were staffed by local business teams. Those who chose not to ride could choose a 5K hike or run through the Park Trails.

At the finish line, the sunshine of the crisp Fall day was a welcome reward along with a delicious variety of lunch sandwiches provided by Amiels Original Subs, raffles, music and an awards ceremony.

In addition to the incredible team at Towpath, we are especially grateful to other local businesses that made this event such a success: Van Bortel Ford & Subaru, Salvatores, Palmer’s Food Services, Artisan Works, Midtown Athletic, MedVed, SMP, & CNB Mortgage. Thanks also to Trek Bikes for the gorgeous raffled bicycle, Sock Guy, Score-this, and Power Bar.

Great things happen when the people who make businesses successful get a brainstorm. We are so grateful to Towpath Bikes for sharing their talent, passion, drive, enthusiasm and commitment in such a meaningful way. Your generous gift of $30,000 means the world to us and to the people we serve!

“Souper”bowl Party

Building on the ever-popular potluck theme, faculty at Mendon Center Elementary school put their culinary talents to use with a creative and delicious fundraiser for the Coalition. The Mix and Mingle Committee of the school collected donations from willing testers of a sumptuous selection of homemade soups and raised an impressive $325 donation for the Coalition.

Dressing Down for Dollars

The staff of Albion Middle School took full advantage of a recent dress-down opportunity and raised $263.20 to donate to the Coalition. Way to sport those jeans!

Helping Hoops

Each year the Women’s Basketball team of RIT dedicates an early February game to Think Pink, an effort that raises money aimed at breast cancer research. Various charities have benefited from this annual effort, and this year, the Breast Cancer Coalition was pleased to be selected to receive a gift of $165.

Hometown Helpers

Many Senior Living communities in our area take great pride in sharing their talents and caring to contribute to local charitable efforts. Groups at Grandville Senior Living created festive Easter themed baskets for raffle. Tickets were sold to residents, staff and families resulting in a lovely gift of $200.

Grandville resident, Evelyn Benoit presents Lori Meath with their gift.
Students Helping the Community

It is especially touching when gifts to the Coalition come as a result of the imagination and hard work of young people. So often, someone in their lives has been affected by breast cancer, and offering a gift to the Coalition is a way of honoring that loved one.

- **Pittsford Youth Hockey** is another high energy team that leaves their “all” on the ice, especially in January each year at the Pink the Rink game. This year the Pittsford Panthers played at RIT for the sixth annual effort. Pink the Rink chairperson Celeste Frohm reported that an impressive 1333 tickets were sold to the game. Some five hundred foam pucks were sold for the chuck-a-puck contest, and spirit wear sales, jersey sponsorships, and game day contributions made for a grand total donation of $6100.

- **The Fingerlakes Freeze U16 Girls Hockey Team** is a tough and fun-loving group of incredibly dedicated athletes who spend many hours each week on the ice, often at times the rest of us are still sleeping or else wrapping up our day and heading to bed. Thanks to this feisty team of young ladies of Webster who skated in a fast-paced exhibition game against Canandaigua at the Blue Cross Arena in January and raised $3120 for the Breast Cancer Coalition!

- **Wayne Central High School Senior Andrea White** chose the Coalition to receive the proceeds of her Breast Cancer Walk at the indoor track of the school. Andrea gathered raffle items and pink scarves to raise $124. Thanks so much, Andrea!

- **Rochester’s Young Women’s College Prep Charter School** fosters a sense of responsibility to community as well as self. As these young women prepare for life, they endeavor to make their own communities places of support and respect. They chose to support our efforts in the Rochester area with a donation of $100.

She did it again!

What do get when you combine one five foot dynamo with the fun loving and generous bowling community? Incredible success, year after year! That dynamo is Kathy O’Neill, and the event is the fabulous annual Bowl For the Cure event at Brighton’s Clover Lanes. Kathy sold out two shifts of bowlers once again, and thrilled each group with an amazing array of raffle items ranging from dinner packages to pasta, bowling balls to small kitchen appliances. Kathy and her merry crew work for months to make this event a celebration of survivors and a gift to the Rochester community. This year, Kathy humbly presented a check for $15,000 to the Coalition. With her usual big smile and warm hugs, she waved goodbye, calling over her shoulder, “see you next year”!

Kathy, you are a treasure to the Rochester community and most certainly to the Breast Cancer Coalition.

We DIG it!

Our new neighbors at Hot Shots welcomed us in a most hospitable way by holding back to back fundraising events in early March.

Friday night we were the recipients of door proceeds from the monthly Corona Cares Beach Party. Corona sponsors these “parties” at various venues around Rochester and donates the admission to a local charity. Thanks to Corona Cares and Hot Shots we received $220.

The following day, Hot Shots hosted a rocking series of volleyball tournaments called I Dig Pink. Though it was cold and snowy March outdoors, inside, it was beach volleyball in the sand throughout the day and evening. Co-owner Sal Gerbino is a lifelong Rochester guy, and took great pride in raising $1215 to share with his new neighbors. We are feeling mighty welcome, Sal!

A Mighty Nice Mitzvah

The journey of a young man to his Bar Mitzvah involves study as well as acts of kindness and charity. Eli Dietz directed his “mitzvah” to the Breast Cancer Coalition. His simple, steady effort collecting cans and bottles resulted in an impressive and most appreciated donation of $1000. Mazel Tov, Eli!
**Unexpected Gifts**

Each year, about 10% of the gifts we receive from the community are unexpected surprises. They generally arrive with a small scrawled note wishing the Coalition the best as we support those dealing with a breast cancer diagnosis. We truly appreciate these quiet givers.

- **The Urban League of Rochester** offered a gift of $55.72.
- **Abundance Food Coop** shared the proceeds of a recent “round up” promotion. Thanks for this gift of $160.86.
- **Solutions Studio and Spa** of Greece sent a day-brightening gift of $190.62. Thanks to Co-founders and sisters Jackie Leturneau and Jennifer Grim for thinking of us!
- **Starbucks** in Perinton sent a contribution of $44.
- **Caraglio’s Pizza** sold specially designed T-shirts and donated $170.
- One especially lovely surprise came to us from the Rochester Transportation Council. This trade organization of area transportation businesses has dissolved after a 90 year presence in Rochester. After much discussion, they decided to donate their remaining funds to the Rochester community. A Board vote selected the Coalition to receive this generous contribution of $2000. We will use this gift to make the Rochester community a better place to be, just as the RTC has always done.
- Another benevolent Rochester group presented us with $2006.74 after the raffle winner at their golf tournament selected us to receive proceeds from the event. Big thanks go to Teamster Local #503M, President Michael Stafford, and event organizer Tom Trapp for your great effort and generous contribution.

**Upcoming/Ongoing Community Fundraisers**

**Colony Dry Cleaners**

Even in today’s “wash and wear” world, there are items that are best handled by a dry cleaning process. Locally owned Colony Dry Cleaners utilizes a less toxic process (no PERC!) to gently but thoroughly clean clothing, blankets and treasured special items.

For all of 2015, Colony is donating 10% of Pink Bag customers cleaning total to the Coalition! Check our website for program details. [http://bccr.org/fundraising-friends/](http://bccr.org/fundraising-friends/)

**Premier Property Maintenance**

Premier Property Maintenance of Williamson is donating 5% of of every new signed contract to the Breast Cancer Coalition of Rochester according to Marcus Eodice, owner.

For example if you sign a season contract for mowing and your weekly bill is $40, $2 every week will be donated to BCCR. If your lawn is mowed 26 times through the season that’s a $52 donation!

Call 585-319-6090 for details

**Trammel Creative Portraiture**

Keith Trammel of Trammel Creative Portraiture will be honoring his wife by having Senior portrait models act as “ambassadors” to distribute information about breast cancer, raise awareness, and contribute a portion of studio sales to the Breast Cancer Coalition.

**Corporate Fundraisers**

**Welcome Bronze Season Sponsors!**

Welcome to The Cabot Group, C.M. Armitage, Kenron Industrial Air Conditioning Inc., and Jeffrey Ellis Carl Cabinetmakers as Bronze Season Sponsors. Each of these companies helped in making our new office space so special and we are delighted to continue our relationship with each of them. Special thanks to Kirk Olsen at the Cabot Group who helped bring all these friends to us.

**Leonard’s Express**

Kyle Johnson of Leonard’s Express, Inc. reports that they have purchased three big pink over the road trucks to add to their fleet. Their Leonard’s “family” has been hard hit by breast cancer in recent years, so they have decided to donate $1 for every 100 miles that each of these special trucks travel. Each will be piloted by a driver “ambassador” who will share their story of how their family was impacted by breast cancer. If you see one of these special trucks, be sure to wave!

**Rapid Crush**

Thanks to Emily and Ben Cummings of Rapid Crush for this quarter’s gift of $500.
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Volunteer Spotlight continued

diligently and uncomplainingly.

We jokingly refer to this bunch as our “volun-tolds”. They may have been “told”, but they respond cheerfully every time, and we are grateful to them for standing with us as we work on behalf of those affected by breast cancer. Our guys are a big part of the reason we fight so hard. To have their support in such tangible, meaningful ways means more to us than they may ever know. »
Kathleen Maxian Interview continued

Pat: Are there any recent developments in the treatment of this disease? If so, what are they and how are they beneficial to patients?

Kathleen: I am happy to report that there have been several interesting and exciting developments in the treatment of ovarian cancer. The FDA recently approved Avastin® (bevacizumab) a targeted antiangiogenic therapy. The drug works by starving the tumor of the blood supply it would need to grow. Avastin® has been approved for women whose ovarian cancers have been deemed resistant to platinum-based chemotherapies or have been heavily pre-treated.

The FDA also approved the first PARP inhibitor Lynparza® (olaparib) for women with BRCA 1 or 2 mutations. An oversimplification of how these drugs work is that they block the cells’ ability to repair DNA damage; the tumors are overwhelmed by faulty DNA and die. If a gene mutation is suspected, it is important for women to have genetic testing to see if they are eligible for this new class of drugs as a treatment. Numerous clinical trials have opened that are showing success with this new type of therapy.

Keep your eyes on immunotherapy vaccine trials for ovarian cancer. Although these are in early phase testing, there have been some significant successes with other types of cancers. The best way to get one of these vaccines is to ask your doctor about a clinical trial.

Pat: What would you like the public to know about ovarian cancer that might not be generally known?

Kathleen: For years, ovarian cancer was called a ‘silent killer’ but studies have shown that there are symptoms and risk factors, and we encourage women to ask their physicians to rule out ovarian cancer first. Sadly, many women spend months going to doctors and specialists before being diagnosed with ovarian cancer, because their doctors just didn’t have it on the radar.

If you experience any of these symptoms, that are not normal for you, almost daily for 2 or more weeks, talk to your gynecologist:
- Bloating
- Pelvic or Abdominal Pain
- Difficulty eating or feeling full quickly
- Urinary urgency or frequency

If ovarian cancer is suspected after a CA125 blood test and transvaginal ultrasound, insist your doctor refer you to a gynecologic oncologist.

The risk factors for ovarian cancer are:
- Age: Increases with age; most women are diagnosed over 55.
- Weight: Studies show higher risk for overweight or obese women
- Family History: A close blood relative who has had breast cancer before age 50 or ovarian cancer at any age.
- Reproductive History: No children or difficulty getting pregnant.
- Personal History: Cancer of breast, uterus, colon or rectum.
- Hormone Replacement Therapy: Menopausal HRT
- Ethnicity: European, North American, Ashkenazi Jewish descent.
- Genetic Testing: BRCA1/2, Lynch Syndrome (HNPCC)
- Endometriosis: A history of endometriosis.

Having a risk factor for ovarian cancer does not necessarily mean that a woman will get ovarian cancer. We encourage women with risk to talk to their doctors.

treatment. The answer was yes.

There were a number of different trials that looked at switching women after 2–1/2 years of tamoxifen to completing 5 years of treatment with an aromatase inhibitor. There were two trials that came out within the last year and a half of looking at five versus ten years of tamoxifen, and both reported a clear benefit to higher risk women. So last summer, we did a focus update to talk about a longer duration of tamoxifen.

Every time there is sufficient new data to make a dramatic impact on how the majority of women with estrogen receptor positive cancer should be treated, they reconvene this guidelines panel. Holly and I both remain on the panel and I think it’s really important to help the general oncology practice or breast cancer oncologists who aren’t in huge academic settings. Making oncologists smarter and giving them access to data in a user friendly way helps a tremendous number of patients.

**Pat:** Your research interests are related to long term quality of life for patients receiving chemotherapy. What does quality of life mean for these people, and what is the best way to achieve that?

**Dr. Solky:** As oncologists, we look at quantity of life, and also at quality of life. In people who have metastatic disease, I’m not sure you do people a service by extending life with miserable quality. It’s always a balance when you’re sitting with a patient and a family struggling to make difficult decisions.

It’s a separate issue in someone who is undergoing potentially curative treatment. In breast cancer, when a patient gets adjuvant chemotherapy, you’re saying that despite the excellent surgery (and possibly radiation) that the patient’s been through, there’s still a risk that some of the cancer cells broke free long before it was ever found. And you want to give the patient the best chance of beating the cancer long term. Some of the medicines we use – chemotherapy and anti-hormonal treatments – cause side effects, some that aren’t reversible. You have to consider whether the risk of that is worth the potential benefit in terms of improving the chances that the cancer doesn’t come back.

Quality of life is not the same for everybody. If you’re talking to a mathematician who is still going to teach math to her students, and chemotherapy makes it much more difficult for her cognitively, that’s a significant detractor for her. If people have trouble balancing their checkbook, that can be difficult on their lives. We always explain that there are risks to people, but overall, it’s trying to make the right balance between risk and benefit.

When Interlakes had an independent, not-for-profit research foundation, we had some studies looking at quality of life issues. Since we’ve joined with the university, we are opening some of the research trials that the university has. We’re just starting to get that up and running.

If, as an oncologist, you’ve seen people benefit from all the research that’s been done, you want more research to help the next person coming along; the daughter of the person you’re seeing now. That’s why we encourage people, when it’s appropriate, to consider going into a clinical trial. I never push it. But if people approach being on a clinical trial by saying, “This is what I’m doing to help not only myself but all cancer patients who come after me,” I think that’s something rich that someone can take out of this experience. It’s not for everybody. I never feel bad if someone doesn’t want to do it.

**Pat:** What, as a medical oncologist, is the most frustrating aspect of your work? What is the most rewarding?

**Dr. Solky:** The most rewarding part – I’ll start with that – is to be part of peoples’ lives when they’re at their most vulnerable and they’re trusting you to help them. I think that’s an awesome feeling. Even when I’ve had a really hard day, I go home and think “Wow, look at the opportunity I’m given. People trust me enough to try and help them through this really amazingly difficult time.” Specifically, I’d say one of the more rewarding things is seeing people who do better than you expect. Whether it’s people tolerating things better than expected or it’s someone with stage 4 disease where we talked about their average survival being one or two years, then it’s four years later and they come in and thumb their nose at me for fun, and we laugh, and they don’t look like a sick person – they’re living their lives.

The most frustrating thing is when you can’t help someone to fight the cancer any more. That’s the hardest part of the job. You can never forget that it’s harder to be on the patient’s side of the desk than the doctor’s.

I have two jobs. One is to be the cheerleader, although I don’t look good in a little short skirt, and the other is to be a realist because people need both.

For more information on the ASCO guideline update panel:
http://jco.ascopubs.org/content/early/2014/05/20/JCO.2013.54.2258.abstract
soul – and never let go.

The fact of the matter is that I am happier and in many ways healthier than I have been in years. I am exercising consistently, eating better, and drinking more water and less Diet Pepsi. I am closer to my kids, I am closer to my boyfriend, I am closer to my parents, aunts, uncles and cousins. I am inspired all the time by unselfish acts of kindness all around me. I sing more. I make a point to really see the things around me, not go through the motions. I do yoga. I do Reiki. I go to parks. I sit and talk to my kids regardless of how many things are on my to-do list. I drive around with the top down on the Jeep. I take walks. I go on my own field trips. I sleep in. I challenge myself. I spend time with the people I care about. I don’t feel bad that I can’t work right now.

There are times when the positive things get away from me - I am only human. When they do, I take a deep breath, close my eyes and say to myself, “I am strong, I am brave,” as many times as it takes to bring me back to that place where everything will be ok.

To stay true to myself, I often go back to this: I will be someone with just the right mix of sweetness and strength. I am someone who doesn’t crumble under pressure. I am a fighter who’s too busy kicking butt to sit down and cry but knows it’s okay to do both. I am a person who doesn’t always ask for support, but has lots of people who would do anything to help.

It wasn’t all pretty though, as anyone who has traveled this road knows. My greatest challenges included losing my hair, having no energy from a low red blood cell count, feeling yucky from chemo, a constant runny nose from chemo, the worry that the tumor was not shrinking, waiting for PET scan results that showed it was shrinking, and fibrosis, cording, and the fear of lymphedema. Yes, it was a year-long project just as my PCP said it would be.

The journey continues. I no longer agonize over another birthday - I am happy to be alive! I no longer take good health for granted and try to live with more intention. Yet, some things have not changed. I was always somewhat of an advocate and during treatment I asked for more nutritious lunch food and snacks at my treatment center, which resulted in being asked to join the patient advisory committee. I am happy to serve and to be a part of the team that looks for ways to go from great to extraordinary. They really do listen!

I loved attending Brown Bag lunches, and continue to do so. I didn’t always have energy to attend evening events. However, I did attend many monthly lectures, a Voices and Vision series, and a TaiChi class. My PALS mentor helped to normalize my feelings and checked in on me regularly without ever being intrusive. When I need to have people around me who “just know” I continue to turn to the Coalition.

Three helpful suggestions from Brown Bag that I followed were to call the pathologist for an explanation of the report; to use an expandable file folder for all medical records and reports to take to all appointments, and take someone to appointments with you to take notes. To that advice, I would add the following: reach out, ask for what you need, ask questions, advocate for yourself, and cry when you need to. You will get through this. ☺

2. The Cancer Fighting Kitchen by Rebecca Katz with Mat Edelson, 2009, Ten Speed Press
Upcoming Events & Programs at the Coalition

Wednesday, July 22, 2015
Allison Magnuson, M.D.
As We Age: Treatment Options and Decision Making
7:00pm

Monday, July 27, 2015
'Tee'd Off at Breast Cancer' Golf Tournament
Brook-Lea Country Club
Noon Shotgun Start

Wednesday, August 5, 2015
Twelfth Annual Terri Schmitt Legislative Reception
5:00 - 7:00pm
RSVP info@bccr.org

Wednesday, August 26, 2015
Understanding Your Pathology Report
7:00pm

Wednesday, September 23, 2015
Lisa Fischer, MS, RD, CDN
Food as Medicine:
*Nutritional Inspiration for Coping, Recovering and Healing*
7:00pm

Saturday, September 26, 2015
ARTrageous Affair Breast Cancer Gala
Holiday Inn Downtown
(formerly Rochester Plaza Hotel)
6:00pm

All events unless otherwise noted are at:
THE BREAST CANCER COALITION OF ROCHESTER
1048 University Avenue

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### THE COALITION’S CURRENT WISH LIST

- A cure for breast cancer
- Books about breast cancer and lymphedema 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, commercial grade*)
- *Batteries, D and AA*
- Food storage containers, beverage pitchers, dish towels
- Mop and bucket

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**The following items are needed specifically for PALS Paks:**

(*all items must be new*)

- Hand knit caps
- Scarves or bandanas
- Fleece throws/blankets (*please, no juvenile, cartoon, logo, or business branded items*)
- Journals
- Satin sleep masks (*lavender or unscented only*)
- Soft socks
- Sleeping masks (*unscented or lavender scented*)

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### When the Going Gets Tough

*By Katrina Kenison*

When the going gets tough may I resist my first impulse to wade in, fix, explain, resolve, and restore. May I sit down instead.

When the going gets tough may I be quiet. May I steep for a while in stillness.

When the going gets tough may I have faith that things are unfolding as they are meant to. May I remember that my life is what it is, not what I ask for. May I find the strength to bear it, the grace to accept it, the faith to embrace it.

When the going gets tough may I practice with what I’m given, rather than wish for something else. When the going gets tough may I assume nothing. May I not take it personally. May I opt for trust over doubt, compassion over suspicion, vulnerability over vengeance.

When the going gets tough may I open my heart before I open my mouth.

When the going gets tough may I be the first to apologize. May I leave it at that. May I bend with all my being toward forgiveness.

When the going gets tough may I look for a door to step through rather than a wall to hide behind.

When the going gets tough may I turn my gaze up to the sky above my head, rather than down to the mess at my feet. May I count my blessings.

When the going gets tough may I pause, reach out a hand, and make the way easier for someone else. When the going gets tough may I remember that I’m not alone. May I be kind.

When the going gets tough may I choose love over fear. Every time.


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**“I never win anything!”**

Congratulations to lucky Hillary Thompson, winner of the $250 Wegmans gift card raffle. Hillary bought her winning ticket from sweet and persuasive Brody Tydings, who was working at out Lilac Festival booth with his mom Lisa and family on Mother’s Day afternoon. Thanks to Hillary and to all who purchased raffle tickets. Your donations will be put to good use for the Rochester community. ❖
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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.

Breast Cancer Coalition of Rochester Presents

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BREAST CANCER GALA 2015

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