We can never forget, especially during the breast cancer awareness month of October, that there are many who are all too aware of this disease; all too aware of the emotional and physical toll it has taken on their lives. Some have personally faced breast cancer. Others have witnessed a loved one or friend deal with it. With that in our minds and hearts, the Coalition sets aside one October evening each year to honor and celebrate lives that have been forever changed.

Lives Touched, Lives Celebrated traditionally begins with a candle-light walk on University Avenue. This past autumn, participants strolled through a chilly rain, mindful of those who have braved much worse in their walk with this disease. Yet there was a spirit of lightness in their camaraderie, and after their short trek, the group gathered in the warmth of our Center. The Reverend Melanie Duguid-May then spoke of healing, hope, and celebration. Poetry and the reading of cards that had been thoughtfully written by participants in honor of those who have faced this disease as well as their caregivers, were interspersed with the soothing, uplifting strains of music from Lisa Winter, adding notes of comfort and serenity.

This annual event recognizes the truth that those who face this terrible disease, and those near and dear to them, cannot be defined by a diagnosis. They are whole in mind and spirit, and we honor each individual journey.

Above, Reverend Melanie Duguid-May offering words of inspiration and healing.

Right, Hillary Perez with baby Evan.

The Breast Cancer Coalition of Rochester is the home of a vibrant, educated Advocacy Committee led by its talented Chair, Marianne Sargent. The mission of the Advocacy Committee is to create and maintain relationships with local, state, and national officials so that we may have opportunities to advocate for and lend support to breast cancer relevant bills and public policies. We have supported many legislative actions since our incorporation in 1997, including screening and treatment programs, research funding programs, risk reduction initiatives, access to quality care for all...the list goes on.

One piece of legislation we have supported through the years would ensure safe, legal access to medicinal cannabis (marijuana). Cannabis is a botanical with many important medicinal properties, including provision of relief from symptoms of cancer and the side effects of its treatment: specifically nausea, vomiting, pain and loss of appetite. Since 1996, twenty states and the District of Columbia have adopted laws that grant access to medical cannabis, including, most recently, Illinois and New Hampshire. In New York, the legislature has been debating a medical cannabis law every year since 1997 and, while the Assembly has passed the bill four times, most recently in 2013, the Senate has never acted on the measure.

The Breast Cancer Coalition of Rochester, partnering with Compassionate Care NY, joins many individuals, groups and organizations throughout the state in celebrating the news that New York Governor Andrew Cuomo plans to bypass the legislature and sign an executive order creating an interim medical cannabis program based on an existing public law from 1980 – the Olivieri Law - that allows the use of controlled substances to treat serious illnesses. Under this program, medical cannabis will be distributed to twenty hospitals throughout the state for patients who meet a narrow list of qualifying conditions. Regulations on this program will be established by the New York State Department of Health with input from experts. This move by the Governor is likely to have a constructive, transformative impact on the medical cannabis debate in Albany and across the country.

New Yorkers overwhelmingly support medical cannabis. A recent poll by Sienna College registered 82 percent support for medical cannabis in New York, including 81 percent of both Democrats and Republicans. Still, the Senate has yet to hold a hearing on the matter. When Governor Cuomo previously expressed opposition to medical cannabis, many in the Senate suggested that, in light of that opposition, they did not need to support the bill. Now that the Governor has announced his support and his commitment to take action, advocates around the state are applauding him and turning back to our Senate to make a final push for comprehensive legislation. Patients around the state, many of whom suffer from devastating illnesses and diseases, are depending on the Senate to do what they are

Continued on page 5
I am not a cancer survivor. However, I am not a walking dead either. I am a woman in her late 50s, who was diagnosed with recurrent breast cancer which had metastasized to the lymph nodes. Sixteen years ago, my second mammogram ever showed suspicious calcifications. Biopsies showed noninvasive ductal carcinoma – a precursor, not the real thing. I underwent lumpectomy and irradiation and accepted the 3% risk of recurrence, certain that with regular screening, any recurrence would be detected at an early stage, in which case, I was prepared to undergo a bilateral mastectomy and be done with it.

Year after year, my mammograms were normal. A year ago, when I felt a lump, studies remained normal – dense fibrocystic breasts with irradiation changes. This summer, when my breast on self-examination was clearly not normal, studies remained normal. Despite the radiographic normalcy, all biopsies showed invasive ductal carcinoma. I was prepared for that. My bilateral mastectomy was uneventful. I left the hospital the next day. However, I was not at all prepared for the pathology report – cancer was present in both breasts, one recurrence, one primary, with involvement of lymph nodes on both sides; stage 3c, with a 50% five-year survival rate.

Currently, I am undergoing chemotherapy. This will be followed by more surgery and more irradiation. “We are going for cure.” What does that really mean? My plans for the future encompassed the next 30 years. I understand my odds for being disease-free for five years. What are my odds for dying of something else at age 80 or 90? The answer is that if I survive the next five years without evidence of disease, I have a chance of making it to ten; and if I make it to ten, I have a chance of making it to twenty, and so on. Well, I made it to sixteen years of apparent cancer-free survival starting out with a precursor. After five years, I was considered to be, by and large, out of the woods, back to routine surveillance. After ten years, I was out of the woods.

I want to live. I have a lot to live for. I have a lot of things yet to do. I’ll do whatever I have to, but I have realized that whatever the outcome will be, I’ll remain forever in the woods. I will be living with cancer, evident or not, for the rest of my life. This may be two years or five, ten years or thirty. I will be a cancer survivor only if I die of other causes.

So far, I have known for only a few months that I am a woman of the woods. Intellectually, I understand that my odds of being alive when I reach retirement age are that of the toss of a coin. Nonetheless, I cannot truly conceive the idea that a perfectly healthy woman like me, genetically predestined to die of old age, should not be around in the foreseeable future. There is nothing wrong with me, other than the notion of residual malignant cells. Most of the time, I feel fine, aside from the constant fatigue and experiencing the limitations of a brain impaired by toxins. This, like the occasional nausea, abdominal pain and malaise are side effects of the medications I am given every one to two weeks, not signs of a sickness. Living in the woods is a mere notion – at least at this point. I have likely been living with the cancer for two or three years. I just did not know about it. I did not feel it grow or spread to the lymph nodes. I felt a lump. It did not hurt. It was not the presence of the cancer that made the difference, it was the awareness of it. It is not so much the idea of living with cancer that is difficult for me to accept. It

Continued on page 29
Have you heard about the collaboration between Anthony Jordan Health Center (AJHC), Highland Breast Imaging (HBI) and the Breast Cancer Coalition? The news is out and here is the story!

The National Cancer Institute has taken a close look at cancer incidence and mortality statistics and found that certain groups in this country suffer disproportionally from the disease and its effects. The most obvious factors in this disparity are associated with a lack of health care coverage and low socioeconomic status.¹ Here in Rochester, the Anthony Jordan Health Center (AJHC) is one agency that works to address the needs of underserved people in the areas where they live and work.

Breast cancer screening is one thing that often falls by the wayside among those who face such barriers as cost and transportation when seeking health care. But thanks to a coordinated effort spearheaded by the Coalition, Anthony Jordan Health Center has been operating a new mammography unit since July, 2013 at their 82 Holland Street facility in Rochester’s northeast quadrant. Funding for the unit was provided jointly by Highland Breast Imaging (HBI), the University of Rochester, and the Coalition.

It all began at a round table discussion of The Community Breast Cancer Collaborative about how to assist women in obtaining free or low-cost mammograms at sites throughout the county. Most places that offer these services are located outside city limits and transportation to these sites is a stumbling block for many. A number of strategies were considered over many months and even years of meetings. One day, while sitting at one of these meetings, it occurred to our Executive Director, Holly Anderson that we were spinning our wheels trying to get women to these sites.

“We ought to be bringing the site to the women,” Holly realized.

A conversation ensued between Holly and another committee member, Susan Swift, then of HBI. They discussed many ideas over coffee after one of these meetings, and Susan took some of their ideas back to HBI. The very next day, Avice O’Connell, M.D, F.A.C.R., Director of HBI, telephoned Holly to discuss possibilities. The following week, Holly met with Bridgette Wiefling, M.D, then Medical Director of AJHC. Susan joined the discussion and the ideas flowed. When Holly learned that it all boiled down to funding, she turned to our Board of Directors, who enthusiastically offered to put up the first $50,000 of the $225,000 it would take to install a unit at AJHC. Build-out costs could be factored in as the AJHC was going through an expansion that would provide an Urgent Care Center on site. They say timing is everything and, in this case, timing was perfect. The Coalition eventually contributed $85,000 to the project. HBI and the University Of Rochester Medical Center also contributed.

Thanks to a partnership between these dynamic local groups, Rochester residents have a new, easily accessible option for breast cancer screening. This could not have happened without the support of a generous breast cancer community, including YOU. If you have ever supported the Coalition through a monetary gift (direct donation, United Way, sponsorship of our walk, gala, golf tournament, etc.) YOU deserve our tremendous appreciation and gratitude. YOU helped make this happen. We want to give a special shout out to Kitty VanBortel of Van Bortel Ford & Subaru for donating a Ford Mustang convertible which was auctioned off in support of this project. She is truly a champion of our organization and of women in general.

Breast cancer affects us all. No one should suffer unnecessarily due to lack of access to health care. Because of this mighty collaboration, the AJHC is now a centrally located option for ANY woman, insured or not.² Live or work downtown? Consider visiting AJHC for your next mammogram!

2. For those who are uninsured or underinsured, no-cost breast cancer screening can be obtained through the Monroe County Cancer Services Program. Call 224-1070 for more information.
CORRECTION – Golf Tournament

Our coverage of the 2013 “Tee’d Off at Breast Cancer” Golf Tournament left out the following sponsor/donor information:

We extend our sincere appreciation to Sylvia and Jim Cappellino for their Golfer/Hole Sponsor Combo and to their son, Mark Cappellino, who donated his parents’ sponsorship and played in the tournament as well.

We sincerely regret that this sponsorship was not included in both the tournament program and the autumn issue of Voices of the Ribbon.

Sylvia is a founding member of the Coalition, having served as the first Chair of the Board in 1997. She is an original member of the planning committee for our annual golf tournament. Sylvia and Jim now live in Tennessee, and return to Rochester to play in the tournament each year. Sylvia also served as Honorary Co-Chair of the ARTrageous Affair in 2012. We deeply appreciate Sylvia for her hard work in the early years of the Coalition, her ongoing dedication to our organization and our mission, and her warm and energetic spirit.

Executive Director continued

in Albany to do.

The Governor understands, as many advocates do, that a law written nearly 35 years ago is unlikely to be sufficient to address the issues patients face in 2014. Thus, the legislature needs to act. The Senate Health Committee has created a logjam by refusing to move the legislation to the floor for a vote, leaving New York the only state in the Northeast without a medical cannabis program.

We agree with Governor Cuomo that New York should have the best medical cannabis program in the country, and we are deeply appreciative for his leadership on this issue. For many years, we have been frustrated by the State Senate’s failure to address this matter. By moving to implement the Olivieri law, the Governor is doing all he can within his executive power to help alleviate the suffering of some patients.

We’re going to redouble our efforts to get the Senate to finally pass the Compassionate Care Act so we can deliver it to Governor Cuomo for his signature. Stay tuned.

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Dear Governor Cuomo,

I am writing to ask you to support legislation to allow New Yorkers with serious illnesses—such as cancer, HIV/AIDS, multiple sclerosis and Parkinson’s disease—to access medical marijuana to alleviate their suffering and improve the quality of their lives. The current medical marijuana proposal has been carefully crafted with strict controls and would create one of the country’s most tightly regulated programs.

Research shows that medical marijuana can effectively treat a range of conditions, including MS, spinal cord injuries, neuropathic and chronic pain, and epilepsy, as well as the side effects of medical treatments, such as chemotherapy, HIV antiretrovirals, and hepatitis C medications. Because Congress won’t act, 20 states and the District of Columbia have passed medical marijuana programs to relieve suffering, including Arizona, Illinois, and New Jersey.

New Yorkers overwhelmingly support allowing seriously ill patients to access medical marijuana under the supervision of their doctor. It should not be a crime for those suffering from painful and life threatening illnesses to find some relief through medical marijuana. It is time for New York to show compassion.

Sincerely,

Name
Address
Phone
Email

Help Establish A Medical Marijuana Program in New York

There is strength in numbers. Please complete and return the letter at left to the Coalition.

Do not hesitate to call the Coalition with questions, 473-8177.
I am excited to announce the release of the Third Annual Progress Report for Breast Cancer Deadline 2020. This initiative, undertaken by the National Breast Cancer Coalition*, has given rise to a series of “Artemis Projects” - or summits - designed to learn how to prevent breast cancer and metastasis of the disease. Here, in a nutshell, are its 2013 achievements. (To read the full report, go to www.breastcancerdeadline2020.org and search for 2013 Progress Report 2020.)

The Annual Meeting for the Artemis Project® for a Preventive Breast Cancer Vaccine was held in March. Updates were presented and small group sessions focused on plans for the next two years. This ongoing vaccine project serves as the model for other catalytic projects.

The kickoff meeting for the Artemis Project® on the Causes & Prevention of Metastasis was held in June. Seventeen scientists and advocates discussed the launch of a project around tumor dormancy, since so little is known about this topic. A follow-up meeting is planned in conjunction with the vaccine meeting.

The Accelerating the End of Breast Cancer Act was reintroduced in both houses of Congress in May. This would create a Presidential Commission tasked with identifying promising and innovative ideas and technology not currently being prioritized for breast cancer. Both New York State Senators and seven area Representatives signed as co-sponsors.

Citizens nationwide signed a petition to the President asking him to make the end of breast cancer by January 1, 2020 a national priority. Tens of thousands of signatures were gathered and delivered to President Obama in October.

Relationships and networks with dozens of other countries are being built.

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**What happened to the Petition I Signed?**

It was an awe-inspiring moment when our own Phyllis Connelly stood outside the White House in the same spot where our foremothers fought for the right to vote. Petitions in hand, Phyllis was ready to deliver the signatures to the President.

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**The Breast Cancer Coalition of Rochester**

**sends representative to deliver Breast Cancer Deadline 2020 petitions to President Obama in Washington**

Rochester, NY – On Wednesday November 13, 2013, 20 breast cancer advocates from across the country met in Washington, DC to deliver petitions to President Obama, asking him to commit to work with the National Breast Cancer Coalition (NBCC) on the Breast Cancer Deadline 2020® campaign, with the goal of knowing how to end breast cancer by January 1, 2020.

Rochester advocate Phyllis Connelly represented the Breast Cancer Coalition of Rochester as part the delegation [second from right, back row in photo], presenting petitions containing signatures that advocates have gathered at local venues for over two years. Connelly, a breast cancer survivor and past Chair of the Breast Cancer Coalition of Rochester and of the Coalition’s Advocacy Committee, lives in Webster.

In Washington, the delegation met with Hallie Schneir, the Associate Director of White House Office of Public Engagement, and Carole Johnson, Senior Policy

Continued on page 28
Will 2014 Bring the Compassionate Care Act to New York?

-By Marianne Sargent

All too many breast cancer patients can identify with the side effects of chemotherapy while undergoing treatment. Others have watched love ones go through this difficult experience. While the costly drugs Kytril and Zofran are routinely prescribed to combat the nausea, pain and loss of energy that so often accompany chemo, they do not always have the desired effect. Allowing New York State physicians to prescribe medical cannabis provides a viable option for some of these patients. This is the goal of New York State Assembly Bill number A06357-A: the Compassionate Care Act.

To date, twenty states and the District of Columbia have enacted medical marijuana laws. The current bill sponsored by Assemblyman Gottfried and Senator Savino represents a vast improvement over prior versions. Lawmakers agree that learning from the experiences and missteps of other states has made the New York version a more tightly regulated, focused piece of legislation.

The New York State Department of Health would oversee the production and dispensing of medical marijuana. Patients must be certified by a doctor, physician’s assistant or nurse practitioner as having a “severe debilitating or life threatening condition”. People living with multiple sclerosis, epilepsy, AIDS, Parkinson’s Disease, fibromyalgia and neuropathy are just some of those in addition to cancer patients who may qualify for this medication. Medical providers would report all patient certifications to the DOH, who in turn issues a photo ID card for each patient to be renewed annually. Prescribed use and amount limits are specified in the law. The law also states that medical marijuana cannot be used in a public place or anywhere smoking tobacco is prohibited. Organizations such as pharmacies, hospitals or hospice centers would register with the DOH to sell and dispense medical cannabis to registered patients or their caregivers. The dispensary license would require renewal every two years. Plants would be grown in a secure, indoor facility ensuring “seed to sale” tracking. Home grown plants are not a legal option. These steps make medical marijuana more closely regulated than other currently legal drugs such as morphine or Oxycontin.

The authors and supporters of this bill have taken the thoughtful concerns of the public into account.

Isn't marijuana a dangerous gateway drug?

There is no evidence to support this opinion according to a 1999 Institute of Medicine report. States that have enacted medical marijuana laws have not seen an increase in usage by the general population or continuation of use by patients after the prescribed time.

Isn't smoking a health risk?

It is; however medical marijuana is produced in several other forms. It can be administered using a vaporizer, or in pill, drop, oil or patch form.

How do we know this is medication that will work?

Studies have shown that marijuana gives relief to the muscle spasms, tingling and numbness MS patients experience. Chemotherapy patients report relief from nausea and pain, as well as increased appetites. Those living with various forms of epilepsy have seen the number of daily seizures decrease dramatically when medical cannabis is used. The chemicals found in cannabis can be adjusted during plant growth or processing to meet the needs of a specific condition. For example, tetrahydrocannabinol (THC), the substance best known for causing euphoric feelings associated with marijuana use, can be reduced or eliminated to fit the patient.

What does research say?

Research supporting the efficacy of medical marijuana conducted by the US Institute of Medicine dates back to the late 1990s. Until marijuana is reclassified by the DEA from a Schedule I substance, the FDA cannot legally conduct further research in the United States. Studies completed in Israel and other countries that have compassionate care laws support the safe, effective use of prescribed medical cannabis.

Please make your voice heard by filling out the postcard on page 5.

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The very eloquent Janet Clark says “I believe the first thing people need to know about metastatic breast cancer is that it is breast cancer which has spread to other places in your body and it now means you are living with cancer for the rest of your life. While it is not curable, it is treatable, but the treatments will never be over until they quit working at slowing down the disease.” Well-intentioned people who learn about Janet’s diagnosis may not grasp the full meaning of this, and she continues, “One question I constantly get is ‘Are you almost done with treatments?’ If people understood about the disease, they would know that you certainly hope not.” Janet would like her friends, family, and co-workers to know that metastatic breast cancer “…is something we are living with every day, and will be for the rest of our lives. But ‘living’ is the key, and those of us with the disease certainly have a heightened awareness of just how precious life can be. We want to make the most of life every day. This is an attitude that is good for everyone whether they have a disease or not.” “Just like everyone else,” Janet continues, “we will have good days and bad days. Some days we need down time. Perhaps we don’t have as much energy as we once did. My hope is that people will be patient with me, laugh with me, cry with me, help me find something to smile about or be grateful for every day. I try to focus on others, thinking about what words I can say, or actions I can take which will make someone else’s day better. It never fails that the joy one brings to someone else reflects back on them.”
At Common Ground, our newest support gathering for those living with metastatic breast and gynecologic cancers, lunches are occasionally provided to attendees thanks to the generosity of Michelle (Micky) Mann and Stephen (Steve) Atterbury. This kind pair has provided funds so that once a month, the group is treated to a delectable meal when they gather to receive the support of others on a similar path. We are deeply grateful to Micky and Steve for their gift from the heart.

Also, thanks to Aria Camaione-Lind for sponsoring one of these lunches.

Those who face metastatic breast cancer speak from the heart about their journeys. This diagnosis has not changed the essence of who they are. Until the time when a cure is found and breast cancer becomes nothing but a bad chapter in history, these are voices that need to be heard. Because we’re all in this together.

Thoughtful, introspective Kathy Raeside went through profound personal changes when she learned that her breast cancer had metastasized. “I would say that the spiritual changes are easily as significant as the physical changes in metastatic cancer,” she muses. Like all who face any form of breast cancer, those with advanced disease are not defined by their diagnosis. There are places cancer can never touch, and connecting with those deep inner aspects of a person, whatever form that may take for any individual, is important for many who find themselves on this particular path.

Carol Henretta sagely expresses her wishes for those with advanced disease, and it is good advice for anyone. “I wish everyone living with metastatic breast cancer would ‘take one day at a time’ and enjoy it to the nth degree. Take time to smell the flowers, really look at the moon, feel the sun, kiss a loved one, enjoy a cup of hot cocoa, pray for a friend, pray for yourself, sing a song, call a friend, play the piano (or other instrument), read a good book, visit the Coalition, take a Yoga class and/or a Qi Gong class, listen to someone in need, help a friend, let others help you. Remember, this is YOUR DAY! Enjoy it!”

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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.

**Friends & Family Networking Group**
We invite those who have a friend, partner, or family member who has been diagnosed with breast or gynecologic cancer to a special group led by Peg DeBaise, LMFT, which meets on the 2nd Thursday of each month from 5:30 until 7:00pm. An RSVP is appreciated, as light refreshments will be served, but don’t let the fact that you haven’t called in advance keep you away.

**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, 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 meets from 5:30 to 7:30pm on the second Wednesday of each month from October 2013 through March 2014.
For more information or to register for our programs, please call the BCCR at (585) 473-8177

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 19 for PALS Program updates.

Young Survivor Soiree

A young survivor may identify with those who have faced breast or gynecologic cancer in the midst of a career climb, or while raising children, or perhaps with those whose family plans have been derailed by treatment. Four times a year, we hold these soirees as an informal way to connect with others who have walked a similar path. The next soiree will be on March 14th. Please call to be added to the invitation list.

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.

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 a professional instructor, 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, Gentle Yoga, Qi Gong, and Tai Chi, 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.
The use of complementary therapies to relieve physical and emotional symptoms related to breast cancer and enhancing quality of life has become more and more mainstream. Evidence suggests that these mind-body-spirit techniques may improve flexibility and range of motion, and can promote relaxation. Often, physicians in our community suggest using these types of therapies in combination with conventional medical treatment to improve overall wellness. They are used along with – not instead of - conventional cancer care to promote healing and an overall sense of well-being.

Since its inception in 2011, our Healing Arts Initiative, which focuses on these complementary healing practices, has flourished beyond our wildest expectations. Survivors gather at our Center on a regular basis to learn and practice mind-body-spirit techniques such as Gentle Yoga, Qi Gong, Tai Chi, and Fluid Motion. Classes are offered at no cost to anyone with breast or GYN cancer; those who are newly diagnosed as well as long-term survivors. Held on Saturday mornings here at the Coalition in four or six-week sessions, they are led by professionally trained instructors. Watch for our announcement of an exciting new healing arts offering in the coming months!

Another option is our Monday evening Gentle Yoga Class, held in six-week sessions throughout the year. Never tried yoga? Don’t let that deter you! Classes are tailored to meet the needs of every participant regardless of ability. Because these classes are so popular and fill up quickly, we are adding sessions in 2014 for those who wish to participate.

The beauty in holding the healing arts classes here at the Coalition is that those who have never tried these practices can do so in a friendly and safe environment with other breast and GYN cancer survivors. It truly is a warm, calming space where all participants, even beginners, feel nurtured and welcome.

The new year is upon us, and with it comes new opportunities to focus on healing and wellness. Take time just for YOU. Join us to see what the Healing Arts are all about.

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

Thanks!

If you are interested in learning more, please feel free to contact me at jean@bccr.org or give me a call at 473-8177.

Breathing in, I know that anger is here.
Breathing out, I know that the anger is in me.
Breathing in, I know that anger is unpleasant.
Breathing out, I know this feeling will pass.
Breathing in, I am calm.
Breathing out, I am strong enough to take care of this anger.

~ Thich Nhat Hanh
Outreach Coordinators' Update

With a staff of five full-time and three part-time members, the Coalition always welcomes new people to join the army of volunteers who make it possible for us to do all that we do. Volunteers help us take our message out into the community, spreading the word about our organization and what we have to offer families dealing with a breast cancer diagnosis.

We host three fundraisers of our own each year: The Pink Ribbon Run and Family Fitness Walk on Mother’s Day, the Tee’d Off at Breast Cancer Golf Tournament in July, and our ARTrageous Affair gala in autumn. Each requires scores of volunteers to do everything from registration to water stops to packing art to serving food or folding t-shirts. We have work for the person who loves to talk to people or the person who prefers to help behind the scenes.

We speak to groups about breast health and our programs, coordinate with other community agencies, and host booths at area summer festivals. We need people to deliver our quarterly newsletters, members for our Advocacy and Research committees, and women who have experienced breast cancer to become peer mentors for the newly diagnosed. There are openings throughout the year on many different days and at many different times.

As we head into the new year, it is a “quiet” time for our organization. But it won’t be long until we will be seeking folks to help us in many ways. Right now would be a great time to come in, attend an evening seminar or one of our other events, and see what we are all about.

Email me at lori@bccr.org if you would like more information. I’d love to meet you and I promise that your efforts are appreciated and truly do make a difference! You are vital and appreciated. 

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Volunteer SPOTLIGHT

Mary Wilkins Carafos

-By Pat Battaglia

Whether you prefer to call her a survivor, thriver, or any other word that fits someone who has endured adversity, Mary Wilkins Carafos has forged her way through multiple life challenges with characteristic determination and energy. Having faced her own breast cancer diagnosis and treatment as a single mother of two sons, who are now college age, Mary has balanced her personal challenges and triumphs, while maintaining a deeply compassionate heart. Since 2009, she has done an outstanding job as the Secretary of our Board of Directors. Mary is an active participant in our fundraising, community initiatives, and programs and, on occasion, has made her volunteer work a family affair by enlisting the help of one or both of her sons Chris and Kevin.

Mary’s most recent family addition is a newly adopted golden retriever puppy named Cali, who lives with a deformed leg. Cali’s kind, compassionate owner has given her a welcoming home and a new lease on a long and happy life. Extending this same caring spirit into the community, Mary enthusiastically steps up whenever she sees a need within the Coalition.

An avid runner and bicyclist, Mary is a regular volunteer for and participant in our Mother’s Day Pink Ribbon Run and Family Fitness Walk. Always ready to help, she has spoken about the work of the Coalition to community groups and attended benefits on our behalf imparting her enthusiasm and gratitude for the work of the Coalition. Mary’s outgoing, friendly manner has endeared her to all of us at the Coalition as she forges adeptly onward with her often behind-the-scenes work on behalf of those who have been diagnosed with breast cancer. Her commitment to this organization is laudable and her persistence in the face of hardship makes her a force to be reckoned with.

Step aside, cancer. Mary is in the room.
We live in an age of information, surrounded by media messages of every description. Many of these are essential to our lives, some probably not so much. Once we’ve determined which messages are important, we must be certain of their accuracy so we can make proper use of them.

A similar situation exists in our bodies. Hormones are a sort of chemical messenger service, delivering instructions that regulate all biological processes in the body from conception through adulthood and into old age. Such vital functions as the development of the brain and nervous system, growth, reproduction, and metabolism are hormone-driven. These chemical messages are produced and released into the bloodstream by a delicately balanced network of glands located throughout the body, to be taken up by receptors in various organs and tissues that recognize and respond to specific hormonal signals. Glands, hormones, and receptors, taken all together, make up the endocrine system.

A variety of chemicals, both man-made and some naturally occurring, are known or suspected endocrine disruptors, which exert their effects at all points of the endocrine system. Some substances increase or decrease the production of certain hormones. Others are chemically similar to natural hormones, mimic their effects, bind with them, or turn one hormone into another. Still others may interfere with hormone signaling, telling cells to die prematurely or to reproduce endlessly.

Endocrine disrupting chemicals (EDCs) that have been released into the environment through human activity have been implicated as having widely ranging effects, including early puberty, rising rates of obesity and diabetes, and certain cancers. Most of these known and suspected EDCs have not been studied. Despite incomplete evidence, the potential for long-ranging damage exists, making it prudent to exercise the precautionary principle and avoid chemical exposures whenever possible.

The Environmental Working Group (EWG) has released a list called The Dirty Dozen Endocrine Disruptors; 12 Hormone-Altering Chemicals and How to Avoid Them. These chemicals, such as Bisphenol A (BPA), dioxin, fire retardants, and perfluorinated chemicals (found in the lining of non-stick cookware) are commonly encountered from many sources: pesticide residues on food; consumer products such as plastics and fire-retardant treated fabrics; air and water pollution; and more. Among the suggestions of ways to reduce our exposure are such common-sense recommendations as eating more fresh food, emphasizing plant-based foods, and avoiding canned and packaged foods. Buying organic foods when possible will further reduce EDC exposures. Filtering tap water is a way to avoid a number of unwanted contaminants. A link to the EWG’s water filter buying guide is provided. Cleaning products are also implicated in EDC exposures and it is suggested that those containing glycol ethers such as 2-butoxyethanol (EGBE) and methoxydiglycol (DEGME) be avoided. And using a vacuum cleaner with a HEPA filter is another good way to remove contaminants present in house dust.

Small changes add up to make a big difference. While there are no guarantees that we can prevent or reverse disease by cleaning up our act in regard to EDC exposures, it is a positive, health-and-life-affirming step to take. At the very least, it will do no harm. It has unlimited potential to offer us a fighting chance in an uncertain world.


To access the Dirty Dozen Endocrine Disruptors; 12 Hormone-Altering Chemicals and How to Avoid Them, go to: http://www.ewg.org/research/dirty-dozen-list-endocrine-disruptors
Walking Together
Reflections on the Eat Well Live Well Experience for Breast Cancer Survivors

As I look back on our latest Eat Well Live Well challenge, I wonder how the folks who participated are doing now. Making even a small change in eating or activity levels can make all the difference in the world.

Do you remember when you received your diagnosis? Do you remember the highs and lows and the feeling of numbness? There were many times after my own diagnosis when the only thing that moved me forward was the next appointment. I had to act "as if" because my mind was overloaded with the "what if's" and "what will I do." There were and still are days when these feelings come and go.

All of life requires transition through good and bad times. Time is the great continuum and moves ever onward. We are constantly transforming, just as the trees lose their leaves and the winds blow colder. They make this change because they can and it is the way it's supposed to be. While breast cancer is not the way it is supposed to be, we are being transformed in ways that will change us forever. We become stronger. We become in tune to life and our surroundings. A baby's laughter may be more meaningful than ever before. Watching the falling snow can be a spectacular observation we make. They all become more important because we have been touched at a level that changes our lives and how we live it.

Take a few moments to think of your changes. You've come a long way. We've come a long way and we will keep walking together. Even though time comes and goes, we are here for each other in the great continuum of change. For that, I'm grateful.

The Coalition participates twice each year in the Eat Well Live Well (EWLW) program sponsored by Wegmans. In addition to the health benefits of counting steps taken and cups of fresh produce consumed, many participants find the camaraderie and increased sense of physical well-being support their emotional health. They also receive motivating messages such as the one above from Kathi Johnson, one of our Co-facilitators. Stay tuned for announcements of future EWLW sessions. –Ed.
On Saturday, September 28, 2013 the Breast Cancer Coalition celebrated the 12th Annual ARTrageous Affair at the Rochester Plaza Hotel. The ballroom was filled to capacity as 470 guests and more than 50 volunteers mingled among the pink balloons, extraordinary artwork, themed gift baskets, tropical centerpieces by Kittelberger Florist, and pink bubbly to support our efforts to “Redeﬁne Pink”.

From our loyal sponsors, to our dedicated ARTrageous Affair Committee, to the many artists, vendors, businesses and individuals who gave their time, talent, goods and energy, we are honored to say thank you for helping us raise a record-breaking $120,000 for the Breast Cancer Coalition. We especially wish to express our gratitude to our generous sponsors.

Mistress of Ceremonies Ginny Ryan and Auctioneer Pam Sherman encouraged the crowd to bid high on the array of silent and live auction items. The guests heard stories from those touched in some way by a breast cancer diagnosis, including honorary co-chairs Linda and Frank Argento, who spoke about Linda’s recent battle with breast cancer, along with this year’s award recipients: Lila Bluestone, presented with the Harriet Susskind-Rosenblum Advocate’s Spirit Award; and Marilyn N. Ling, MD, recipient of the Laurie Pask Heart & Hands Award. We sold more of our signature prize-ﬁlled pink balloons than ever before. Thank you once again to Glen Moscoe Jewelers for providing the Pink Balloon Grand Prize and congratulations to the lucky winner of a pair of stunning 18kt yellow gold stud style diamond and pink sapphire pierced earrings.

Auctioneer Pam Sherman kicked off the live auction with an exciting package of hockey tickets to Buffalo Sabres and Rochester Americans games plus a signed jersey and hockey stick. The live auction also included original

Continued on page 19
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Above, some of our fabulous volunteers

Lauri Nevel
Jessica Nightingale
Patti Prato
Raquel Perez
Donna Peterson
Natalie Redmore
Mindy Sammon
Valerie Snipe
Jean Sobraske
Cecelia Spinelli
Miriam Steinberg
Karen Straub
Valerie Sulyma
Claudia Sweet
Greg Sweet
Amy Weetman
Nancy Weinmann
Connie Zeller

Ron Turk with his "score"
OUR ARTISTS

Jason Ackerman • Jerry Alonzo • Priscilla Anderson • Renee Ange • Jennifer Apetz • Eric Arcese
Frank Argento • Karen Ashbaugh • Pamela Babuscio • David Barclay • James Barclay • Pamela Bernstein
Fran Bieck • Connie Bills & Kelly Letky, Blue Muse Jewelry • Carol Ann Bosk • Virginia Braun
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artwork by Frank Argento, Albert Paley, Ramon Santiago; a beautifully handcrafted wooden baby cradle by James Barclay; one of Dr. Wendy Logan’s coveted fossil necklaces; a Wine and Spa package; a Nantucket Trip for Two; a Xerox Rochester International Jazz Festival Package; a Buffalo Bills package with suite tickets plus jerseys and footballs signed by Thurman Thomas; and a unique offering of a homemade Sweet Treat prepared by a member of the Coalition’s staff or Board of Directors and delivered to the lucky winner each month in 2014.

Never losing sight of the reason for the evening – to celebrate the breast cancer warriors among us – we accepted bids for the Coalition’s Warrior Wall. This year’s Breast Cancer Warriors raised a record amount of $15,250.

Nik Lite entertained our guests and kept them on the dance floor with their high energy performances.

We hope you will consider joining us next year for another night of celebration and reflection at the 13th Annual ARTrageous Affair, to be held on Saturday, September 27, 2014.

Members of the Research Committee visited the laboratory of our 2012-2013 breast cancer research grant winner Ryan Dawes at the University of Rochester in September. Mr. Dawes and his advisor Kelley Madden, PhD gave an informative and interesting tour. They were excited to share that their research was progressing well. To date, the data supports their hypothesis that “psychosocial stress activates the sympathetic nervous system (SNS) and hypothalamic-pituitary-adrenal (HPA) axis to augment tumor cell proliferation, angiogenesis, and immune suppression.”

In October, the Research Committee members visited 2012-2013 grant winner Ashwani Sood, PhD at Roswell Park Cancer Institute. Dr. Sood reported considerable progress on his proposal “Immunologic Targeting of PDEF (prostate derived Ets factor) Oncogene in Breast Cancer.” He has been able to generate sufficient supporting data from the work funded by the Coalition to apply for larger grants to continue his research.

KEY DATES FOR 2013-2014 RESEARCH INITIATIVE ARE:

Tuesday, December 31, 2013
Research Grant Proposals due at the Coalition.

Thursday, February 6, 2014
Proposal Review Panel meets.

Tuesday, March 25, 2014
Press Conference to announce grant winner.

The Research Committee continues to follow the work of our grant winners, past and present, with interest.

It always seems impossible until it is done.  
~ Nelson Mandela
So You Want to Get a Massage? -By Jean Van Etten, LMT

Jean Van Etten is among 18 oncology-trained massage therapists who participate in the Human Touch Initiative, a local nonprofit organization that provides people with cancer access to massage. For more information on the organization, or to find out how to participate, go to www.humantouchinitiative.org, or call (585) 672-6222.

Consider the following:

SCENARIO ONE: You've been given a gift certificate for a one-hour massage that you are excited to redeem. Upon arrival at the massage office or spa, the therapist takes one look at your health history form, is too nervous to give you bodywork, and declines.

SCENARIO TWO: Same as above but instead of declining, the therapist asks you all the right questions and proceeds to give you a great, relaxing massage.

My oncology clients have experienced both of these scenarios and it’s no surprise which they preferred. So how do you ensure that when seeking a massage during treatment or recovery you receive bodywork suitable for your condition and needs?

Here are a few tips:

Seek out a therapist trained and experienced in oncology massage. In New York State, massage therapists receive 1,000 hours of training and then must pass a licensing exam. Very few of those hours are devoted to specific training in oncology work in spite of the fact that, in Monroe County alone, an annual average of 2,122 women and 2,174 men¹ are diagnosed each year. Many thousands more are living with a cancer diagnosis. Beginning in 2012, New York State massage therapists must take an additional 36 hours of continuing education every three years. Here’s where good, oncology-specific training adds to the therapist’s massage foundation. So how do you find that person? There are several ways:

• Ask! Interview prospective therapists about the oncology massage training they have taken. Ideally, especially if you are in treatment, it should be a three-day, 24 hour class. In addition, ask about the therapist’s history of working with people in treatment or recovery.
• Check out massage websites like the Society for Oncology Massage (www.s4om.org) or the American Massage Therapy Association (www.amta.org). Each of these has massage therapist locator services that list skills and services. FYI, to be a member of S4OM, a therapist must have taken a 24-hour continuing education class.
• Have a conversation with members of your support group or cancer organizations for massage therapist references.

Once you find a therapist, have a chat before scheduling your session. Of course, questions about office location, hours and fees are important, but here are some other things to consider:

• Have a frank, honest conversation with a prospective therapist about your diagnosis, treatment and current side effects. Oncology trained massage therapists know the importance of asking more than perfunctory questions in order to design for you a safe, effective massage. Particularly important is knowledge of your current white blood cell and platelet counts. If the former is low, delaying the session would be appropriate, and in the case of the latter, massage pressure may need to be moderated.
• Also important is letting your therapist know if you have had lymph nodes under your arms, in your groin or neck removed or radiated, thus increasing your risk of lymphedema. Trained therapists will know how to give you a good massage without triggering a lymphedema flare-up.
• And finally, be sure to let your oncologist know that you are planning to include massages, particularly if it is during your treatment.

Massage therapy is increasingly becoming an integral part of care at hospitals and treatment centers because research supports the hypothesis that it is effective in reducing stress, anxiety, pain and acute fatigue². So consider trying a relaxation massage yourself.

Charlotte Johnson - By March Birthday Ladies

Charlotte was an exceptional woman, wife, mother and friend. We shared many things, including our love of family and God. We loved listening to her worship with her beautiful gift of song. We have celebrated our birthday March month annually for the past 18 years. Charlotte was too ill to join us in 2013; however, we felt her spirit in the fellowship we shared.

She lived a full life devoted to God and her family. We initially cried when we learned that our dear friend had passed away. Then we celebrated her life and legacy.

We thought of you today,
but that is nothing new.
We thought about you yesterday,
and days before that too.
We think of you when we worship,
We often speak your name with adoration.
Your beautiful voice was a gift,
with which we will always have in our heart.
Now God has you in his arms,
and we know that you are safe from harm!

Your body and your soul rests eternally in heaven next to God, we loved you dearly friend.

We love you dearly,
March Birthday Ladies

Scholarship Opportunity

The Community Foundation is offering the William Jackson Hawley Scholarship to help a student whose parent has recently died from cancer, or is undergoing treatment, to remain in school and receive a baccalaureate degree. This needs-based scholarship is offered to students residing in Monroe County who are currently attending college full time or will be graduating from high school and continuing on to college. Students must have a GPA of at least 3.0 out of 4.0 and have financial need as a result of their parent’s cancer. Applications are available on the Community Foundation’s website, www.racf.org. Completed forms must be submitted with an essay and letter of support by April 1, 2014.

Tributes Welcomed

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.

Diane Holden
Alice Jackson
Cathy Solazzo

Friends Remembered...

Would you like to write about someone you have lost to breast cancer? We welcome submissions from friends and family members and are particularly interested in stories about how they touched and changed your lives. Please send your submission (300-500 words) with a digital photograph to Pat Battaglia, Voices of the Ribbon Newsletter Editor, at pat@bccr.org. We would be happy to honor your loved ones.
Our Fundraising Friends

Standing Proud, Healthy, and Grateful

Young survivor Jennifer Orcutt, pictured on left with the Coalition’s Outreach Coordinator Lori Meath, knows that fortuitous timing and high quality medical care deserve much of the credit for her five years of health after breast cancer. But she also knows that the power of knowledge and the support of family, friends, clients, and the Breast Cancer Coalition helped her to be well as she faced surgery and uncertainty after her diagnosis.

In her own gentle and positive way, Jennifer offers that same support to women who, with amazing regularity, cross her path in her Fairport salon. Jen’s infectious enthusiasm influenced her staff at Chateau Salon and Spa to join her in hosting The Standing Proud Fashion Show on October 16 at Eagle Vale.

In spite of never having produced any event of this type, Jen and her crew arranged everything from models and hair to food and fashion. Donations and sponsorships were secured from clients and business friends, and tickets were sold.

And then, Jennifer worried. Would anyone come? Would the show go well? Would they raise the money they so hoped to donate?

By all accounts, Standing Proud was an elegant, lively event. The guests were treated to a high quality display of fashions from Stein Mart. Models whose lives had been touched by a breast cancer diagnosis shared their stories of gratitude, resilience and hope.

Jennifer’s show was indeed successful. The Standing Proud Fashion Show honored the Breast Cancer Coalition with an incredible gift of $6500.

Cheer for Charity

Nearly 50 teams from the Rochester area came together on October 12 to showcase their talents at the 10th annual Cheer for Charity. This event is hosted by the Webster Thomas Titans with a lot of help from coaches, classmates, and Titan Cheer families.

Nearly 2,000 spectators were thrilled by the two minute routines which included cheers, complex jumps, choreographed gymnastics, high flying stunts, and advanced tumbling routines. The Coalition’s Jody Dietz was thrilled to attend and express the appreciation of all who use Coalition services.

Funds raised at the event benefitted the Breast Cancer Coalition of Rochester which was designated the Titans’ “signature charity”. With the support of the enthusiastic crowds, the tremendous Titans offered a gift of $5,125.

Kick for the Cure

Zeta Tau Alpha Fraternity of RIT has once again put their “all” into the annual Zumba and Turbo kick event. In cooperation with Bounce Aerobics, over 100 energetic exercisers kicked, stepped, and danced for two hours to raise money for the Breast Cancer Coalition.

Thanks to returning organizer Miss Dylan Kohn for her hard work and to all of the kickers for their part in making a donation of $968.

Canines in the Pink

The Dog Obedience Training Club of Rochester NY (DOTCorny) held its Fall dog agility trial at Boom Towne Canine Center in Farmington in November. Dogs and their handlers were attired in pink as they demonstrated their skills for the crowd. The Breast cancer Coalition was pleased to accept a donation of $125 from this event. WOOF!

Sharing their Love

Best wishes to Amy and Adam Maciaszek for making a donation to honor Amy’s mom, a survivor. In lieu of traditional wedding favors, they gave a gift of $150 to the Coalition.

Joyce Jennings

PS. For more information about these and other programs, please contact us at info@breastcancercoalition.com or call (585) 244-1447.
Lovin’ the Links

Aerotek Staffing has a young, dynamic, high energy staff and, for several years, has dedicated an annual Golf Tournament fundraiser to a local charity. Each year, based on a “personal connection” to staff, a charity is chosen. This year, the combined Buffalo/Rochester event benefitted our Coalition. Avid golfer and organizer Michael Finnegan has fine tuned his tournament to run like a well oiled machine yet manages to make it a lot of fun for all involved. Thanks to Mike and all of the Aerotek staff for their generous gift of $4903.

Learning More Than the Three Rs

Many local school groups raised funds for the Coalition. It seems there is no end to the quirky fun ways young people can think of to raise money!

Unfortunately, many are personally acquainted with the difficulties a diagnosis of breast cancer causes for the entire family. We thank these young people for their caring and commitment.

- **Rochester School for the Deaf** held their annual Denim Day Fundraiser and raised $205.
- **School of the Arts**
  - Girls’ Volleyball Teams held basket raffles and collected donations from staff and students and gifted $472.
  - A basketball game during **U of R Alumni Weekend** raised $580.
  - Co-ed students at **MCC** challenged staff to a touch football game and raised $47.
  - **The Irondequoit High School Service Club** sent an unexpected gift of $100
  - **Greece Arcadia** took Homecoming to the max with a Homecoming Carnival! The Freshman hosted a bounce house, the Sophmores a giant inflatable slide, the Juniors a blow up obstacle course, and the Seniors set up a dunking booth and convinced school administrators to get wet for the Coalition. The Carnival raised $300.

Hillside Happenings

- Hillside student, **Becca presents Holly Anderson with their generous donation**

Under the guidance of Claudia Herman, some 75 students and 40 staff members pooled their resources into a creative effort for the Coalition. They baked, sold bracelets and magnets, and created cards for sale to all who work, learn, and visit the Hillside Center. They proudly presented a check to our Executive Director, Holly Anderson, in honor of October’s breast Cancer Awareness month totaling over $308. Nice work, all!

Donations are BOOMing

Crossfit aficionados are a determined lot and put their best effort into anything they do. This is certainly apparent when their considerable strength and get-it-done attitude is focused on a charitable fundraiser. The Breast Cancer Coalition is once again the grateful recipient of Webster’s Crossfit Boomtown October event. With support from generous sponsors the lifters, rowers, runners, and climbers of Boomtown donated $1,825. Great work!

Working Toward Wellness

With emphasis on healing and returning to wellness, our friends at **Callan-Harris Physical Therapy** offered a Wellness Fair on September 21. Donations were accepted and generously directed to the Breast Cancer Coalition. Thanks, CHPT, for your gift of $1290.
STRIKE!

Wonderful Windjammers Grill, winner of Rochester ROCS Best Wings 2013, has done it again! Each year, the Breast Bowl gets bigger and better under the guidance of Doug Phillips and owner Lee Selover. Dewey Lanes hosted this year’s event and a great time was had by all. Nice work Doug, all the folks at Windjammers, and all the benevolent bowlers for a wonderful contribution of $4,420.

One Stitch at a Time

Inspired by the Marie Bostwick novels that center on the lives of women dedicated to quilting, Michele Sanderson was moved to share her talents to benefit women dealing with breast cancer. With the design help from the Webster Quilt Guild and fabrics from Café Sewciety, “Power of Pink” was created. This stunning queen sized quilt was raffled in October. The lucky winner is Cathy Catcagno and tickets sales resulted in a gift of $876 for the Coalition. Additionally, when Michelle saw the enthusiasm her creation garnered, she created and donated two more pieces to our annual Artrageous gala!

95 Miles of Autumn Adventure

A crisp, sunny Saturday in September made for many happy riders at the 6th annual Cycle Stop “Dice & Bust” motorcycle run. New this year was a concurrent “bash” at Nashville’s where non-riders and returning riders enjoyed entertainment, food, 50/50, and an amazing and very successful basket raffle.

Cycle Stop enlisted the sponsorship of local companies once again and was gratified with the enthusiastic response. In all, thirty-two local businesses and individuals donated to make this D & B Run the most successful yet. A check for $4,590 was presented to the Coalition, bringing the six year total to an amazing $19,000!

The Heart of the Matter

Local Playwright Bradley Craddock tackles the flood of emotions his character “Helen” faces as she is diagnosed and treated with breast cancer in his original work, Pink Ribbons. Helen is surrounded by friends, a medical team, and a loving husband, yet finds that it is up to her to glean the tools she needs for her journey. The play debuted during the Fringe Festival and Brad hopes to offer it locally again. Ticket donations totaled $700 and were directed to the Coalition. Any future performances will be publicized on our website. Don’t miss it!

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We were gratified by the many individuals and businesses who chose the timing of this national campaign to direct their efforts LOCALLY to the Breast Cancer Coalition of Rochester. So many of these donors mentioned that they are pleased to have their gift used for the research, advocacy and supportive networking of women and their families here in the Rochester area.

- Upstate Vape Smoke Shop, $400
- ROC the Barre Fitness Studio, $400
- Genesee Valley Pennysaver, $227
- AME Zion Men’s Ministry, $200
- Lon Lockwood Electric, Webster, $265
- Charlotte Harbortown Senior Living, $254
- Blossom North and South Care Facilities, $211
- Scrapbook Creations/ Keri Gray, $255.85
- Gastroenterology Associates of Rochester, $110
- Dr. Joseph Viola Dental, $136
- Wegmans Controllers Department Pink Day, $227
- Greece Public Library Denim Day, $105
- Nolan’s On the Lake Canandaigua, $300
- DePaul Horizons (pie throwing contest), $67
- XPEDX Packaging Jeans Days, $76
- Perinton Republican Committee, $150
- Rochester Management, Norton Village apartments, $100
- Stantec Consulting, $200
- Magnolia's Restaurant staff, $250

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Donations ending September 30, 2013

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 September 30th will be included in the spring newsletter.) We apologize for any errors and/or omissions on our donor pages.

### In Honor of:

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<td>Karen Morris</td>
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<td>Mary Carafos</td>
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<td>Chrysa Charno</td>
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<td>Carol Serio</td>
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<td>Wedding Guest of</td>
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<td>Taylor Smith &amp; Blair Veenema</td>
<td>Bernie Todd &amp; Clifford Smith</td>
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<td>Susan Ames</td>
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<td>Buffalo News</td>
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<td>Jackie Capparelli</td>
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<td>Mary Caserta, M.D.</td>
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<td>The Castro Family</td>
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<td>Damian Krysan, M.D., PhD.</td>
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<td>Faculty &amp; Staff of the Industrial &amp; Systems Engineering Dept. - RIT</td>
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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)
- Blank CDs and DVDs (writable)
- Computer paper, white
- Fleece throws/blankets for our PALS Paks
- Foam core (new)
- Gift cards: Wegmans, Tops, DiBella’s, Staples, Target, Barnes & Noble, Michaels, pizza, etc.
- Journals
- Note cards
- Sleeping masks (lavender or unscented only)
- Thank you cards
- Paper products: napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam products)
- Large glass display case for merchandise
- Tablecloths 70x90 and 70x108 (white, sage green, pink)
- New, unused fabric
- Poly-fil stuffing for pillows

Making It Easier to Ohm

Recently, the Coalition received a gift that will make instructor Susan Meynasdesy’s Gentle Yoga classes even more accessible for anyone dealing with the challenges of cancer.

Class participant Lee Alger has generously donated sturdy cork blocks and cheerful Mexican-style cotton blankets to our Healing Arts program, providing comforting props for class yogis.

These great materials will be appreciated by many, for many years. Thanks, Lee for such a kind gift!

Sharing the Caring

The good-hearted students of the Charles Finney School have once again chosen to donate items for our PALS packs. A small but lively crew under the direction of Dr. Peter Burch visited the Coalition to drop off items such as journals and blankets, as well as office supplies. The effort is part of the Finney School’s ongoing Project Compassion. We really appreciate the giving spirits of these young people.

Gifts in Kind

**Friends’ Circle $50-$99**

- Thomas Balk
- Michelle Bizari
- Catherine Brice
- Roberta Buttino
- John Clifford
- Maryanne & John Dee
- German Brothers Marina
- James Ingalsbe
- Susan Mondi
- William Monteverdi, Jr.
- Carol Robinson
- Jane Steinbugler
- Donna Torpey
- Beverly Zimber

**Contributors’ Circle $1-$49**

- Anonymous
- Carol Brown
- Tamara Brown
- Angela Cataldi
- Irene Delgado
- Joyce & Morrey Goldman
- Greater Beneficial Union District 790
- Nancy Hackett
- Joanne Kelsey
- Lisa Korneliusen
- Suzanne Lanyak
- Cheri Levine
- Josephine Marinetti
- Geraldine Muoio
- L. Edith Parris
- Elaine Quirin
- Ridge Culver Professional Fire Fighters Association, Local #4176
- Clare Shaffer
- Particia Sharkey
- Todd Stevens, Jr.
- Cathy Vajentic
- Christine Versteeg
- Josephine Wood-Widener

**Gifts in Kind:**

- Scott Adair
- Julie Beckley
- Cheryl Bovard
- Marlene Caroselli
- Linda Gaylord
- Marcia Gitelman
- Julie Overbeck
- Susan Reedy
- Judi Stewart
- Cyndi Vassallo
- Amy Weetman

Wells Fargo Home Mortgage - ‘Tee’d Off at Breast Cancer - Hole Sponsor

Joyce Wichie

Luann & Timothy Young

**Gifts in Kind**

**Sharing the Caring**

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- A cure for breast cancer
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- Large glass display case for merchandise
- Tablecloths 70x90 and 70x108 (white, sage green, pink)
- New, unused fabric
- Poly-fil stuffing for pillows
Compassionate Care Act continued

The Breast Cancer Coalition of Rochester is joining with organizations such as New York State Nurses Association, American Academy of Family Physicians and the Hospital and Palliative Care Association in support of the Compassionate Care Act. A 2013 poll by Siena Research Institute found that 82% of New Yorkers support the passing of a law that allows for medical marijuana use by seriously or terminally ill people if prescribed by a physician. Some breast cancer patients have shared their frustration in being advised by some doctors to obtain marijuana on their own to manage pain and nausea. We believe it is in the best interest of cancer patients and others to have a medication that is reliably produced and legally obtained.

To learn more, visit www.compassionatecareny.org, or search for Assembly Bill A.6357-A (Gottfried) and Senate Bill S.4406-A (Savino) at www.assembly.state.ny.us/leg/.

Petition continued

Enjoy the Breast Cancer Coalition Library
What is a peer advocate? How can they help the newly diagnosed?

A peer advocate is someone whose words and actions uphold and stand for a cause or a person. Peer advocates offer support to others based on similar life experiences. For participants in our PALS Program, those experiences center on having been diagnosed with breast cancer.

This life-altering diagnosis touches all aspects of a person’s life. Immediate medical needs must be addressed by a health care team. There are treatment decisions to consider while learning the ins and outs of the landscape of breast cancer. In most cases, families and friends provide a strong safety net of support. Yet some aspects of life altered by this disease can often be best addressed by someone who has walked a similar walk; who has faced the same surgeries, side effects of treatment, uncertainties and fears. Enter the PALS Mentor.

Although most people can say they know someone who has been affected by breast cancer, not everyone facing this diagnosis can say they know someone similarly diagnosed. As the newly diagnosed carry forward into the unknown terrain of treatment and survivorship, connecting with someone who has “been there” can be a powerful experience. Our peer advocate mentors are trained to provide empathy and down-to-earth practical advice that can complete the circle of support for those facing breast cancer.

In turn, PALS can be a positive experience for mentors, many of whom have shared with me how meaningful it is to be in a position to help another human being. While deriving some satisfaction from the arrangement isn’t a motive for reaching out to others, it is a very real side benefit. It is quite an honor for me to be in a position to help another human being.

Whatever you are newly diagnosed with breast cancer, have moved beyond active treatment, or are anywhere in between, there is a place in the PALS Program for you. Contact me at pat@bccr.org to find out how to receive support or offer your own to someone else.

A Personal Journey continued

is the possibility of dying from cancer that I cannot wrap my head around, an idea to which I object. I feel that my time has not yet come. However, I know that I have no say in that. My preference in this matter is irrelevant.

The difference from being in or out of the woods is the likelihood of a distant future, is the realm of possibilities. The odds have changed against my favor. The treatment options for a potential cure are exhausted, at least for the time being. Future treatment, if necessary in case of a recurrence, is likely intended to be palliative. On the other hand, whatever the odds are for any one woman, it comes down to one or the other: the cancer returns or it does not. 50/50; this leaves room for hope. New treatments are emerging faster and faster. There may be a cure tomorrow where there is none today. This too leaves room for hope.

How does one handle being stuck in the woods? There is no manual, no preparation. There are no tips and tricks. I am lucky to have support from my husband and my teenage daughters, my friends, and the people I work with. Though I am not religious, I am deeply touched by those many who include me in their prayers. As far as my personal coping skills are concerned, I just do what I have to do and take it one day at a time. It is like everything else in life for me, or anybody for that matter. We all play the cards we are dealt as well as we can. I have to learn better still how to make every day count. I am hoping for the best and trying to brace for the worst. With time, I’ll adapt to this new reality. As part of it, I also want to be with other women of the woods.
Wednesday, February 26, 2014
Alissa Huston, M.D. and Luke Peppone, Ph.D.
Vitamin D, Dietary Supplements
and Breast Cancer
7:00 - 9:00pm

Wednesday, March 26, 2014
Kate Winnebeck, L.C.A.C.P.
New York State Pollution Prevention Institute
Clean, Green & Healthy:
Choosing Safer Household and Personal Products
7:00 - 9:00pm

Friday, April 4, 2014
The 11th Annual
Cindy J. Dertinger Advanced Breast
Cancer Seminar:
Tools for the Journey
This event held at the Memorial Art Gallery
RSVP Required, 473-8177
1:00 - 5:00pm

All events unless otherwise noted are at:
THE BREAST CANCER COALITION OF
ROCHESTER
840 University Avenue
(Between Culver and Goodman)
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

$5000 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

Gifts of $100 + receive a complimentary Comfort Heart.

Breast Cancer Coalition of Rochester
840 University Avenue Rochester, New York 14607
585.473.8177 • 585.473.7689 fax
info@bccr.org • www.bccr.org

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840 University Avenue Rochester, New York 14607
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Voices of the Ribbon
Published Quarterly by the Breast Cancer Coalition of Rochester
Tel. 585-473-8177 • Fax 585-473-7689 • E-Mail: info@bccr.org • Online at 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.

MAY 5.11.14
Genesee Valley Park
MOTHER’S DAY Pink Ribbon Run & Family Fitness Walk

FOR MORE INFO OR TO REGISTER ONLINE VISIT WWW.BCCR.ORG OR CALL 585.473.8177