As a new Mother’s Day dawned, hundreds of volunteers and thousands of runners, walkers and supporters gathered at our new “home”, Genesee Valley Park, for the Twelfth Annual Pink Ribbon Run and Family Fitness Walk.

The new location appeared to be a big hit with the participants. Walkers and runners alike enjoyed the new routes that provided scenic views of the Genesee River and historic Erie Canal. Lilac and other ornamental trees were in bloom and the park provided a beautiful backdrop for the sea of bright pink t-shirts and other accessories donned by women, men, children and even dogs...all drawn together to do their part to fight breast cancer and support those who have fought the battle.

Bright sunshine helped warm the happy faces despite chilly temperatures and a brisk wind. The nice weather prevailed until the last race prize was announced and a light rain began to fall.

-By Cindy Dykes

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Our Executive Director

Holly Anderson

“I wish there were an organization like yours for my cancer.”

The Breast Cancer Coalition has strived over many years to be a warm and welcoming place for those in the aftermath of a breast cancer diagnosis. Our programs and services have been developed so that there is almost always “something for everyone”: programs such as Breast Cancer 101; our PALS (Peer Advocates Lending Support) Project; support and networking groups for early and advanced breast cancer survivors; our Friends and Family group; the Healing Arts Initiative (Yoga, Qi Gong, Tai Chi, Fluid Motion, Pilates); the Voices and Vision Writing Group; and our more informal groups such as Brown Bag Friday, Book Club, and Young Survivor Soirees. Our Advocacy Committee tackles legislative issues, and we turn our attention to prevention of breast cancer and halting its progression with our Research Committee. We evaluate our programs regularly. We appreciate feedback of all kinds from those who utilize our services. We listen and adapt wherever we can.

“I wish there were an organization like yours for my cancer.”

From time to time we are visited by those with a different type of cancer. Often they are picking up information for a friend or family member just diagnosed with breast cancer. Sometimes they attend an evening seminar because the topic for that particular evening appeals to those with any cancer type. In all cases, we listen. In many cases, we are able to refer them to another community organization, a hospital support group, or a national resource. Most of the time, we can find something to meet their needs.

“I wish there were an organization like yours for my cancer.”

But hearing the above refrain over and over again, especially for a cancer that relates in many ways to breast cancer, weighs on us. This has been the case for Ovarian and GYN cancers, especially in the aftermath of Angelina Jolie and the Supreme Court ruling that overturned corporate rights to patent our very own genetic material: BRCA I and BRCA II.

In April 2012, we began to consider offering some of our programs to those facing Ovarian and GYN cancers. First, as we do with all new program ideas, we began a community assessment to see what might already be out there. We knew of a group existing at Gilda’s Club so we reached out to two of the founding members. From an oncology social worker at Highland Hospital, we learned of an emerging GYN Oncology support group on track to begin that fall at the American Cancer Society. From time to time we are visited by those with a different type of cancer. Often they are picking up information for a friend or family member just diagnosed with breast cancer. Sometimes they attend an evening seminar because the topic for that particular evening appeals to those with any cancer type. In all cases, we listen. In many cases, we are able to refer them to another community organization, a hospital support group, or a national resource. Most of the time, we can find something to meet their needs.

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During all of this, we knew that we needed to speak with the Ovarian and
Life was a whirlwind for Astria DiLorenzo through the late months of 2011. The wedding of one of her three sons was a high point for her entire family. Afterwards, Astria decided it was time for some self-care, and scheduled her yearly checkup with her OB-GYN. At that appointment, it was discovered that ovarian cysts, which had been monitored for some time, were growing larger. Astria and her doctor decided that an ultrasound might help them gain a clearer picture of what was going on. But between the time of this decision and the ultrasound, the cysts grew even more.

Another decision loomed; a surgical one. Astria opted for a hysterectomy and removal of the ovaries. The procedure was done in January of 2012, and the subsequent biopsy revealed that the cysts were benign. Astria was ready to move forward, grateful in the knowledge that the cysts would never bother her again.

Shortly after this, one of Astria’s girlfriends found a lump in her breast. With Astria’s encouragement, she went for a mammogram and biopsy. When the diagnosis revealed the growth to be benign, both women felt enormously relieved. Then another girlfriend was diagnosed with colon cancer. As Astria supported and assisted her friends, a small voice in her ear grew clearer. It had been nine years since her last mammogram. It was time to schedule some screenings, including a colonoscopy and mammogram.

Astria called the breast screening center, and was pleasantly surprised to learn that, due to a cancellation, there was an opening for her two days later. She walked into the center at the appointed time, expecting a routine visit. The mammogram revealed an area of concern, and more images were called for. Afterward, the radiologist explained to Astria that she had detected what seemed to be a suspicious area. An ultrasound was performed, which strengthened the radiologist’s suspicions. The area in question was biopsied, and an MRI was scheduled for two days later. Through all of this, Astria’s lump remained impalpable – it could not be felt by anyone who examined her, or by Astria herself. “Even after they knew it was there, no one could feel it – it was that tiny,” she recalls. The biopsy result confirmed the radiologist’s suspicions, and Astria was diagnosed with breast cancer.

The next step was to consult a surgeon, who, upon examining Astria and looking over her diagnostic information, agreed that the area involved was very small, and recommended a lumpectomy. Two weeks later, the tumor was removed, along with a small area of tissue surrounding it. Astria was well on her way to healing when the surgical pathology report came back, bringing a bit of good news and an unexpected twist in the road. The margins of the area removed during surgery were clear – that is, they were free of any cancerous cells. The tumor had been completely removed and no further surgery would be needed. Also removed were four lymph nodes. One of these nodes was found to be cancerous. Astria’s cancer, though small, had begun to move beyond the original area of the tumor.

This development brought a

“Travel is more than having a destination in mind; it’s discovering a place in your heart you’ve never been before.” - Mark Amend

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“Advocacy drives research”, a statement by researchers at the 2012 Washington DC Summit, exemplifies the importance of what trained and passionate advocates can accomplish through organized effort. Advocates help define issues and determine priorities; they address these issues with legislators and policy makers and, in a best case scenario, they help design and implement solutions.

Long before breast cancer became a part of my own journey, I became a health care advocate while a medical case manager working with some of the earliest HIV/AIDS patients. My own breast cancer diagnosis in 1997 made me a committed breast cancer advocate. While breast cancer is very much on society’s radar screen, there remains an ongoing need to make people aware of how many women, men and families are impacted, and to keep access to care in the forefront of political importance. In a world consumed with economic challenges, health care standards and research funding need consistent, focused attention. In a sea of pink ribbons, we need to further the organic awareness that both the physical and social environments play a role in how cancer happens, is detected, and is treated.

The Coalition has built strong and effective relationships with local legislators, and has had an important voice in local and state issues. The Monroe County Pesticide Neighbor Notification Law of 2006, which requires warning prior to pesticide spraying, was passed through consumer efforts in which the Coalition played a part. Legislation to limit the use of BPA, a known toxin, in an array of products on the market was the direct result of advocacy work. And the list goes on …

The Advocacy Committee meets on the fourth Thursday of every month, but being a committee member, while welcomed, is not the sum total of your chance to be heard.

Can you play a role? Absolutely. It’s as simple as a phone call or an email to support a policy or a bill, or being present at a meeting or a function (where speaking is not a requirement). Advocates write articles, take part in meetings, and help educate others. We also travel to Albany on a biannual basis, a one day trip in which everyone is invited to join; in addition, a delegation attends the national conference and Lobby Day in May every year.

Two national priorities that are in process:

The Accelerating the End of Breast Cancer Act: H.R. 1830, S. 865: First introduced last year, this bill was re-introduced in the current Congress and calls for the establishment of a Commission with the mission of helping end breast cancer by January 1, 2020 via strategic research planning and systemic changes, such as pushing for pharmaceutical transparency. Our seven regional members of the House - Chris Collins, Richard Hanna, Brian Higgins, Dan Maffei, Bill Owens, Tom Reed and Louise Slaughter - and New York’s two senators, Kirsten Gillibrand and Charles Schumer, have all signed on as co-sponsors. Please call or email your rep and our senators to thank them, and encourage them to increase sponsorship among their peers. breastcancerdeadline2020.org

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$150 Million for the Department of Defense (DoD) Breast Cancer Research Program for FY 2014:
These monies, first budgeted in 1992, must be re-appropriated every year. This year, the “ask” was $120 million from the House and $150 million from the Senate. All our representatives have signed on; however, this amount will almost certainly be cut due to the Sequestration. Again, please call or email your representative and thank them for their support. View Congressional voting records at: thomas.loc.gov/

In New York State:
Call for Scientific Standard Health Impact Assessment of Hydrofracking: Hydraulic fracturing (hydrofracking) is a critically important issue. The New York State Breast Cancer Network (NYSBCN) supports a comprehensive, independent Health Impact Assessment to be done prior to the governor’s decision about whether to allow hydrofracking in New York State. At least 25% of the 600+ chemicals used in fracking are linked to cancer; another 37% interfere with human hormone systems and have been implicated in numerous cancers. If your New York State Assemblyman and New York State Senator have not supported this Health Impact Assessment, urge them to do so.

www.assembly.state.ny.us
www.nystatesenate.gov

Who are your representatives? In Monroe County, contact the Board of Elections at 753-1550, or online at www.monroecounty.gov/elections

Make Your Voice Heard continued

In 1998, Terri Schmitt, a mother of five and Town Supervisor of Rush, was diagnosed with breast cancer. This powerhouse of a woman connected with the Coalition, and soon stepped into a leadership role in the fledgling organization. As the group struggled with difficult questions, Terri’s professional expertise was instrumental in helping to provide answers that would guide the formation of the Coalition’s basic structure. Unfortunately, Terri’s cancer recurred in 2001, and a year later, at the age of 43, she died of the disease.

But the organization she helped find its wings lives on. Terri believed passionately in the potential for legislation and public policy to affect, in a positive way, the lives of those who have been touched by breast cancer. In her honor, we hold the Annual Terri Schmitt Legislative Reception, and Wednesday, August 14, marks the tenth celebration of this event.

Members of the breast cancer community and the general public are invited to mingle and chat with lawmakers from the local, county, state, and national levels. In our area, we are fortunate to have legislators who are supportive of issues such as health care and the environment, that impact those affected by breast cancer. The Legislative Reception provides a unique opportunity to put names and faces behind the statistics that lawmakers must deal with.

Personal experiences are powerful. Please come and share your story with those in a position to enact laws for your benefit. Mingle and enjoy some light refreshments with others similarly affected. Breast cancer doesn’t discriminate - we are all on equal footing in its presence and aftermath. It is ultimately a human experience that binds us all as we strive for its eradication. »
DCIS – Ductal Carcinoma In Situ – represents breast cancer at its earliest diagnosable stage. Often called Stage 0 disease, it consists of abnormal cells in the lining of a milk duct. Because there is no spread into the surrounding tissues, DCIS is a non-invasive condition. The frequency of this diagnosis has increased markedly in the United States since the use of screening mammography has become widespread, with more than 50,000 new diagnoses each year. For most who receive this diagnosis, surgical removal of the area is likely to be sufficient. But DCIS can, in some cases, recur after it has been removed or progress to become invasive cancer if it is left untreated. Because it is difficult to predict which cases might recur or progress, all cases are treated as if they might. For most, this means the addition of radiation therapy.

OncotypeDX is a diagnostic test that first became available in 2004. It is used in early-stage, estrogen receptor positive breast cancer to measure the activity of twenty-one specific genes taken from a sample of tumor tissue. This analysis provides important information about how likely the cancer is to grow and to respond to treatment. The results are summed up in a Recurrence Score, which is a number between 0 and 100. Lower scores indicate a lower risk that the cancer will return, while higher scores point to increased risk and the possible need for additional treatment to reduce that risk.

It is crucial to assure the health and longevity of those who are diagnosed with DCIS. It is also important that patients receive only the treatment they need to effectively deal with their situation. The use of modified OncotypeDX testing methods to determine recurrence and progression risks in DCIS is being explored. Researchers at the Albert Einstein Medical Center in Philadelphia, PA were able to develop an OncotypeDX scoring system specific to DCIS. A group of 327 patients was chosen to test the accuracy of the new system. Those whose scores fell into the low-risk range experienced a 10.6% rate of recurrence within 10 years of diagnosis. Those in the moderate risk group had a 26.7% recurrence rate, while the high risk group recurred at the rate of 25.9%. Those who went on to develop invasive breast cancer in the low, moderate, and high risk groups did so at the rates of 3.75%, 12.3%, and 19.2% respectively.

The OncotypeDX DCIS Score appeared to be predictive of both recurrence and progression, while the standard Recurrence Score did not. However, neither score was predictive of adverse incidents in the unaffected breast. Some of those who participated in the study were on tamoxifen therapy while others were not, and the results were consistent in both groups.

The authors of the study conclude that OncotypeDX DCIS Scoring represents a potentially valuable tool in determining which DCIS patients stand to benefit from adjuvant radiation therapy, while singling out those who can be treated by surgery alone. But their work was conducted with a relatively small and select group of patients. They agree that additional studies using a broader base of patients will be needed first.

2. http://jnci.oxfordjournals.org/content/early/2013/04/30/jnci.djt067.full

By Pat Battaglia

A New Tool in the Works for Predicting DCIS Recurrence

For more information call 585.473.8177 e-mail cindy@bccr.org, or visit our website at www.bccr.org

ARTrageous Affair

BREAST CANCER GALA

SEPTEMBER 28, 2013
A Surgeon’s View:  
Ten Major Developments in Breast Cancer Since 1981

By Pat Battaglia

From the time she began to practice surgery in 1981, Doctor Ruth Hetland’s interest in breast cancer grew steadily as increasing numbers of patients turned to her with the disease. Having devoted considerable personal time to the study of breast cancer treatment, Dr. Hetland recently made the decision to close her general surgery practice and devote herself entirely to breast surgery.

Dr. Hetland was the speaker at our April, 2013 Evening Seminar entitled Updates and Trends in the Surgical Management of Breast Cancer. She took this opportunity to look back on her career and presented the group with a list of her own Top Ten Developments in Breast Cancer Since 1981.

To borrow a phrase, we’ve come a long way, baby.

Ruth Hetland, M.D.’s Top Ten Developments in Breast Cancer Since 1981

10. The maturation of chemotherapy. Better medicines are available, and we have become better at deciding who will benefit from chemo.

9. The development of breast reconstruction. New surgical techniques have been developed and refined through the years, offering women a range of options.

8. Refinement of the technique in partial mastectomy. The technical term for any surgery that removes the cancer without removing the whole breast, partial mastectomy is more commonly known as “lumpectomy”. Dr. Hetland often uses the latter word with her patients because it is friendlier and people are familiar with it, but cautions them not to be concerned when they see “partial mastectomy” on their surgical paperwork. Whichever term you prefer to use, the use of imaging technologies such as MRI to pinpoint the tumor during these procedures has greatly reduced the need for re-excision of the surgical site.

7. Advances in mammography. In addition to the refinement of traditional mammography, digital and three-dimensional mammography technologies are enabling radiologists to zero in on areas of concern with greater accuracy.

6. Advances in breast ultrasound. Used most frequently to complement other screening tests, ultrasound has become an important tool in the arsenal for detecting breast cancer.

5. Core needle biopsy and stereotactic core biopsy. These techniques employ the use of imaging, such as ultrasound or x-ray, to help ensure the accuracy of tissue samples taken for diagnostic purposes.

4. MRI. Used primarily to screen high-risk women, to gain more information on a suspicious area found during mammography, or in some cases, to monitor for recurrence after treatment, MRI has become a very important diagnostic tool.

3. Sending patients home with drains in place. Surgical drains are left in place for a length of time that varies greatly from one patient to the next. Patients and caregivers are now taught the simple management of these drains, allowing them to return to the comfort of home sooner than had been previously possible.

2. Prognostic factors and genetic counseling in breast cancer treatment. The increased understanding of factors such as the HER2 growth factor, hormonal receptors on tumor cells, and the availability of genetic counseling (and, in some cases, genetic testing), has helped inform the surgical decisions of many who have faced a breast cancer diagnosis.

1. The sentinel node biopsy. The development of nuclear medicine techniques to locate the first few lymph nodes into which a tumor drains, and the removal of these nodes only, means that many are spared more extensive procedures, with virtually equal survival benefit.

And, Dr. Hetland says, the biggest thing we have yet to learn is…. WHAT CAUSES BREAST CANCER? We have indeed come a long way, and the end of the road is not yet in sight. Thank you, Dr. Hetland, for your work and for sharing your insights with us.
I lived cancer free for seven years after my initial breast cancer diagnosis. Then, in 2011 I had two kidney infections in one month, the second of which landed me in a hospital in France, where I was on vacation. I don’t speak French. My husband speaks a little, but certainly not medical French, so there were a lot of charades going on. The doctors got the message across that I was to follow up with my own doctor. When I got home, I had blood tests and scans, and eventually learned that my cancer had metastasized.

With hopes of handling it naturally, I immediately checked into a health institute in West Palm Beach, Florida, where I learned about the raw vegan lifestyle, had non-invasive treatments, and detoxed. Although I was committed to the regimen, the diet wasn’t for me and I became very ill. I was in the hospital for ten days to get my pain under control. I was too sick for chemo and dropped to 90 pounds. With intravenous feeding pumped into my port nightly for six months, I gradually got well enough to start chemo.

There are some significant differences between my experience with the first diagnosis and the second. My sense of isolation was greater the first time. In 2004, I didn’t bond with my medical team, and everything felt so rushed. My friends were in shock. I wish someone had given my husband the book, Breast Cancer Husband, by Marc Silver. That might have helped.

But in 2012, my husband stayed by my side day and night, especially in the hospital. Friends and family came from out of state and overseas to stay with me for weeks during the worst of my illness. Others cooked for me and found us a housekeeper. I was very, very grateful for that. I didn’t have to worry about anything but getting better.

The first time they put together a meal train for me, I cried - I didn’t want to be the sick one. But learning to accept help lets others feel useful. I learned humility. It lessened my sense of isolation, and I gained an appreciation for the fact that I couldn’t do it all alone. It was a difficult lesson, but it enriched my life.

Another difference between the first and second diagnoses is that there is no tried and true path when cancer has spread. The first time, a strict regimen of aggressive treatment was followed. I looked forward to getting back to my “real” life when treatment was over. This time, my doctor is more like a partner. There is a lot of trial and error going on, and I play an active role in my care. Treatment is less aggressive and has fewer side effects because the aim is to control the disease for as long as possible.

Emotionally, a metastatic diagnosis is staggering. You can’t prepare for it because it manifests itself in

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unexpected ways. The symptoms and side effects of treatment are a part of your life, and it’s necessary to learn to cope with their permanence. Palliative care is useful for this.

The first time I called my home nurse and they answered the phone, “Palliative care,” I was devastated. I thought that meant that they couldn’t do any more for me. Now I know that palliative care focuses on alleviating symptoms of chronic illnesses, while receiving treatments that may extend your life.

My medical team is a big part of this experience. My oncologist patiently answers my questions and understands that quality of life is the most important thing to me. In the past year, my care focused on pain and symptom relief, optimizing the way I function, and assessing the needs of my family.

My doctor and I deal with the symptom that’s bothering me most. At one point, I had lymphedema in my legs. They were so large it was hard to bend them. A friend wanted to take me for a ride in her little sports car and I couldn’t get in! When my doctor heard this story, she wrote orders for a lymphedema therapist to come and teach my husband and me how to massage out the fluid. It was very effective, and lymphedema doesn’t bother me anymore.

Last fall, my husband and I wanted to visit his mom in England. It meant a lot to me to go. The doctor said it was fine to go off chemo for a few weeks. At the time I was on liquid nutrition for twelve hours each night and my doctor suggested that I could go off that while I was gone. I can hardly express my happiness at the sense of normalcy that trip gave me.

Nobody knows what’s going to happen tomorrow – nobody. I walked around for a couple of months after my diagnosis feeling my death was a certainty in the next couple of years. My emotional well-being was threatened. But I came to understand that everyone lives with uncertainty. Most people don’t think about it consciously. We learn to live with uncertainty, as do people who have lost their jobs or are going through a divorce. And we must keep a little hope alive that our cancer could go into remission or become stable.

My biggest challenge now is to get back in shape. I started gentle yoga and a short exercise regime, but it exhausts me so far. I’m hoping to see some improvement soon.

I give myself lots of time to rest and I indulge in complementary treatments like acupuncture, reiki, and qi gong. They give me a better sense of how my body is handling the medical treatments. They help me cope with chemo brain, and even lower my blood pressure.

Although I lead a full, wonderful life, I mourn the loss of control over my health. My metastatic cancer diagnosis has forced me to re-evaluate what I’m capable of and what my priorities are.

My goal is to move ahead and enjoy the uninterrupted periods because I am very much alive right now. Each of us affected by this disease has the ability to give each other strength to stand up to this disease. And indeed, if we look back on our lives, the unexpected challenges and detours have the greatest impact and are the most inwardly transformational.

“Healing can be found even in the presence of disability, disease and death. Wholeness consists in finding a meaning in any human situation; rather than going where one likes, one likes where one is going.” —Beth Lenegan, PhD

“Uncertainty is the refuge of hope.” —Henri Frederic Amiel
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 Support Group
We invite those who have a friend, partner, or family member who has been diagnosed with breast 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.

Common Ground: Living with Metastatic Breast Cancer
Designed to lend support to those living with metastatic breast cancer, this group is led by Peg DeBaise, LMFT, and meets on the 2nd and 4th Thursdays of the month at 9:30AM. There is no need to RSVP – just come when you can.

RISE I & II
RISE I is for survivors under age 50 and meets on the first Friday of each month at 6PM. RISE II is for survivors 50 years of age and older, and meets on the first Friday of each month at 2PM.
Both groups are open to all female survivors regardless of marital/partner status or sexual orientation.
Peer Advocates Lending Support: P.A.L.S. SM

The concept of this program is simple: individual breast cancer survivors reach out to those who are new to the disease, providing a foundation of caring through one-to-one contact, helping them connect to needed resources, and instilling confidence in the face of a difficult situation. 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.

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 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.

Voices & Vision: A Writing Workshop for People with Breast Cancer

This well-loved group gives people with breast 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 breast cancer survivors. Advance registration is required.

Young Survivor Soiree

A young survivor may identify with those who have been dealt a breast cancer blow in the midst of a career climb, or while raising children, or perhaps with those whose family plans have been derailed by breast cancer treatment. Four times a year, we hold our Young Survivor Soirees as an informal way to meet and network with others who have faced a similar journey. The next soiree will be on September 20th. Please call if you would like to be added to the invitation list.

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 are held in four-week sessions on Saturday mornings throughout the year.
While dealing with the aftermath of a breast cancer diagnosis is certainly overwhelming for the newly diagnosed, it can have a profound effect on those who love her or him, too. There is so much information to process. And there are multiple appointments with different medical providers. Making sure your loved one is comfortable and well-cared for during treatment can be a challenge. Preparing meals is another hurdle. If there are children involved, keeping their routines as ‘normal’ as possible can be next to impossible. To top it all off, friends and family members need to take care of themselves so they can be at their best for the newly diagnosed person. Often, when a loved one is given the news that they have breast cancer, their friends and/or family members may find themselves in need of support, but simply don’t know where to turn.

Here at the Coalition, we offer a group specifically designed to provide support and guidance to friends, family members and/or caregivers. This group, led by Peg DeBaise, a licensed therapist, meets on the second Thursday of each month from 5:30-7:00 pm. Spouses, sisters, brothers, mothers and friends gather to share experiences and support each other as they help their loved one deal with cancer. It’s an opportunity to talk with others who “get it” in a safe and comforting place. Rest assured that there IS support for friends and family members. You don’t have to face this journey alone. We at the Coalition are here for you, too.

This GREAT IDEA comes from Kathy Cook, a treasured member of our survivor community. During a recent Brown Bag brainstorming session, participants noted that it can be very difficult for patients to know what they are agreeing to when signing their pre-surgical forms. This is generally done minutes before a procedure, at a time full of stress and anxiety. The discussion gave rise to the larger issue of all the forms patients are asked to sign, and those in attendance agreed it would be ideal to be able to view these forms beforehand. Kathy came up with the following suggestion: if doctors and health care institutions were to post these forms on their websites, patients could take all the time they need to read and understand them in advance, and could address any questions or concerns they may have about them to their health care providers before signing. This simple step would be profoundly reassuring to many.
Community Coordinators' Update

The lilacs were truly spectacular, the entertainment exceptional, the food decadent and delightful, and the weather...well, after a rough start, it ultimately became nearly perfect.

Fifty amazing volunteers covered ninety shifts over ten days, greeting thousands of festival-goers at the Coalition’s booth. We braved rain, feisty winds, bitter cold and snowy bursts, then watched in amazement as those days gave way to brilliant sunshine, perfect temperatures, and record crowds.

People stopped to talk. Some sought information, validation, and support. Quite a few shared triumphant, appreciative stories of their own breast cancer journeys or those of loved ones, A few needed to cry, and we listened, Many folks who stopped by knew right where to find us at our usual spot. Others had no idea we existed.

The message we share at events like this is “We are here whenever you need us.”

As always, we could not do what we do without the volunteers who give up their time with families, their weekend chores, to serve in all kinds of weather. Thank you, thank you to those who made it a family affair: the Deichmillers, McJurys, Steinberg-Spezios, the French-Seus’, Woods, Weetmans, and the entire Burke family. Thanks to my own husband Michael and sister Liana, and to Connie Zeller’s clan, who came in response to an urgent “help” call. Kudos to some brand new Lilac volunteers: Mindy Sammon, Cherie Maillie, Janice Barnum, Natalie Grigg, Carol Serio, Aryanna Jackson, and Brenda Tartaglia. A big warm hug to the die-hards who worked multiple shifts: Maureen Kingston, Pat Battaglia, Cherie Maillie, Marcy Lazio, Betty Digby, and the tireless Nancy Weinman. We

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Taking time out ... just for yourself helps you live a healthier, happier life. “Relieving stress can lower blood pressure, help you sleep better, and even help you maintain a healthy weight,” says Berit Brogaard, a professor of psychology and philosophy at the University of Missouri in St. Louis.

Here are 10 ways to sneak some “me time” into a busy summer day.

-By Gina Roberts-Grey; Medically reviewed by Rosalyn Carson-DeWitt, MD

**Just say no.** It’s okay to push back from a few volunteer projects or to let the dishes sit for a few hours so you can take time out for yourself. “Don’t feel bad saying ‘no’ now and then,” says Bo Bradley, a life coach and the author of Achieving the Balance Dream. It’s important to free up time to take a walk, work a crossword puzzle, or watch your favorite TV show.

**Forage for finds.** Lose yourself in a stroll around a flea market or neighborhood garage sale. The hunt for a one-of-a-kind treasure is a great way to snap out of your routine.

**Create a musical escape.** Can’t leave the house? Turn everyday chores into relaxing moments. Play classical music, or some other type of music that you find soothing, while you’re folding laundry or preparing dinner. Instead of feeling rushed and annoyed that you’re searching for matching socks, you’ll find yourself relaxing.

**Join a “time off” team.** If you have young children, join forces with other busy parents and arrange playdates or sleepovers. Spend your night off unwinding with friends at a café or coffeehouse. “Just be sure to order decaf so you’re not counting sheep at midnight!” says Brogaard.

**Clear your head.** A half hour of meditation or yoga can clear your head and relieve stress, helping you feel more relaxed and calm. “These activities regulate the brain waves responsible for our conscious states,” says Brogaard, “and literally make the brain less busy.”

**Bury yourself in a book.** The quiet atmosphere at a library encourages relaxation, and the cool air can be a welcome relief when the temperature outside is climbing. Spend an hour flipping through your favorite magazines or looking for a fun summer read. “Just make sure you leave the kids at home so you can truly immerse yourself in the experience,” says Brogaard.

**Go green.** Spending time outdoors resets your natural rhythm, says stress management expert Debbie Mandel, MA, the author of Addicted to Stress: A Woman’s 7-Step Program to Reclaim Joy and Spontaneity in Life. Take a nature walk, eat lunch outside, or take a chore outside — such as balancing your checkbook out on the deck. “Any opportunity to get outside will help you feel like you’re part of the summer season,” says Mandel.

**Talk to the animals.** Sure, the zoo is a great place to take the kids. But feeding the ducks and watching elephants splash in their pool is a great way for grown-ups to unwind too. Playing with your pets at home is another fun way to enjoy some animal company.

**Get schooled.** Sign up for that ceramics or pastry class you’ve always wanted to take. Learning something new can fuel your creativity and give you a chance to make new friends with similar interests.

**Stop by the silver screen.** Spend a rainy or sticky summer day at the movies. “A comedy or romance is a great treat for busy, overscheduled parents,” says Mandel. “It’s good for your mental health to laugh and feel like you’re putting your interests first now and then.”

With a little planning and some ingenuity, you can find time this summer to relieve stress and nurture yourself, which will help keep you healthy and give you more energy to meet your family’s needs.

http://www.everydayhealth.com/healthy-living/take-time-for-yourself-this-summer.aspx
**Blueberry Jalapeno Salsa**

**Ingredients**
- 1 fresh jalapeno (or more to taste)
- 3 cups fresh blueberries, rinsed and divided
- 3/4 cup red onion, chopped
- 2 juicy limes
- 1 tsp. salt
- 3/4 cup fresh basil, thinly sliced
- 1/2 cup fresh mint, thinly sliced
- 1/2 cup fresh Italian parsley, finely chopped

- Grill the jalapeno on the barbeque or over a gas flame until it is blackened and soft, about 7-8 minutes. When cool, slip the charred skin off and cut off the stem. Slice in half and taste the chili. If it’s mild, use the seeds, otherwise scrape the seeds out. Chop the jalapeno and set aside.
- In the bowl of a food processor, pulse 2 cups of blueberries, the jalapeno and the red onion together about 5 or 6 times. Mix should be coarse.
- Pour mixture into a serving bowl. Add the remaining 1 cup blueberries, the juice of 2 limes, salt and the fresh herbs. Stir to combine.
- Makes about 2 cups.
- Serve with a wedge of Brie cheese and baguette slices or with grilled fish.

**Roasted Corn with Basil-Shallot Vinaigrette**

**Ingredients**
- 3 cups fresh corn kernels
- 2 T. extra-virgin olive oil
- 1/4 cup chopped fresh basil
- 1 T. minced shallot
- 1 T. red-wine vinegar
- 1/4 tsp. salt

- Preheat oven to 450 degrees. Toss corn and oil to coat and spread out on a large baking sheet. Bake, stirring once, until some kernels begin to brown, about 20 minutes. Corn may also be grilled on the barbeque whole, in the husk for about 30 minutes. Cool, shuck and slices kernels from the cob.
- Combine basil, shallot, vinegar, salt and pepper in a medium bowl.
- Add the corn, toss to coat. serve warm or cold.
- Serves 4

**Ten Healthy Snacks for Road Trips**

Hitting the road this summer? Be ready for on-the-road snack attacks with carry-along foods that are delicious, healthy, and will quell those hunger pangs.

1. **Fruit** is one of nature’s finest convenience foods. Berries and grapes are in ready-to-eat form, while larger fruit can be cut into bite-sized pieces. Placed washed, prepared fruit in containers and store in a cooler until needed. Dried fruit is another good option, and doesn’t need to be kept cold.

2. **Veggies.** Washed, cut up veggies can also be stored in containers in the cooler. Great on their own, they are also wonderful dipped into…

3. **Hummus.** That Mid-East staple of chick peas, sesame tahini, lemon, garlic, and varying spices, all blended smooth, hummus is

*Continued on page 19*
As people gathered at the park, they were treated to the lovely voices of the ladies from Vocal Point, a University of Rochester a capella group, and lively warm-up exercises led by fitness instructors from Bounce Aerobics.

Runners took to a path from Moore Road near the top of the park through the lower part of the park and finished 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 cheered them on from the river in their pink boat.

Moving an event of this size is a great undertaking and it would not have been possible without the hard work and dedication of many volunteers who helped out before, during and after the event to make sure everything went smoothly and safely. We want to thank all of our volunteers, especially the Pink Ribbon Committee members who spent many hours thinking, re-thinking and planning this year’s event, led by Debra Bonsignore, Event Director; Bix DeBaise, Race Director; and Benita Aparo, Walk Director. Special thanks go out to Coalition staff members: Susan Meynadasy and Jean Sobraske who served as Walk Captains for the two walk routes, and Pat Battaglia who served as team captain for food distribution.
OVERALL FASTEST TIME CATEGORY

WINNER
Sarah Loerch, Age 27, 18:06
$300 Cash - Sponsored by Wegmans

SECOND
Karen Blodgett, Age 36, 18:10
$100 Wegmans Gift Card

THIRD
Allison Carr, Age 46, 18:31
$50 Wegmans Gift Card

BREAST CANCER SURVIVOR CATEGORY

WINNER
Amy LaRussa, Age 49, 24:19
Pharoah’s Hairum Spa Rejuvenation Package & Jim Dalberth Sporting Goods Gift Certificate

SECOND
Heather Garigen, Age 35, 24:47
Park Avenue Salon & Day Spa “Mini Retreat Package”

THIRD
Charlene Zaffuto, Age 56, 26:52
Massage Certificate from Jean Van Eiten & Jim Dalberth Sporting Goods Gift Certificate

FOURTH
Mary Kummer, Age 58, 27:23
Massage Certificate from Jean Van Eiten

Thank you to Bounce Aerobics for leading the stretch session!
THANK YOU TO OUR GENEROUS RACE SPONSORS!

DONORS

- Ballantyne RV & Marine
- Dunkin Donuts
- Gallea’s Tropical Greenhouse
- Jack n Jill Child Care
- Jean Van Etten, LMT
- Jim Dalberth
- Sporting Goods
- Larijames Salon & Spa
- Park Avenue Day Spa and Salon
- Pharaoh’s Hairum Salon & Spa
- Rockcastle Florist
- Wegmans

iPad Raffle Winner: Jean Aurio

Jean Aurio with Cindy Dykes
Ten Healthy Snacks continued

4. Crackers. Whole grain crackers travel well and are great on their own, dipped in hummus, or topped with…

5. Cheese can be cut into finger-friendly pieces, wrapped tightly, and popped into the cooler. Or purchase pre-wrapped string cheese.

6. Nuts are nutritional powerhouses, full of protein and healthy fats to fill empty bellies. Small portions will go a long way. Or you might take those nuts and use them to make your own…

7. Trail mix. A combination of nuts, dried fruit, and varying other ingredients, trail mix is a great all-purpose snack. It can be purchased, or mix up your own. Classic GORP – Good Old-fashioned Raisins and Peanuts – is quick and easy on its own. Or you can add more nuts, maybe a handful of sunflower seeds, another dried fruit such as apricots, perhaps some granola, and toss in a sprinkling of chocolate chips to make your own creation. If you like, while on the road, you can stir your trail mix into some…

8. Yogurt. A source of quality protein and calcium in a creamy, delicious form, yogurt keeps well in a cooler and will quickly soothe those hunger pangs.

9. Sandwiches – pre-made sandwiches and wraps are another item that can be kept in the cooler for a quick, nutritious alternative to a fast-food stop. Use those wraps instead to stretch your legs and enjoy the scenery.

10. Beverages are needed to avoid dehydration on long rides. Plain old water is always good to have on hand. You can also add fruit and/or vegetable juices, spritzers, and seltzer to your cooler.

Community Coordinators’ Update continued

had our “old faithfuls”, Betty Miller, Connie Schmeer, and Jeanne Verhulst; Board members Tom McJury and Pam Bernstein; those who work to honor loved ones, such as Dan Deckman; a Founding Member, Judythe Roth; the entire Coalition staff; and a couple of high school seniors offering their help at a very busy time of their lives: Moira McJury, Corinne Scripps, and Charity, a young woman who stopped by to chat and stayed to help. Deepest appreciation also to Tracy Cahill, Nancy Germond, Nicole Knight, Jen Lanning, Rebecca Solomon (it was so cold!), and Kathi Johnson. Some of you defy categorization, some fit into multiple categories!

What you do – all of you – is important, kind, and generous, and the Coalition appreciates you!

2013 Research Review Panel
By Eileen M. Collins

On February 7, 2013, after a year-long grant application and revitalization process, the Breast Cancer Coalition Research Committee and four medical doctors from the Coalition’s Research Advisory Board convened for Grant Proposal Review Day. Eight grant proposals were reviewed with the intention of awarding a breast cancer research grant from monies collected through local Coalition fundraising activities. The proposals reviewed were submitted by medical researchers from the regional area served by the Coalition. Hosted at the beautiful Genesee Valley Club on Rochester’s East Avenue, the panel worked for eight hours, debating the merits of each proposal while adhering to strict guidelines developed by the Research Advisory Board. This pleasant location combined with a wonderful breakfast and lunch sustained the hard working review panel through their decision making.

Two grants were awarded; one each for “Breast Cancer Exosomes: Novel intermediaries in Psychosocial Stress-induced Tumor Pathogenesis” and “Immunologic Targeting of PDEF Oncogene in Breast Cancer”.

As a breast cancer survivor, I have a keen interest in discovering the causes, prevention and treatment of this disease. As I observed the passionate and informed debate for each grant proposal reviewed, I felt great pride in the Coalition staff, survivors, and medical community reviewers who volunteered endless hours in considering the structure and function of these grant awards. The input from breast cancer survivors in the awarding of research monies is unique and critical. Someone who has intimate knowledge of the disease’s devastation of both mind and body has a point of view that adds a special dimension to the focus of research. Breast cancer has a media image that can trivialize the devastation of the experience of cancer. Smiling faces and pink ribbons tell only part of the story. The grant proposal opportunities created by the Coalition focus on fostering medical research that explores the darker side of the story. The reality of breast cancer - including its causes and the fact that it often requires life altering interventions - is being addressed by the research grant option offered through the foresight of Coalition goals. Local fundraising and research expenditures provide those in the region served by the Coalition the opportunity to work past pink ribbon images and focus on cause, care and cure.

The Research Panel Review Day was a wonderful example of what can be accomplished by team work among cancer survivors, Coalition staff and the medical research community. Shared goals and focused energy create awesome results and educate everyone involved in the process.
In the Balance: 
Weighing the Complexities of Difficult Health Care Decisions

-By Pat Battaglia

It may be the understatement of the millennium to say that diagnosis of breast cancer is a difficult thing to go through. Each person affected faces it in her or his own way, but it's a safe bet to say that hearing the words, “You have breast cancer,” is a universally life-altering experience.

In addition to managing the complex emotions that arise, the fact that breast cancer has an array of variables means that many will sift through a confusing assortment of treatment options. Whether deciding on further diagnostic procedures, sorting through surgical options, considering radiation therapy, or systemic treatments including chemotherapy and hormonal therapy, the path ahead for some may be relatively straightforward, while for others it might seem to disappear quickly into a dense fog. But whether things are clear or murky, taking the next step can be extraordinarily difficult.

Getting Help

Decisions faced after a breast cancer diagnosis have far-reaching consequences, and can be exquisitely difficult. When faced with tough decisions, ask tough questions. Breast cancer is serious business and there are no silly questions when dealing with it. Learn all you can about your diagnosis and the treatment options proposed for you.

Seek a health care team that clicks with you; people you feel you can talk with openly and honestly about risks and benefits, who give you the opportunity to understand the treatment choices and then let you decide. Shared decision-making is a collaboration between you and your health care team— they are your partners in this process.

Some tough questions:
- What is my diagnosis?
- When will my test results become available? How can I obtain a copy of my pathology report?
- What treatment options are most likely to work for me? Why?
- What are the pros and cons of the proposed procedure/treatment?
- How long will recovery take?
- What are the long term outcomes?
- What can I do to alleviate side effects?
- How will my quality of life be affected?
- How long will I need to be treated?
- How will I know if treatment is working?
- How much time do I have to think these things over?

Also in this picture are your family, friends, and others who are part of your life. Although the words of those closest to you will carry the most weight, all will be affected to some extent by your diagnosis, and all will have their own reactions and thoughts. Listen to the type of language others use - there are many different words that can convey the simple message, “I’m here for you. We’ll figure this out together.” The person behind that message can be trusted.

Talking with others who have undergone the same surgery or treatment options you’re considering can help you gain another level of understanding about your own situation. The community of breast cancer survivors within the Coalition can help sort through the plethora of information, and in the process instill hope in the form of human connections with others who have faced similarly difficult decisions. Whether connecting through a BC101 session, Brown Bag Lunches, a PALS Mentor, support groups, or any of our other offerings, it is in meeting others and learning their stories that many have begun to put the pieces of their own puzzle together.

Seeking Second Opinions: when and why

If you’re buying a major appliance or a car, it makes sense to shop around. With all that’s at stake when facing breast cancer, the same principle should apply. But you’re not simply looking for the best deal when seeking a second or even a third opinion. You’re consulting with experts on your health care and putting together a team that will help you through an extremely difficult situation.

In some cases, there may be uncertainty about the diagnosis or the best way to proceed. Others may be torn between different surgical or treatment options. A few have been diagnosed with rare types of breast cancer

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

Susan Ames
Judy Buchanan
Beverley F. Donald
Kimberly M. Facteau

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 hearing stories about how they have touched and changed your lives.

Please send your submission (300-500 words) with a digital photograph to Susan Meynadasy, BCCR Voices of the Ribbon Newsletter Editor, at susan@bcr.org.
We would be happy to honor your loved ones.

Susan Ames
- By Peg DeBaise

Sometimes the best heroes are the quiet, soft-spoken ones who face their daily challenges courageously and without bitterness. Judy Buchanan is one of these. Even as she openly acknowledged the difficulty of her diagnosis and treatment, she focused on her sense of purpose—and her sense of humor. Her beloved husband Ray was at her side throughout the journey.

Despite the uncertainties of living with breast cancer, the devotion of this couple to one another remained solid. Their children and Judy’s sister offered their support as well, as did a growing cadre of friends—both long term friendships and those formed within the breast cancer community after Judy’s diagnosis. Despite her illness, Judy participated in Fairport’s Relay for Life every year to show her gratitude to all who supported her.

Judy maintained a part time job, and drew strength from her strong spirituality. She once shared with me that “I thank God each day for fifty positive things that happened that day. I don’t always make it to fifty, but I do try.” Her efforts to maintain normalcy in her daily life were not in denial of her diagnosis, but a way of staying grounded in on the things that made her life meaningful. Along the way, she reached out a helping hand to others who found themselves living with breast cancer, offering support and encouragement, and the occasional punch line. One of her favorite quips was “I’ll never again have a bad hair day!”

Whenever I think of Judy, I have to smile in a peaceful, “life-is-good” kind of way. I think she would like that.

We are very saddened by the loss of Susan Ames who passed away on June 23rd after four years of living courageously with breast cancer. A devoted wife and mother, Susan’s sons Mike and Zachary were her world. Despite her illness, she wanted to make sure that Zack got to do fun things—like family trips to theme parks. As an Administrative Assistant in the Department of Pediatrics at the University of Rochester Medical Center, Susan was an inspiration to her colleagues. I will always remember the support and encouragement she gave to her fellow survivors. Her caring spirit will truly be missed.
An infusion of Spring

Sean Fico of AP Property Services honors his survivor Mom in a BIG pink way- with a 39,000 pound loader!

AP is the proud and generous host of Loads of Love, which this year sponsored a party to kick off the Garden Artisans Expo. Guests of the event, held at Southtown Plaza, were enveloped in music, the smells of local food fare and the exquisitely designed and crafted gardens. The Garden Artisans Group was proud to host Loads of Love as one of two designated charities this year. Proceeds from the show were shared between Cure Childhood Cancer and the Breast Cancer Coalition of Rochester, resulting in a much appreciated gift of $1000.

In the Pink

In a festive departure from the more common dress down/jeans day, the employees of Adecco at Rochester Tech Park held a "Dress Pink" day. For a $5 donation, folks could sport any manner of pink they chose, lending a rosy glow to an otherwise grey and drab April Friday. There must be quite a passion for pink at Adecco, because they raised over $340 for the Breast Cancer Coalition in one day!

Girls Night Out- Friends and Fine Food

In what is becoming a happily anticipated annual event, friends gathered at GiGi’s Italian Kitchen on East Ridge Rd to share laughter, fun, food, and raise some funds for the Breast Cancer Coalition. Thanks, ladies, for your kind donation of $844. It’s great when something so nice comes out of such a pleasant evening with friends.

Opa!


The annual Greek Festival had it all, once again. And once again, the Breast Cancer Coalition was a grateful recipient of $1000 as one of the Festival’s ten chosen organizations. The generosity of this wonderful community organization is a reflection of the strength and beauty of its culture. We thank them for their commitment to the Rochester Community and the women we serve.

Honoring Mom

Gail Palluconi went toe to toe with breast cancer twice, and was only one of many women in her family to do so. So daughter Marisa Mercone decided to honor the strong women of her family by holding a Zumbathon at S&S Fitness in Hamlin. Clad in pink, ruffled and tutu’d participants donated $20 to participate and enjoy refreshments, lunch, a raffle of donated goodies and door prizes. A DJ kept the place lively, and this event collected $2261 that will be used to provide educational and support programs to local women dealing with breast cancer. Gail Palluconi, you raised a pretty amazing young woman!
**They Give…and Then They Give Some More**

The **Duke Company** of Henrietta is one our favorite benefactors. Besides being ambitious and incredibly generous, they are just a lot of fun! Once again, we had a great time (not to mention a great steak!) at the Annual Contractors Steak Lunch in the Big Tent on Jefferson Rd. The Duke people cooked over 800 steaks as a thank you to the companies and independent contractors they serve. In addition, Duke sold hundreds of promotional items at bargain prices and donated all the money to the Coalition! Most impressive of all was the generosity of the nearly 1000 attendees who expressed their thanks to Duke by donating to us. Ultimately $2261 was raised in a whirlwind lunch time. Thanks, Duke!

**Cruise for Charity**

In the long, dark days of Rochester Winter, several Coalition program participants took advantage of a five day vacation to sunny Grand Cayman and Cozumel. Whitaker and **Deprez Travel** in partnership with Royal Caribbean Cruises put together this package on the Jewel of the Sea. Guests enjoyed on board miniature golf, rock climbing, sun bathing and a spa pampering, and the Breast Cancer Coalition was pleased to receive a $250 donation from the proceeds.

**It Never Hurts to Laugh**

The best humor is real, it is kind, universal and so often pokes a funny finger at some rather un-funny life situations. Such is the case with the **Breast Laugh Show Out There**, organized by funny guy Chris Sanzone. He lined up four area comics who, with Chris, donated their talents to raise $1100 for BCCR. The Comedy Club in Webster hosted this second annual event, servers came in to work on their night off, and even Chris’ Mom pitched in. They packed the room, raffled some nifty prizes, and made a lot of folks laugh out loud.

**Grass-Roots Efforts For Good Causes**

CoreLogic in Henrietta coordinates office wide events and activities throughout the year to raise funds for local charitable organizations. To our surprise and delight we received a generous check for $457.50. This kind of grass-roots effort is so appreciated, and we will put your kind gift to careful use for the women we serve. Thanks, CoreLogic!

**Elves at Work**

Along with the three R’s, many of today’s students are learning and practicing the principles of charity and community concern. The “Elf Day” event at **Spencerport High School** this Spring was dedicated to the Coalition, and we thank them for their gift of $280. Way to go, students!

**Celebrating Claudia**

It was a party that beautiful **Claudia Tripi Sanger** would have greatly enjoyed. The people who loved her celebrated her well-lived but too short life with joy and tears, food and friends, and a spirit of great generosity. Claudia lost her long fight with breast cancer in April 2012. On April 6, 2013, her spirit rocked the Polish Falcon Club in Cheektowaga. Almost 60 people gathered, bidding on glorious gift baskets filled with wine and chocolates, garden items, spa packages, an afghan, a Scotch Whiskey sampler, and even a lottery tree! When the party was over, a big-hearted $1500 had been raised for BCCR, to fund the programs that had helped Claudia along her breast cancer journey. What a lovely legacy for a remarkable woman.

**A Double “Feel Good” Event**

Question: What could possibly feel better than a therapeutic massage from Licensed Massage Therapist **Stephanie Vaisey** of Penfield? Answer: A massage that also results in a donation to the Breast Cancer Coalition of Rochester! Thanks, Stephanie, for your gift of $40 from some October massage services.

**Fashionable Fun**

On April 13, the Community Room if the **Greece Public Library** was transformed into a late 19th century parlor to host a fashion show of Jane Austen period costumed models and Regency era dancers and singers. Those willing were able to learn a dance that Jane might have enjoyed at a party. The raffle of two brimming baskets raised $138 which the Library kindly donated to the Coalition.
Mini-Walks on the Atrium at MCC

It was a mini pink parade for Over 30 members of the Monroe Community College Chapter of the American Assoc. of Women in Community Colleges on a May Friday. Members decorated the Atrium, the indoor turf field (PAC), hung balloons and streamers, and sold pink bracelets. They also honored some special survivors with pins. This wonderful organization honors us with a donation each year, to use in the community where we live and work. Thanks to AAWCC at MCC for their gift of $138.

Gifts in Kind

Wishes Do Come True!

Thank you to Annette & John Stenglein for their generous donation of paper products from our wish list!

Cards in Honor of Kathy

Kathy Doolin & Ronieka Burns, (pictured at left) from MICU at Strong brought in cards and other items donated by the staff at Strong in honor of Kathy Doolin.

Beautiful Bangles

Once again this Spring, we were thrilled (and dazzled!) to have Mallory Dixon appear at the Coalition just in time for the Lilac Festival with hundreds of her gorgeous beaded awareness bracelets for us to sell. They shimmered in the sunshine and attracted lots of visitors to the booth, not only giving us an opportunity to talk about the Coalition, but also to raise hundreds of dollars in just a few days. Mallory’s creations are her way to honor a treasured Aunt lost to breast cancer. Mallory, your generosity and beautiful spirit are such a gift to us!

Caring Cassandra honors Grandma

For a young lady’s tenth birthday, typical requests might include jewelry, clothes, or toys. This was not the case when Miss Cassandra O’Connor turned “double digits” recently! Instead of gifts for herself, Cassandra honored her Grandmother’s fight with breast cancer by requesting items to fill the PALS packs we offer to each newly diagnosed woman. Comfort items such as notes, journals, blankets and gift cards as well as $50 to purchase more items were given to the Coalition. Also, supplies for our programs such as copy paper and refreshment supplies were included. Cassandra, our dream for your generation is that you will never need our services, and we appreciate your participation in making this dream come true. Thank you!

Calling All Quilters!

The Webster Quilt Guild is sponsoring a series of pink block parties culminating in a Pink Quilt Day on October 20. The concept was gleaned from the delightful Marie Bostwick books, in which the owner of the quilt shops in the story has a pink day. The idea intrigued Michele Sanderson of the Webster Quilt Guild and she decided to put the plan to work for our benefit. All events will be held at the Café Sewciety shop in Webster, and have been coordinated by Michele Sanderson and her fellow Guild members for the benefit of the Coalition.

Anyone who picked up their Pink Ribbon Run and Walk packets at our office last May had a chance to see the first gorgeous quilt created for us, which will be raffled off in October. The Guild has created a masterpiece with a subtle pink ribbon design that will fit a queen size bed.

For more information, or obtain a pattern and fat quarters for the Antique Tile block, please contact Michele at michele.sanderson73@yahoo.com or stop by Café Sewciety, Patricia’s in Pittsford, or Sew Creative in Fairport.
that doctors don’t often see. Still others may have a more straightforward diagnosis and treatment plan and want to leave no stone unturned in ensuring they have a clear understanding of their situation. For the above reasons and more, many women choose to seek opinions outside of their original health care team. Doctors and insurers are on board with this type of thinking. Consider the time spent in seeking a second opinion to be an investment in your health and peace of mind.

Making a Decision That’s Right for You
When making complex decisions, it can help to break the process into simpler steps. Your decision may take minutes, days, or weeks to make. Take all the time you need within the time frame that’s available to you to make the best possible decision for yourself. Then move forward and don’t look back.

Things to consider:
• **What are you trying to decide?** Ask your doctor to state the decision that must be made, the options available to you, and the time frame in which your decision should be made. Let your doctor know of your intention to share in the decision-making process.
• **Get the facts.** Learn all you can about your diagnosis and the options available to you. Your doctor is your first resource. In addition, the Coalition offers a resource center, as do many cancer centers. Be very careful when searching the internet for answers. Find out about reliable websites from your doctor or the Coalition.
• **Reach out to others.** Also available at the Coalition is the gathered wisdom of a large group of others who have walked this walk in all of its variables; a community that extends a welcoming and supportive hand to those who are newly diagnosed.
• **What do you think?** Ask yourself some soul-searching questions about your values and needs. Think about what the best possible outcome of your situation would be. Sort through the options available to see you through to that end. It may help to make lists of the pros and cons of each option and share these lists with your doctor to be sure you have all the information you need.
• **Narrow down your choices.** Pick what seems to be your best option, or at least a very good one, and try it on for size. Consider the pain, recovery time, side effects, and long-term outcomes of that treatment. Talk with others who have made that same choice. Decide if it really is your best option.
• **Own your decision.** Whether your choice was straightforward or gut-wrenching, or anything between the two, let go of any feelings of ambivalence once you’ve made your decision. You’ve done the best you can with the available knowledge and resources, and you can move forward to put your cancer-fighting plan into action.

You Are Not Alone
It can seem like a real balancing act to gather all the information, weigh the pros and cons of multiple variables, and come to a decision that works for you. It’s complicated. Each diagnosis is individual, and each person who faces this diagnosis is unique. Your decision will be yours and yours alone. But you don’t have to face the decision-making process alone. Reach out to your healthcare team, your friends and family, and a strong support community such as the one that exists so vibrantly at the Coalition. **We’re here for you.**

Resources:
http://www.effectivehealthcare.ahrq.gov/options/
http://decisionaid.ohri.ca/docs/das/OPDG.pdf
http://www.breastcancer.org/treatment/second_opinion/making_sense
http://www.sanfordhealthplan.org/members/resources/worksitewellness/
worksitewellnessprogram/livinghealthy/makingwisehealthdecisions/index.cfm

Executive Director’s Column continued
GYN Cancer survivors themselves. To that end, the Breast Cancer Coalition will be holding a series of focus groups for those who have been diagnosed with any type of GYN cancer. We want to hear from them as we move forward to implement programs and services that truly fit their needs. What do they wish they had known when they were first diagnosed? What have they learned that would be helpful to others? What would have been helpful during their own cancer journeys? What services are needed in our community? What is done well? Where are the gaps?

These focus groups will convene in September. If you know of any woman, or their partner or caregiver, with a history of ovarian, fallopian tube, uterine (endometrial), cervical, vaginal or vulvar cancer, please let them know that we would value their input and would like to incorporate their ideas as we move forward. Any assistance you might provide in getting word to friends, coworkers, neighbors, family members and others would be greatly appreciated. They may contact me directly at holly@bccr.org or either Jean or Holly by phone at (585) 473-8177. Is the Coalition changing its mission? Not a chance.
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 March 31st will be included in the spring newsletter.)
We apologize for any errors and/or omissions on our donor pages.

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*Donations ending March 31, 2013*
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Patty Sofia  
Marie & Robert McNeil

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Friends of Pittsford Hockey - *Pink the Rink*  
Thomas McJury  
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Temple Sinai  
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Barbara Stetson  
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Amy Weetman & Girl Scout Troop  
60716 of Webster  
Wisteria Flowers - Jennifer Ralph

**THE COALITION’S CURRENT WISH LIST**

- A cure for breast cancer
- Book 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
- Someone with sewing skills who can make surgical pillows for PALS Packs *(we would be happy to help find or design a suitable pattern)*
- 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
- A Pantone Matching Guide
sudden shift in Astria’s treatment plan. Originally, the intent was to remove the tumor and radiate the area to offset the slight chance that cancer cells might begin to spread. Once there was a positive lymph node in the picture, things became a little less clear. The next step was to consult with a medical oncologist.

The oncologist Astria chose was participating in a research study, and her case fit the criteria for that study. Designed to fine-tune the protocol for chemotherapy recommendations in early-stage breast cancer, the study involved the use of the Oncotype-DX test. This genomic assay of tumor tissue provides specific information on certain types of breast cancer that can help inform treatment decisions. The results of this test are expressed as a Recurrence Score, which is a number ranging from 0 to 100. Those with a higher score are more likely to benefit from chemo, while those receiving lower scores may not see as much benefit. In the particular study in which Astria’s doctor was participating, those with a Recurrence Score of 25 or higher were automatically designated to receive chemo. Those with lower scores were randomly assigned to either receive chemo or not.

Astria enrolled in the study and a sample of her tumor tissue was sent for analysis. When her score came back, it was 19. An already murky picture became even less clear. A score of 19 is normally considered to fall in a “gray area”, in which patients may still see some benefit from chemo. “I had already thought about (this possibility) while waiting for the results,” recalls Astria. With her beloved family members – husband, three sons, her daughters-in-law, two grandchildren, and many more – foremost in her mind, Astria made the decision to sign out of the study and proceed with chemotherapy. She had the full support of her family and her oncologist in this decision.

Apprehensive but determined, Astria began her chemo treatments. Her family rallied behind her, preparing meals, cleaning, and taking care of errands so Astria could make her way through the fatigue and other side effects that became a temporary but overwhelming part of her life. She cut her long hair short in anticipation of losing it to treatment, and when it began to fall out in earnest, she shaved her head and sported a wig. That is, sometimes she sported it.

“I really couldn’t stand it,” she says of wearing the wig at home. But for the first couple of weeks she kept it on. One day, her granddaughters were in her care when one of the girls, age 6, noticed that something wasn’t quite right with her Grandma and asked about it. When Astria answered that the wig was bothering her, the child replied “Take it off!”

“Well, I don’t want to make you uncomfortable,” Astria answered. “Grandma, you’re the one who has to be comfortable. And if you can’t be comfortable in your own house, where can you be comfortable?”

From the mouths of babes often comes wisdom – as well as a great deal of compassion and unabashed truth framed in simple words. From that day on, Astria never wore her wig in the house. “It came off as I walked in and went on as I walked out,” she says with a smile. Her family loved her all the more for it, and she enjoyed the freedom and comfort of a beautiful, bald head.

While she was still in chemo, Astria’s youngest son was married. She may not have been feeling her best, but she participated fully in this happy occasion. Life had been a dizzying series of highs and lows through the last months of 2011 and well into 2012. And with a joyful occasion to celebrate, and another family member to welcome into the fold, Astria’s heart was fully in it.

The days of treatment passed slowly but steadily – months of chemotherapy were followed by weeks of radiation. Finally, it was all over. As she began to recover and gain strength, Astria found herself yearning to talk with others who had faced breast cancer. As she began to fully process the events of the past year, she felt the need to hear the voices of others who had “been there”. Wanting to resume her role as a fully functioning member of her family, but still feeling the need to come to terms with her own experiences, Astria began an internet search for support groups.

She wisely kept her search focused and local, and quickly zeroed in on the Coalition. “I made a call and spoke to Jean (Sobraske – our Programs Coordinator). She was very sweet on the phone and mentioned Brown Bag,” Astria recalls. “And I came to Brown Bag, and I love it.” Astria has become a regular at the Coalition’s lunch table every Friday at noon, sharing her concerns and triumphs, fears and joys, and deep wisdom with the group of survivors that gathers each week. In sharing her story openly, she offers a welcome ray of hope to the newly diagnosed that join in the Friday gatherings.

continued on page 29
A recent Brown Bag discussion focused on the term “survivor”. Participants were asked whether or not they felt that the word fit their experience. Astria responded that she doesn’t feel the word “survivor” suits her, and while the term “warrior” may reflect a part of her experience, there is another word that fits her best. “I feel I’m a traveler,” she said. “I’m going through life and there are happy moments and there are sad moments. There are things that get in your way, that you kick out of the way and move forward...The direction you choose is a choice you make. The journey is there and I want to enjoy it and travel through it.”

Probing the thought more deeply, Astria recalls past days when she visited Bavaria. “There are lots of forests and houses and beautiful gardens, and we’d walk through it,” she remembers. “It gives me that feeling when I think about what I’m going through – (the feeling of) being in the woods. But not all the woods are scary or bad. The path is taking you through the unknown but then you come out on the other side, and it’s beautiful and the sun is shining.”

One step at a time, one day at a time, Astria has traveled through some difficult places. As her journey continues, she knows that her path will not always be easy. Nor will it always be hard. And it’s those bright places that keep her steps steady as she journeys onward.

We at the Coalition are honored to be sharing the journey with Astria, an insightful and compassionate traveler.

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**Linda Gaylord** is a beloved member of the Coalition’s survivor community and a “frequent flyer” in our Voices and Vision group. Those who participate in these sessions are often given writing prompts, and each responds in their own uniquely perfect manner. Linda penned the poem below in response to the prompt, “What serves as your fountain?”

**The Fountain**

This place, this room serves as my fountain. 
This place is filled with the energy of all those who have entered here before us. 
These walls are resplendent with the images and memories of those who have shared this place. 
For me, this is a place of reverence, a welcoming place, a healing place; a place for connections and harmony. 
This place nourishes and nurtures my soul. 
Come, 
Follow me, 
Drink deeply, 
This is my fountain and these are my people, and this is my haven of hope.

~Linda Gaylord

---

**Better Than Before**

My body speaks; this is what you hear it say: I’m tired and achy, says my back, but so much better than before. I’ve been radiated, and medicated, but I’m better than before. My back says I’m so weary, but will carry on. As you see, I’m so much better than before.

~JoAnn Popovich
Upcoming Events & Programs at the Coalition

Wednesday, August 14, 2013
The Tenth Annual
Terri Schmitt Legislative Reception
5:00 - 7:00pm

Wednesday, August 28, 2013
Karin Cole, L.M.T.
Massage Therapy & the Power of Touch
Molly Branch
Acupressure & Acupuncture
7:00 - 9:00pm

Wednesday, September 25, 2013
Topic to be Announced
7:00 - 9:00pm

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

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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

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

Gifts of $100 + receive a complimentary Comfort Heart.

☐ $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

Breast Cancer Coalition of Rochester
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(585) 473-8177; www.bccr.org
Voices of the Ribbon
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Tel. 585-473-8177 • Fax 585-473-7689 • E-Mail: info@bccr.org • Online at bccr.org

Towpath Bike's 3rd Annual Breast Cancer Ride
to benefit the Breast Cancer Coalition!

Sunday, October 13
at Mendon Ponds Park
Support women who have been diagnosed with breast cancer.

Towpath donated $25,000 of the proceeds from last year's ride to the Breast Cancer Coalition. All of the funds raised this year will come directly to the Coalition!

Organize a team of friends, co-workers, family members and register online at: http://bit.ly/PSV2hY, or look for a link on our website at www.bccr.org