Pink Ribbon Run and Family Fitness Walk 2013

By Cindy Dykes

Mother’s Day, Sunday, May 12
At Genesee Valley Park

This phenomenal event has grown by leaps and bounds over the past 11 years. As more and more of you turned out to walk and run with us on Mother’s Day, we started experiencing growing pains at Ontario Beach Park. First it was traffic and parking congestion, so we added shuttle parking. Then the sheer number of participants prompted the police to separate the walk and race routes. The resulting walk route at last year’s event was not as appealing or scenic as the previous route, so we started looking at other locations to provide a beautiful, safe and enjoyable event for all participants. We feel we have found the perfect home at Genesee Valley Park!

This park provides a central location with access from all directions plus lovely views of the Genesee River and Erie Canal for participants and spectators. Some parking will be available at the University of Rochester and we will provide free shuttle parking from Marketplace Mall.

Visit our web site, www.bccr.org, for more details, maps and to register. If you have questions, call us at 473-8177 or email cindy@bccr.org.

We hope you will start your Mother’s Day celebration by joining us at Genesee Valley Park for the Pink Ribbon Run & Family Fitness Walk!  

Research Grant Awarded to...

By Alison Currie

Holly Anderson, Ryan Dawes, Alison Curry, Dr. Ashwani Sood and Patti Cataldi

The Breast Cancer Coalition of Rochester is proud to announce the award of two breast cancer research grants in the amount of approximately $50,000 each. Ashwani K. Sood, Ph.D., Assistant Professor of Oncology at Roswell Park Cancer Institute, will receive funds to investigate immunologic targeting of PDEF oncogene in breast cancer. In lay terms, Sood’s work could lead to the development of a vaccine to prevent tumor recurrence and progression. Ryan Patrick Dawes, a graduate student at the University of Rochester, is receiving our second grant. Dawes will study breast cancer exosomes, novel intermediaries in psychosocial stress-induced tumor pathogenesis. If exosomes are shown to be predictors or agents of stress induced cancer changes, Dawes’ work could lead to the use of exosomes as biomarkers, or to the development of therapeutic strategies to block exosome release or activity.

Our Research Committee seeks participants to assist with the Coalition’s research initiative and generating the required funds to keep it viable in the future. If you are interested in helping, please contact Alison Currie, Research Administrator, at alison@bccr.org.
The Breast Cancer Coalition of Rochester is a community-based, grassroots, free-standing organization. What does this mean?

Breast cancer is the second leading cause of cancer-related death among women in New York State. Nearly 14,000 New York State women are newly diagnosed with breast cancer each year, and approximately 3,000 die from the disease annually. It is estimated that 220,000 New Yorkers are, right now, living in the aftermath of this disease.

Early detection of breast cancer through mammography and clinical breast examination has led to a significant increase in the numbers of individuals who survive breast cancer, both in the state and nation. We have long understood that the earlier breast cancer is detected, the better the chances of survival. Improved treatment options have also led to increased survival among those diagnosed with breast cancer.

What does it mean to be a community-based, grassroots, freestanding breast cancer organization?

Enter the Breast Cancer Coalition of Rochester. We’re here for you, whether you’re newly diagnosed, have finished your walk with the disease, or live with it every day. We are:

**Community-based.** This means that our organization strives to be representative of our entire community and that we are engaged in meeting the unique needs within our very own breast cancer community. We do not take direction from, nor are we affiliated with any national breast cancer organization. As we are the stakeholders, we are also the decision makers. We are empowered to support causes that we believe are important and relevant to breast cancer, and frequently support legislation brought forth by state and national organizations.

**Grassroots.** We are governed by a Board of Directors comprised of members of our own community. More than half of these Directors are personal stakeholders having experienced their own diagnosis of breast cancer. Others have been touched by breast cancer through partners, friends or family members. Together we set the course for our work. Because we are all members of this community, we have firsthand knowledge of the challenges faced and, thus, have a personal stake in the success of our solutions to these challenges.

**Freestanding.** We are not affiliated with, or physically connected to, any of our hospitals or cancer centers, though we are supportive of all of them. We feel fortunate to live in our region where, if you have to receive a diagnosis of breast cancer, there are many choices. As we do not provide referrals to caregivers or cancer centers, we are able to work collaboratively with all of them. All of our programs and services are available to everyone in our community, free of charge.

Additionally, we do our own fundraising. We do not utilize fundraising agencies or engage in telephone solicitation. Just about all of our donors have let us know that they appreciate that every penny of their donation stays right here...supporting your very own grassroots, community-based, freestanding breast cancer organization. Thank you!
Entering my university freshman writing seminar, I was shocked to find copious red ink scrawled on my writing assignments. I had taken advanced placement English in high school with a tough teacher who praised my writing. The freshman seminar instructor’s criticism without encouragement left me with the message “You cannot write,” and thereafter I threw myself into the sciences, which relieved me of the obligation to produce prose text.

During my year after college, while I considered entering medical school, I enrolled as a Jesuit volunteer and began a year’s work in social service, working with impoverished families in West Los Angeles. For a small-town, lower-middle-class young woman, witnessing the ravages of poverty, the challenges of immigration, hunger, and unplanned pregnancy went straight to my heart. As a way of coping with these new and often unsettling experiences, notwithstanding my “inability to write,” I began to journal and found myself recording stories from my clients, mostly undocumented immigrants from Mexico and Central America. Writing helped me reflect on the burden of immigration and poverty. Sharing this writing helped my own family of origin understand my work and learn about a perspective on poverty that many of us in middle-class America never personally encounter.

During medical school, I again found myself in the world of facts, equations, and biochemical cycles, with little need to write prose. I often felt oppressed by the content and volume of biomedical information, which seemed so removed from what I imagined my future patients would want me to know. As an antidote to this rote learning, I enrolled in a humanities “selective.” We wrote poetry, narrative, book reviews. I don’t know whatever became of my writing from this epoch of my life. I do remember the catharsis of putting words to page and sharing with others. I can recall one poem I wrote to remember my maternal step-great-grandmother who suffered from severe dementia. I had inherited and reupholstered her special chair; seeing it made me recall the times I cared for her to give my grandmother respite from caregiving. Writing this poem brought forth my ability to reflect, to remember, to observe, and to create.

As a third-year resident, I enrolled in medical family therapy coursework. My family of origin course required a final essay—I hadn’t written a required essay in years. However, the topic, writing about my family of origin, was easy, if not entirely straightforward. The seminar prompted me to learn more about my ancestors. My paternal grandmother Katherine, the eldest daughter of Polish farmers who settled the rocky Connecticut hills, put herself through nursing school in the “big city” of Bridgeport at a time when women’s career choices included homemaker, nurse, or secretary. She married late, age 27, after completing her education and beginning her career, which she continued, on the night shift, as she raised her family. As a child, I occasionally ran into elders in my hometown who fondly remembered her compassionate nursing care. Writing about her life gave me insight into one of the strong women in my family and helped me connect my family of origin to my own path to becoming a physician.

Other strong women in my family included my maternal great aunts, who told me tales of driving over the narrow country roads in northwest Connecticut to New York State to fill prescriptions for diaphragms. Connecticut in the 1940s claimed the most restrictive laws in the nation, prohibiting the sale, dissemination, or use of contraceptives. As Roman Catholic women, this gave them no small measure of guilt, flouting both church and civil law. Eventually, they decided simply to no longer confess this “sin” to the priest. Writing this story helps me remember how much our foremothers endured for our success and how far we have come.

As a new attending, working with migrant farm workers in rural western New York, I finally began to care for those patients who I had

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Shaune O’Neil, 50, wanted the “bestest, baddest” treatment after her January 2011 diagnosis with triple-negative breast cancer. The Palmer, Alaska, woman consulted her doctor, who recommended a dose-dense regimen of doxorubicin and cyclophosphamide, followed by paclitaxel. The combination, known as ACT (for Adriamycin, Cytoxan and Taxol), is standard therapy for early-stage breast cancer.

But after Shaune agreed, her doctor delivered surprising news. “She told me she had two other patients with leukemia who also needed the Adriamycin, and she didn’t have enough,” Shaune says.

Like thousands of Americans, Shaune was forced into a situation when drug shortages robbed her of her first-choice treatment. Shortages tripled in the last five years, most involving generic, injectable medicines like chemotherapy. For you and your doctors, that means planning ahead—and asking questions about what can be done.

**A COMPLEX ISSUE**

At press time, doxorubicin remains among the several cancer medicines in short supply, FDA reports. Also recently listed were paclitaxel, cisplatin (Platinol) and pegylated liposomal doxorubicin (Doxil), sometimes used in metastatic breast cancer. (See the list at fda.gov/Drugs/DrugSafety/DrugShortages.)

Shortages have not just affected chemotherapy. Antibiotics, anesthetics, vaccines, pain medicines and nutritional supplements fill the agency’s 100-plus-item list. Although federal law allows FDA to address shortages, until recently it did not require manufacturers to report them. Some did so voluntarily, but the system left doctors uncertain about supply.

“When we decide a treatment regimen, we now add to the list [of issues to consider] how available is this drug going to be in the next three or six months,” says Rick Frame, MD, a medical oncologist at Utah Cancer Specialists in Salt Lake City. “We find ourselves living in this environment of, what next? When? And the ‘why’ is even more complicated.”

Experts point to multiple causes. Consolidation in the drug industry means nearly three-quarters of generics are made by just three companies. A quality-control problem at just one plant—such as fungus or glass in medicine—can halt production for multiple drugs. And if that medicine is made by only one company, it could take months for supply to recover. Even worse, some companies stop making older, well-studied generics because they yield little profit.

Injectable medicines like chemotherapy are complex to make and have a short shelf-life. Sometimes ingredients run low or run out. Typically, practices buy only what they need, but shortages may have led to hoarding. FDA is cracking down on so-called “gray markets,” when unscrupulous people buy up generics and charge buyers as much as 3,000 percent above market value.

Also contributing to shortages is the 30-month wait time, on average, for FDA to approve New Drug Applications (NDAs) for generics. Others point to 2003 legislation that caps Medicare reimbursement for generics at 6 percent above the average wholesale price. That fails to cover administrative costs, so practices use brand-name drugs instead, squeezing the generics market further.

**IMPACT IN BREAST CANCER**

Due to the complex causes, drug shortages are unlikely to go away anytime soon. But as a woman with breast cancer, you may be less likely than others to face a shortage yourself.

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A new drug conjugate known as T-DM1 recently received FDA approval for use in the treatment of HER2 positive metastatic breast cancer. Approximately one in four cases of breast cancer is found to produce an excess of the human epidermal growth factor 2, or HER2. T-DM1 is a drug conjugate, chemically linking trastuzumab (Herceptin), an antibody that zeroes in on HER2 receptors, with the powerful chemotherapeutic drug maytansine (DM-1). Trastuzumab attaches to these receptors, delivering chemotherapy directly into these cells, sparing healthy ones. The promise of this type of targeted therapy is more effective, less toxic treatment.

Another aspect of this proposed trial: T-DM1 will be researched in combination with systemic chemotherapy, with no arm of the study designated to receive the new therapy alone. The Coalition, along with forty-two other breast cancer advocacy organizations throughout the United States, signed a petition drawn up by the National Breast Cancer Coalition (NBCC) urging Genentech to include a group in their trials that will receive only T-DM1. Stressing the need to move away from toxic therapies in the treatment of early stage breast cancer, the petition states that the only way to do so is to take the bold step of eliminating these regimens in some arms of the trials. Patients on T-DM1 alone would still be receiving chemotherapy, but since it is designed to zero in on the tumor, they would
Drug Shortages continued

“We are fortunate in breast cancer, because we have a lot of approved regimens,” says Ruth O’Regan, MD, a medical oncologist at Emory’s Winship Cancer Institute, in Atlanta. “It’s been inconvenient in breast cancer, but in something like Kaposi’s sarcoma or refractory ovarian cancer, we have fewer options.”

The Doxil shortage is concerning to women with metastatic breast cancer, says Musa Mayer, MS, MFA, the longtime advocate who runs AdvancedBC.org and monitors the message boards of BCMETS.org. Doxil is not FDA approved in breast cancer, but it is sometimes used when cancer progresses after other therapies.

“These women know there are a finite number of treatments that will work for them, and they want to stay on a treatment that is working for as long as they possibly can,” Ms. Mayer says.

Dr. O’Regan, who practices at both Emory and Grady Memorial Hospital, has faced shortages of Doxil at both locations. For two women, that meant switching treatment: the first, to a clinical trial; the second, to eribulin (Halaven), a new chemotherapy.

In some cases, Doxil may be the last treatment option. But much of the time you will have many choices. There is no standard sequence for treatments in metastatic disease, so you can move among therapies. If you are taking Doxil and have to stop, you might be able to take it again; Dr. O’Regan switched one woman back after Doxil returned to stock.

Community practices may feel shortages more acutely than large institutions, says Eric Winer, MD, a medical oncologist at Dana-Farber Cancer Institute in Boston. With 84 percent of people receiving treatment at local clinics, according to the Community Oncology Alliance, the number of women with breast cancer adds up.

Still, drug shortages in breast cancer have not reached a crisis level. “It seems that most oncologists have been able to navigate the issue, by either finding another drug or finding another source for the drug they need,” Ms. Mayer says.

Shaune’s doctor recommended she take epirubicin (Ellence), which is similar in structure to doxorubicin, because it works just as well and has fewer side effects on the heart. “Knowing I had an alternative, I felt confident I was going to come out of treatment as good as I could,” Shaune says.

HIDDEN (AND NOT SO HIDDEN) COSTS

Other generics in shortage have similar brand-name equivalents. With paclitaxel, for instance, your doctor can use nab-paclitaxel (Abraxane) or the generic docetaxel (Taxotere). All medicines have differences, so ask about effectiveness and side effects.

Brand-name medicines have higher co-pays than generics, a cost that gets passed along to you. If you don’t have insurance, talk with your care team about patient assistance programs. But even with insurance, you can run into problems. Shaune faces $40,000 in bills because her claim was denied.

“In the middle of treatment, they called and said [the epirubicin] wasn’t approved,” Shaune says. “The emotional slam and mental burden [of that news] was almost as bad as the treatment. I continued, and I appealed. Finally, I hired a lawyer.”

Stress from drug shortages can affect your relationships with your providers. But your care team probably feels just as frustrated as you.

“[Drug shortages] didn’t register for me until I had to sit down with one of my patients, look her in the eye, and say, ‘I can’t get Doxil for you,’” says Dr. Frame, recalling a woman with ovarian cancer. “She couldn’t believe it. And neither could I.”

PLANNING AHEAD

Trust in your care team is key. Shaune’s doctor looked at alternate regimens and clinical trials but felt the epirubicin combination would give Shaune the best results.

“If your doctor won’t tell you that, or you don’t trust your doctor when she tells you that, then you need to find a new doctor,” Shaune says.

Ask questions. Your doctors should be prepared with, or willing to get, answers for you. “We try to anticipate future shortages, or avoid regimens where there is going to be trouble getting the drugs,” Dr. Frame says.

Educate yourself about treatment options. A good place to start is nccn.org, the website of the National Comprehensive Cancer Network, says Ms. Mayer. NCCN maintains treatment guidelines, which include

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be spared many of the side effects of standard chemo infusions.

In a webinar hosted by NBCC on January 31, 2013, Fran Visco, President of the organization, informed the public that the studies of T-DM1 in early breast cancer will proceed as originally planned – with no arm for those receiving T-DM1 alone. Listeners learned that in response to the NBCC petition, Genentech had convened a T-DM1 Advisory Board which was held at the annual San Antonio Breast Cancer Symposium last December. Officials from the FDA were invited, as were representatives from various advocacy groups including the NBCC, as well as unaffiliated advocates. NBCC agreed to send representatives. However, signing a confidentiality agreement was a condition of being included in this group – an agreement that would have made it impossible to speak to the public and advocates about what was happening. The NBCC, after proposing less restrictive counter-agreements that were ultimately rejected, saw no choice but to withdraw from the proceedings. Ms. Visco explained. “That's what we do – we are here to talk to people.” Being bound by secrecy was unacceptable.

With no NBCC advocates on hand to voice their objections, the decision was made to proceed with the trials unchanged. A teleconference after the SABCS meeting was held between Genentech officials and NBCC leadership in which the drug manufacturer remained unswayed in its determination to move ahead as planned, citing faster FDA approval of the drug as a motivating factor behind this decision.

Tests of new chemotherapeutic drugs have historically been done by adding them to existing therapies. The current standard of care in early stage HER2 positive breast cancer is to treat with a combination of chemotherapy and Herceptin. The new studies slated to begin within the next couple of months (as of this writing) will add T-DM1 to that regimen for a select group of patients.

Because T-DM1 combines the two treatments that are already in use – Herceptin and chemotherapy - different clinicians that have been approached by NBCC around the issue of trial design have all been supportive of a new methodology that does away with the old “add-on” approach. NBCC will continue to push for the trial designs of T-DM1 that they have demanded.

T-DM1 opens the door for the development of more drug conjugates, so it is important to work toward a complete understanding of what this therapy can do. It has the potential to save lives, enhance quality of life, and offer a model for future research. But all variables and scenarios must be taken into account before it can be determined whether or not that promise can be realized. It will be a long time before we know the real capability of this new therapy; perhaps decades, according to Ms. Visco.

We at the Coalition stand in support of innovative research that paves the way to better treatments, with the goal of ending this disease always in mind. We are a proud co-signer of the petition, and many of us have breathed a sigh of dismay at its rejection. As progress against breast cancer is made inch by painstaking inch, we find moments of joy and times of heart-sinking, head-shaking frustration. This recent decision by Genentech reflects the latter. As Ms. Visco stated, “We need to do what's best for women.” At the Coalition, we will add men to that equation and continue to be a voice for change.

In an amazing fete, the Women’s Council of Realtors went above and beyond to produce yet another outstanding fashion show at Locust Hill Country Club this past October, with funds raised going to four charities, including the Breast Cancer Coalition. Led by Fashion Show Chairperson, Janine Pajek, with assistance from Co-chair Carol Snow and their extraordinary committee, Locust Hill was rockin’ to this year’s theme “At the Hop!” Kicking up heels to 50’s music, model after model paraded down the runway with stunning outfits that took our breath away. Oo-la-la! Always a spectacular event, it was made even more special when we learned later that we would be the recipient of $6,500! Thank you, Women’s Council of Realtors! As Elvis Presley (spotted that afternoon) would have said, "We can’t help... falling in love with you!"

Thank you again to our good friends at the Women’s Council of Realtors!

Holly Anderson accepting the generous donation check with Carole Snow, Janine Pajek, Janet Romano and Kathy Dexter
Living with Advanced Breast Cancer: Emphasis on

LIVING

By Pat Battaglia

Who hasn’t heard about breast cancer? Arguably one of the most widely publicized forms of cancer, the pink ribbon has become synonymous with awareness of a disease that was once considered by many to be unmentionable. With strong emphasis on early detection as their best bet, women are exhorted, often in pink-ribbon-bedecked messages, to get their yearly mammograms.

But there is another side to that pink ribbon. Nationally, there are more than 200,000 new cases of breast cancer every year. Monroe County holds the unfortunate distinction of having the highest rate of new breast cancer diagnoses in New York State, with 144.4 new incidences per 100,000 people in 2009, compared to 125.8 new cases per 100,000 statewide.* While these numbers represent mostly women, men make up a small (about 1%) but significant percentage of this group. These statistics have remained stubbornly persistent despite ongoing progress in understanding and treating the disease.

As with all cancers, breast cancer is grouped into four stages according to its extent and severity. In its early stages – stages I through III - the disease is serious, but curable. Women and men complete an individualized course of surgery and treatment, and come to a place where no traces of cancer are detectable in their bodies. But about 30% of the time, depending on the type of diagnosis, rogue cells break away from the original tumor and travel to different sites within the body, seeding the growth of new tumors. This process is called metastasis, and the disease is known as metastatic, or advanced breast cancer.

It is estimated that over 150,000 women and men are living with advanced breast cancer in the United States. Approximately 6% of breast cancers are metastatic at diagnosis; this is considered to be stage IV breast cancer. The rest have metastasized at some point – months or years after the original diagnosis.

At this stage, the condition is not currently curable, but it is treatable. In other words, there are a number of different options available to slow or even reverse the progression of the disease. These choices run the gamut, depending on individual circumstances, and can include chemotherapy, radiation, hormonal therapy, and others. Complementary and alternative therapies are sometimes added to deal with the side effects of treatment, promote healing, and optimize health.

For the majority, the cancer will eventually progress, and different treatments are used in succession as one regimen stops working and another is tried. This is referred to as “lines of treatment”. The approach to metastatic breast cancer is, ideally, to use ongoing lines of treatment to manage it as a chronic disease, to prevent progression for as long as possible, and to minimize the impact of treatment on the patient’s sense of well-being.

Symptoms of the disease and side effects of treatment can usually be dealt with effectively, and those affected can – and do – live for years with a good quality of life. “It’s limiting in some ways,” says Kathy Raeside of Penfield, a metastatic breast cancer survivor. “It’s not something I can leave behind. I do try to enjoy my life, but it’s always there.” Acupuncture, Reiki, and QiGong are among the things that have helped Kathy cope.

As a mother of two, Kathy shares that being here for her family is of utmost importance. “To live as normal a life as possible is my goal,” she says. Having a strong support system has helped her through some rough patches. Kathy speaks highly of her doctor, saying that “She takes the
whole picture into account regarding quality of life.” And the support doesn’t end there. “My friends and family are ‘doing it.’ They help with housekeeping, take me to treatments, and they stay in touch. I think that’s the most important thing – staying in touch.” Helping others who are hurting because of this diagnosis is also high on Kathy’s list of priorities, and she has reached out to other metastatic breast cancer survivors at the Coalition.

Many of those facing this disease have done everything right, including getting regular screenings and engaging in good overall healthcare habits. The reasons why breast cancer metastasizes in some and not others remain unclear. As Kathy says, “It’s no one’s fault.”

Advanced breast cancer is not a road anyone needs to travel alone. Many among us have learned to live full, active, and meaningful lives with the disease. There is a sisterhood of women living with it right here in our community. They can be found at the Coalition, where they gather regularly for companionship and support, reaching out helping hands to empower each other, and inspiring those who know and care for them.

You can meet them as they mingle with others at Coalition functions. If you have been faced with this diagnosis, they will be there for you. You are not alone.


Our “Common Ground” Living With Metastatic Breast Cancer group meets the second and fourth Thursday of the month at 9:30am. For more information see page 10.

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### Complementary Therapies

Complementary therapies are those that exist alongside the realm of conventional medicine. They don’t discount or replace the benefits of standard medical treatments when necessary, but offer the additional benefits of a gentle, supportive approach to the body’s natural healing processes. There are many complementary therapies that have the potential to help those in treatment for breast cancer.

A few examples are:

- **Reiki** is a gentle laying of hands on or near the body. It is a healing technique intended to balance the flow of life energy in a person. When this energy is in balance, according to Reiki practitioners and many who avail themselves of this treatment, it can help ease stress, pain, and many other side effects of cancer treatment.

- **Yoga** is an ancient system of coordinated movements and postures linked with breathing techniques. Many who have faced cancer have found yoga to be a supportive practice. Dr. Karen Mustian of the University of Rochester Medical Center has put yoga to the scientific test and found it to be beneficial to cancer survivors in terms of fatigue, depression, and overall quality of life.* Her most recent findings will be presented to the American Society of Clinical Oncologists in June of this year.(2)

- **QiGong** is an ancient Chinese therapy that combines meditation with a series of coordinated movements and breathing techniques intended to balance the qi (chi) or life energy. Researchers in Shanghai found that women who participated in QiGong classes while undergoing radiation treatment for breast cancer reported better quality of life and less depression.(1)

- **Acupuncture** is another ancient healing practice centering on the chi. It involves inserting extremely fine needles through the outer surface of the skin at strategic points of the body, known as meridians, which affect the flow of energy. Some Western doctors believe it works by stimulating nerve responses. Whatever the mechanism, there is evidence that it helps a number of symptoms and side effects of cancer treatment, such as pain, nausea, hot flashes, and fatigue.(3)

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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 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.

Brown Bag Fridays
Any given Friday at noon finds a group of survivors conversing over anything from the latest research on Herceptin to our own locally-funded initiatives...from hair loss to funky re-growth...from neo-adjuvant therapy to the latest clinical trials...from prosthetics to bathing suits...from American Idol to The Voice...and on and on. Feel free to drop in for this non-traditional support group. Bring your lunch and we will provide delectable desserts.

RISE I & II
Relationships Intimacy Sexuality Empowerment
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.
For more information or to register for our programs, please call the BCCR at (585) 473-8177

Peer Advocates Lending Support: P.A.L.S.℠

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 June 14th. 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.
They are wives, mothers, daughters, teachers, pastors, physicians, Girl Scout leaders. They are survivors who share a common bond other than their breast cancer. They are young survivors.

Despite the fact that breast cancer risk increases with age, the reality is that, while uncommon, breast cancer does indeed strike younger women. At a time in life usually devoted to family growth and/or building a career, the issues of treatment, recovery and survivorship become the shocking and challenging reality for these women.

Four times throughout the year, the Coalition hosts a Young Survivor Soiree for these women, providing a safe, supportive place for them to network in a casual, social atmosphere. The Soirees are intended to be an opportunity for mingling with acquaintances, meeting new friends and chatting about issues related to being diagnosed with breast cancer at an early age. Above all, these gatherings are an enjoyable way to spend a Friday evening out!

On Friday, March 8, Crystal Dolan (shown left) from F. Oliver’s Oil & Vinegar shop on Park Avenue graciously agreed to join us for our Young Survivor Soiree. She offered tastings of fresh oils and vinegars from around the world. From popcorn drizzled with Smoky Chipotle Olive Oil to plain Greek yogurt topped with Raspberry Balsamic Vinegar, the ladies enjoyed many savory treats. Who would ever think to add infused vinegars to sparkling water to create a delicious fizzy drink? Yum! We learned about so many interesting flavor combinations. Laughter, friendship and networking with those who share a common bond can be very healing. I encourage all young survivors to join us on June 14 for our next Young Survivor Soiree. Food, friendship and fun...it doesn’t get much better than that! ♥

“We don’t heal in isolation, but in community.”
- by S. Kelley Harrell

Charlene Sudore and Kathy Cook, above. Johanna Johnson below

Enjoy the Breast Cancer Coalition Library

To learn more about our support programs and the information available at BCCR, please call Jean at 585-473-8177.

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!
As we welcome the longer days and warmer weather of spring, we also prepare for another busy season of health fairs, festivals and major fundraising events, starting with the Pink Ribbon Run and Family Fitness Walk on Mother’s Day, May 12.

Even during these relatively quiet months, The Breast Cancer Coalition has had a presence at several area Health Fairs and Community Fundraisers.

Big thanks to super volunteer Benita Aparo, who represented us at the amazing Bowl-for-the-Cure event at Clover Lanes in February and brought along her own helper. Welcome to our merry group, Clare French, and thank you for your enthusiastic assistance. We look forward to working with you again soon.

Our hard-working Board members Tom McJury, Mary Carafos and Patti Cataldi offered their presence at the Churchville-Chili Saints hockey event, Pittsford Hockey’s “Pink the Rink”, and Lilac Disposal’s Pink Tote fundraiser, respectively. We deeply appreciate the willingness of our Board to pitch in. We also extend our gratitude to our Board of Directors member, Aria Camaione-Lind, who spoke to an interested church group on behalf of the Coalition.

It takes the efforts of many to carry our message into the community, as well as to show our appreciation for the hard work and generosity of community groups. We would love to have YOU join our effort!

Correction

In our previous issue, we honored Jessica Nightingale in the Volunteer Spotlight and erroneously reported that the name of her husband is Rob. In fact, it was Jessica and Richard (Rich) Nightingale who attended the Artist Reception shortly after returning from their honeymoon. We regret the error and humbly beg the pardon of Jessica and Rich.

Volunteer SPOTLIGHT

Ann Breen - By Pat Battaglia

Anyone who has attended our evening seminars has probably met Ann Breen. She is usually the person with the smiling face behind our greeting table, extending a warm welcome to those who have come out in all kinds of weather, for all kinds of reasons, to attend these informative sessions.

Ann first became acquainted with the Coalition shortly after our center opened in its current University Avenue location. At the time, she worked as a receptionist in an office on Park Avenue, near our former location. Her employer was the cousin of one of the Coalition’s founding members, and Ann learned much about the organization. She had even attended our gala courtesy of her thoughtful boss. On occasion, people would stop in and inquire at her desk about the whereabouts of the Coalition, not realizing that our center had relocated.

After walking with a co-worker to make a delivery to our new office one day, she knew exactly where to direct those who were seeking our help. A new employment opportunity opened for Ann, and she took the offer, but never forgot the Coalition. This new situation came with an option to participate in a program for those who wished to give back to the community, and Ann knew what she would do. She came back to the Coalition, and has stayed with us ever since.

In addition to being our evening seminars greeter, Ann has been on hand to help with pre-registration for our Pink Ribbon Run and Family Fitness Walk. And she has also sold a large number of the beautiful, handmade bracelets (so generously donated to our organization by Mallory Dixon) to her co-workers, all for the benefit of the Coalition.

Jean Sobraske, our Program Coordinator, is especially grateful for Ann’s presence at the evening seminars. “She is a huge help in preparing the food and beverages, with clean-up, and greeting at the seminars. She has a warm, kind personality, and is always eager to assist.” Ann arrives quietly, lends a hand wherever needed, and leaves us feeling grateful for her dependable help and her gentle, gracious demeanor.

For lending a hand so conscientiously, and for so long, we shine the volunteer spotlight on a kind, considerate soul who shines with her own special light: Ann Breen.
The Good Food Collective

The Good Food Collective is a multi-farm version of Community Supported Agriculture (CSA), offering membership programs that connect people to local, sustainable foods and some of the best farmers in the area. The collective fosters a cooperative relationship between consumers and farmers, allowing people to buy fresh vegetables and fruit directly from local growers.

Like a traditional CSA, members pay in advance of the growing season and then receive fresh, quality produce during each week of the season. Unlike a CSA, which builds a community around and with a farm, the Good Food Collective seeks to build a network of farms around and with a city: Rochester.

For more information, check their very informative website: thegoodfoodcollective.com

Strawberry BBQ Sauce

Ingredients
- 1 TB olive oil
- 4 cups strawberries
- 1/4 cup chili sauce
- 1/4 cup ketchup
- 1/4 cup apple cider vinegar
- 3 cloves garlic, minced
- 1 tsp fresh cracked black pepper

- Heat olive oil in small pan and sauté garlic quick, about a minute.
- In a large saucepan over medium heat, combine half of the strawberries, the chili sauce, ketchup, pepper and sautéed garlic.
- Bring the mixture to a soft boil and simmer for 20 minutes to thicken. Add the remaining strawberries and cook just until heated through.
- Makes about 5 cups.
- Delicious with grilled pork or chicken. Also makes a great sauce to serve with cornbread.

Northeast Organic Farming Association of New York

Since 1983, NOFA-NY has led a growing movement of farmers, consumers, gardeners, and businesses committed to creating and maintaining a sustainable, local, organic food and farm system that's good for people and the planet. It is one of seven northeastern state organizational chapters that comprise the Northeast Organic Farming Association (NOFA).

The group works toward their vision by:
- Providing education, assistance, and support to regionally-based, sustainable farmers and individual gardeners to help them thrive.
- Educating consumers about the value in buying local, organic products.
- Helping consumers connect with regionally-based farmers.
- Working to make local, organic food available to all people.
- Advocating for policies that support a sustainable food and farm system.

Among NOFA-NY’s offerings are informational events on Community Supported Agriculture, called CSA Fairs, throughout the state. For more information on these events and more, go to their website:

www.nofany.org

These and many other delicious recipes can be found on the websites provided for these two fine organizations.
Mange-tout (Sugar Snap Peas) Pasta

Ingredients
1 (8 ounce) package dry penne pasta
3/4 (4 ounce) package cream cheese, softened
1 1/2 ounces Gorgonzola cheese
2 tablespoons cream
1/2 pound sugar snap peas, trimmed
2 tablespoons butter
salt and ground black pepper to taste

Bring a large pot of lightly salted water to a boil over medium-high heat. Add the pasta, and cook until al dente, 8 to 10 minutes. Drain, cover pot, and set aside.

Stir the cream cheese, Gorgonzola cheese, and cream together in a bowl until smooth. Set aside.

Bring another large pot of lightly salted water to a boil over medium-high heat. Add the sugar snap peas, and cook, 1 to 2 minutes, maintaining crispness. Drain in colander and run under cold water for 15 seconds to slow cooking but stay warm.

Toss peas with butter. Stir cream cheese mixture into peas, and toss to coat evenly. Serve immediately over cooked pasta.

Tip: After blanching the peas, submerge them in iced water or pour iced water over to slow, even stop the cooking process.

Serves 4

Announcing Our Spring 2013 Eat Well, Live Well Challenge

Join us for the next session of Eat Well Live Well. Sponsored by Wegmans, the purpose of the challenge is to form groups in which participants inspire and support each other in building healthy lifestyles using four simple “eat well live well” principles:

- Strive for 5 cups of fruits and vegetables every day
- Get moving
- Calories count, so watch your portions
- Measure your progress

Eat Well Live Well encourages individuals to become more physically active and increase the amount of fruits and vegetables they eat. Participants are asked to do three simple things for eight weeks:

1. Wear a pedometer (available free at the Coalition for survivors, $5 for friends and family) each day to count your steps. The goal is 10,000 steps a day.
2. Keep track of how many cups of fruit and vegetables you eat, with a goal of five cups per day.
3. Aim to make at least one meal a day follow the “half plate guide”: fill half your plate with veggies, fruit, or salad, and fill the other half with anything else.

Eating five cups of vegetables and fruit a day isn’t hard when you break it down meal by meal.

- Have fruit for breakfast. Top waffles, cereal, or yogurt with cut-up fruit. Or have your fruit with toast or a bagel. (1 cup)
  - Salad makes a great lunch. Two cups of airy salad greens count as one cup. Toss in shredded carrots, some garbanzo beans, bell peppers, and a handful of grape tomatoes, to easily add another cup. (2 cups)
- Keep fresh produce on hand for those mid-afternoon munchies. A cup of berries or a piece of fresh fruit will fit the bill nicely. Or you may choose carrots sticks, crunchy fennel, or any other crispy vegetable. (1 cup)
  - Build your dinner plate using the half-plate guide. (1 cup, at least)

Voila! 5 cups - goal accomplished!

You can check out the Eat Well Live Well website for more information about the program: www.eatwelllivewell.org

Call the Coalition, or email Alison Currie at alison@bccr.org.
We set aside an evening on March 13 to recognize the efforts of our many wonderful volunteers at our annual Volunteer Appreciation Party here at the Coalition. This event gives us an opportunity to honor and say “thank-you” to those who have so generously donated their time and talents to help us in many, many ways. We couldn’t do what we do without our faithful volunteers, and we are indeed lucky to have them!

There are many opportunities for volunteering throughout the year at the Coalition. You can choose from daytime, evening, and weekend events to fit your schedule. If you are interested in working a shift in our booth at the Lilac Festival that runs from May 10 through 19, or the Park Avenue Festival on August 3 and 4, please contact Lori Meath at 473-8177 or lori@bccc.org. And if you prefer a more active role, please consider helping out with the Pink Ribbon Run & Walk on Mother's Day, the “Tee’d Off at Breast Cancer” Golf Tournament on July 29, or the ARTrageous Affair Gala on September 28. We have something for everyone!
How You Can Help

COMMUNITY EVENTS
Volunteer representatives of the Coalition, who know of our mission and can answer general questions about the organization, help to maintain our presence in the community at the many area festivals, health fairs, and other events that take place throughout the year.

ADVOCACY
Members of the Advocacy Committee discuss issues of importance to those affected by breast cancer, attend educational conferences and workshops, and forge connections with our elected officials to ensure our voices are heard by those in a position to make changes.

RESEARCH
Members of the Research Committee participate in the decision-making process of how breast cancer research gets funded in our own region.

PINK RIBBON RUN AND FAMILY FITNESS WALK
We depend on an army of volunteers to help us in many different ways through the planning, preparation, and on the day of this heartwarming display of community support. It is also the only women’s 5K race in Rochester.

ARTRAGEOUS AFFAIR
Our annual gala and art auction is a complex undertaking, and there are opportunities at many levels to make a meaningful contribution to the running of a very lovely, colorful event.

TEE’D OFF AT BREAST CANCER GOLF TOURNAMENT
Our premier golf tournament, held on the third Monday in July, is another opportunity that offers multiple ways to make a difference; and to do that in a beautiful setting.

OFFICE / CLERICAL
If you have a few hours to spare and can help us manage data or catch up on a backlog of work, we’d love to have you.

PALS MENTORS
The PALS (Peer Advocates Lending Support) Program offers the support of a trained peer mentor to those who are newly diagnosed with breast cancer. No matter what side of that equation you may be on, this program may be just the thing for you.
Fond Memories From our 2012 Holiday Open House

Carl Foucht & Gail Levy

John & Alison Currie added musical entertainment for the evening

The beautiful centerpiece donated by Rockcastle Florist
The Bravery of Sisterhood
By Dominique Boller

“You’re so brave, you’re so strong, I could never handle that the way you did” a woman says to me. Why am I so brave? I didn’t stride through breast cancer walking tall with my head held high, smiling and upbeat. I did what I had to do, what I was asked and expected to do; nothing more nothing less. Mentally, I was dragged through this illness kicking and screaming.

Martyrs and saints, they’re valiant and brave. The soldier, firefighter and police officer, they’re courageous and full of daring. They make the choice of self-sacrifice. They make it their duty to put their lives on the line for us every day. I am a coward compared to that type of heroism. If I were given a choice, I’d never choose breast cancer. I’d never choose to lose my breasts. I’d never choose to be this lost, this uncertain, this scarred.

Then again, maybe I am brave for not blaming the world for my cancer. Maybe I am brave for asking tough questions and accepting difficult answers. Maybe I am brave for keeping my faith in God and my doctor’s appointments. Maybe just the simple act of getting out of bed every morning and not succumbing to depression is an act of bravery all its own.

I don’t feel brave, courageous or strong. I do feel like a positive role model, an encouraging story, a young survivor, a part of that unwilling sisterhood that is breast cancer. 

Photos from Dominique’s personal photography collection.

To Our Generous Donors
By Holly Anderson

The Coalition has received calls from those who are concerned about solicitors that identify themselves as being with a breast cancer charity organization. WE DO NOT SOLICIT FUNDS IN THIS MANNER. Though some charities may be deemed worthy by you to support, be careful about charities you have never heard of before.

We are approaching the season of fundraising walks, runs, races and bike-a-thons, thus we are using this opportunity to advise kind-hearted supporters about some precautions they can take when donating to charitable causes. Information included here is compiled from assorted Attorney General sites from around the country and from our own experience here at the Coalition.

Listen
When contacted by any organization soliciting contributions, listen carefully to what they tell you. Learn the name of the person to whom you are speaking, as well as the name and address of the organization; whether the organization is raising money for itself or if it is a fundraiser hired to solicit contributions; and whether the donation is tax deductible. The Breast Cancer Coalition NEVER solicits contributions by phone.

Make sure the organization representative is not using a sound-alike name. For example, the Breast Cancer Society is not the Breast Cancer Coalition of Rochester or the American Cancer Society.

Ask
If the solicitor comes door-to-door, ask for identification and written information about the charity. If the solicitor calls on the phone, ask for a brochure to be sent to your home. Legitimate charities should welcome your questions. They want people to know what they are doing for the community. Be suspicious of those who pressure you to donate right away.

Learn
Take time to find out about the charity. If this is a local organization, call them. Read the brochures provided by the organization at your own pace.

Call
Call the beneficiaries of the charitable funds: local schools, shelters, workshops, etc. Find out whether they are aware of the solicitation and have authorized the use of their names.

When you have decided to donate:
• Write a check and make the check payable to the charity, not the individual or group doing the fundraiser.
• Use the full name of the charity not just the initials.
• Do not send or give cash and never give a credit card number to anyone over the phone.

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Drug Shortages continued

level of evidence for each therapy. Among the questions to ask your team:

- Will this medicine be available throughout my treatment?
- If it runs out, what are my other options? Are they similar to my original therapy?
- Why is it unavailable? When will you have it again?
- What are the differences in effectiveness with the new medicine?
- What are the differences in side effects?
- Will insurance pay for this treatment? If not, what resources exist to help?
- Can I get treatment through a clinical trial?
- If I switch treatments, can I return to my original therapy when you get it again?

Even if you never personally face a shortage, consider what you can do to help others.

“As a whole, drug shortages are clearly a problem,” Dr. Winer says. “That it’s less of a problem for women with breast cancer shouldn’t make us take it any less seriously.”

HOW TO GET INVOLVED

Congress, government and advocates are working to address drug shortages. In July, President Obama signed a law which for the first time charges companies a fee to make generics. Money goes toward speeding FDA reviews of manufacturing plants and New Drug Applications. The law also requires companies to report known or anticipated shortages at least six months in advance.

The American Society for Clinical Oncology and American Cancer Society work to raise awareness of shortages, as does CPAN, the Community Oncology Patient Advocate Network. Dr. Frame, who serves as CPAN’s medical chairman, says women help because “when the doctor says something, it’s not as powerful as when the patient says it.” You can also write to your legislators, Dr. Winer says.

To learn more about getting involved, visit asco.org, cancer.org and coaadvocacy.org.

Hannah Walpole: Songs For a Cure
by Rebecca Solomon

Hannah Walpole began her second benefit concert for the Coalition last fall with Good Morning, Heartache, a smoky torch song that evokes gloom and darkness. If Hannah’s voice is any indication, however, her future in vocal jazz performance is extremely bright. And with her dedication to making a difference, Hannah’s impact on social issues will surely bring light to many causes.

The 17-year-old Pittsford Mendon senior, who will soon decide which school she will attend to further her music training, entertained a packed ballroom at Monroe Community Hospital on the evening of November 9th with a program of songs that showcased the range of her vocal talent. Existing fans and new ones enjoyed a cabaret of song along with an array of delectable desserts and drinks donated by local vendors, all amidst candlelight and glitter. Some hospital residents, attracted by the music, were also welcomed into the room to enjoy the show. All funds raised were donated to the Coalition.

Accompanying Hannah were Nick Weiser on piano and Vincent Criscuolo on drums.

“I am honored to have had the opportunity to work with the BCCR, raising funds and awareness for such an amazing organization,” said Hannah. “I view performing as a way of touching others, and I look forward to continuing to share jazz music through passion and joy in the future.”

We gratefully look forward to watching this young woman on her journey.

To Our Generous Donors continued

- When you donate over the internet, make sure the site is secure. The Coalition uses Paypal and/or First Giving for online giving. Both are secure websites.

Remember to save all your records such as cancelled checks or billing statements. They will be essential if you ever have to file a complaint, and will come in handy when you file your income tax return.

Get Involved!

There really is no better way to be certain that the charitable organization asking for your support is deserving than to become involved. Speak to the organizers. Participate in events. Volunteer. Contribute directly to these charities and you can be sure your money will be doing the most good.

All funds donated to the Breast Cancer Coalition of Rochester stay here in your own community!
Jean Guthrie - By Holly Anderson and Pat Battaglia

An amazing midwife - in the truest sense of the word - to many, on so many levels, we are grateful that Jean shared her life so openly. She had a generosity of spirit, a sense of presence, a gift of forthrightness and absolute honesty, and told us about her experience with no holds barred as this harsh disease progressed. Her spirit, that sense of who she was in this world, was always magnificently intact and never diminished.

Always ready with a warm smile and a kind word, Jean’s love of all living things was readily apparent. As she moved through months of ups and downs while facing her disease head-on, Jean’s daily struggles did not keep her from her beloved pets and the animals she cared for so well in her work as a veterinary technician. Nor did it cause her to retreat into herself. She always found a way to stay connected to the family she cherished and who cherished her right back. Our hearts are with her family, including her husband, Sean, and sons, Conor and Aidan, as well as her mother and sisters. Her loss is deeply felt.

Jean touched many lives in her solid, steady walk through her own, and she brought smiles to those who had the pleasure of crossing paths with her. We consider ourselves to be among those fortunate ones.

Snow Geese

Oh, to love what is lovely, and will not last! What a task to ask of anything, or anyone, yet it is ours, and not by the century or the year, but by the hours.

One fall day I heard above me, and above the sting of the wind, a sound I did not know, and my look shot upward; it was a flock of snow geese, winging it faster than the ones we usually see, and, being the color of snow, catching the sun so they were, in part at least, golden. I held my breath as we do sometimes to stop time when something wonderful has touched us as with a match, which is lit, and bright, but does not hurt in the common way, but delightfully, as if delight were the most serious thing you ever felt.

The geese flew on, I have never seen them again. Maybe I will, someday, somewhere. Maybe I won’t. It doesn’t matter. What matters is that, when I saw them, I saw them as through the veil, secretly, joyfully, clearly.

- by Mary Oliver

Friends Remembered...

Ed Connelly
Christopher Ellis
Jean Guthrie
Ann Nancy Hamond
Jan Skuse

Tributes Welcomed

Would you like to write about someone you have lost to breast cancer? We welcome submissions from friends and family members and are particularly interested in 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@bccr.org.

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

Pittsford Pink Panthers vs. Webster Thomas Hockey “Pink the Rink”

Coalition board member, Mary Carafos accepts the generous donation from the Panthers

In what is getting to be an awesome tradition, the Pink Panthers again took to the ice at MCCs Sports Centre on Ground Hog Day to benefit BCCR. And again this year, they managed to raise an amazing gift of $5310.00 for us to share with women and their families. Hey, did the goalie see his shadow??

Ridge Road Fire Department “It’s All About Community For These Firefighters”

Randy Jensen and Sue Davis with Holly Anderson, Lori Meath and Jean Sobraske

In their “spare time” between calls for help of all types and at all hours, the folks at Ridge Rd. Fire Dept. put their “all” into a monthly project to benefit the greater community. This year, as in the past, the sale of T-shirts resulted in a generous offering of $910.00 to the Coalition. Randy Jensen was particularly proud that, at his insistence, this year’s shirt was a lovely shade of rose pink. In spite of some doubters, the fantastic shirts SOLD OUT! We love your community spirit.

Kickin It For the Cure

On October 28th, Iota Psi Sorority at RIT presented Kick for the Cure to recognize National Breast Cancer Awareness Month. Kick for the Cure was two hours of a high intensity aerobics work out, including Zumba and Turbo Kick. All proceeds went to the Coalition through RIT’s United Way campaign. Over 100 people participated and helped raise over $1,032.89 Great work out for a great cause!

Aquinas Institute “Jar Wars”

Fall 2012 Spirit Week at Aquinas included a celebration of Awareness Day, during which the student body sported all manner of pink and engaged in a feisty competition between grades to raise money for charity. This year’s very grateful recipient of the $800 result was our own Coalition. THANK YOU, generous and spirited students, for your efforts.

Lilac Disposal Pink Totes “Local Supporting Local”

Karen Gutzmer and Lilac Disposal certainly have jazzed up the curb on refuse collection day in the Penfield and Webster area lately. And those pink totes represent a donation directly to Breast Cancer Coalition of Rochester from each customer who requested one. Wheel your tote out with pride, knowing that the Coalition received a kind donation of $1000.00 for the effort.

Trumping Breast Cancer, One Hand at a Time!

The lucky hands at St. John’s once again raised a much-appreciated $500 at their annual Euchre tournament. Thanks to Sue and Ray Tiede, pictured left, for coordinating this event.

Clifton Springs Dollar Tree

Customers and staff at the Clifton Springs Dollar Tree collected $400 in October to honor the strength of loved ones surviving or lost to breast cancer. Store manager Loretta Gute coordinated the “Memory Tree” project in memory of her own Mom, Dorothy Kriegelstein. Pink ribbon pins and candy filled glasses were sold and a memory ribbon added with each contribution. The reaction was overwhelming, and resulted in twice the anticipated amount being raised. Thanks so much for such a thought-filled gift.
Under the fearless and tireless leadership of Kathy O’Neill and her merry helpers a stunning $10,971.00 was raised at this annual event. This is the eleventh year for Kathy’s crew and they packed Clover Lanes to the brim for two shifts of bowlers. Many teams “dressed” for the occasion, and it should be noted that apparently pink tutus DO improve one’s score! Anyone who did not already arrive decked in pink must have visited our merchandise table which raised another $417.00. It is hard to imagine any group having more FUN while giving so generously. A thousand thank you hugs to everyone involved!

The ice rink at Scottsville was positively PINK in every way on a cold Saturday, January 26th as the Churchville Chili Saints hockey team donned specially fashioned pink jerseys, pink-taped guards, socks, and skate laces to meet Batavia and raise money for BCCR. Clearly, real men do, indeed, wear (and play hard in) pink! Thanks to Kevin Clar and all the folks who made this amazing event happen I such a BIG way. $2179.94 was raised WOW!!

Our deepest thanks go to Ellen Brenner and Boots Bourtiller of Fleet Feet Sports and Yellow Jacket Racing for holding a series of events during Breast Cancer Awareness Month (October) that resulted in a generous gift of $3000. A portion of proceeds from Pumpkins in the Park, Asic shoe sales, Diva Day bra sales, and Pink Ribbon shirt sales were designated for the Breast Cancer Coalition. Boots, Ellen and their amazing staff are always on the lookout for creative ways to give back to the community, and we really appreciate their efforts on our behalf.

Sweet and sassy harmonies thrilled over 150 in a smiling audience for Pinkappella at RITs Webb Auditorium January 27th. Thanks to the young ladies of RITs Encore and Vocal Accents a cappella groups for a well planned and executed afternoon of GREAT music. Also big thanks to the U of Rs two co-ed groups, After Hours and Trebellious for joining in the fun and fund raising, making possible a donation of $415.00 to our efforts.

If you bake it, they WILL come! Sophie (pictured here with her yummy treats) sure proved that one Friday lunchtime during her school break. She and her Mom baked up a storm, offering such delectables as cake pops and something fabulous they called “baklava bars” as well as other awesome treats. The staff of surrounding offices as well as our Brown Bag ladies definitely appreciated the treats, buying everything Sophie had and helping her raise $94.36 for the Coalition.

Penfield Peds staff savored the chance to wear their comfy blues to work, paying a small “fee” for the privilege, and offering the $170 result to the Breast Cancer Coalition. Thanks for thinking of us!

We love unexpected gifts, and especially love them when they come from youth organizations. We received a gift of $275.00 from the hard-playing Wayland Redskins Youth Football League. Thanks, kids, for sharing your spirit and generosity with the Breast Cancer Coalition.

Fleet Feet Goes the Distance!

Pinkappella “Sweet Sounds for a Cause”
In Honor of:
All Breast Cancer Survivors
Fran Mann
Celia Abeloff
Susan Fox
Holly Anderson
Anne & Michael Bishop
Arlene & Dr. Kenneth Davidson
Deb Cleveland
Renee Eberling
Connie Lembaris
Maura Steed
Judith Stewart
Tom & Holly Anderson and Family
Crystal Doody & Maria Grice
Pat Battaglia
Holly Anderson
BCCR Staff & Volunteers
Anne & Michael Bishop
Suzanne Snecker
Mel Bianchi
Helene Ehmann
Cathy Bishop
Susie Smith
Patricia Cataldi
Angela Cataldi
Jessica Cataldi
Aria Camaione-Lind
Barbara Pearl
Mary Carafos
Mike Carafos
Sabina Wells
Chrysa Charno
Ellen Bacon
Bonnie Chiappone
Alicia Rogers
Janet Clark
Richard Clark
Barbara Compa
Jane Oertel
Phyllis Connelly
Helene Ehmann
Laurie Cook
Michelle Cook

Claire Cunningham-Kaler
Kay Grady & Alan Frost
Sharon Dawley
Jennifer Collins
Angie Demyda
Holly Anderson
Margaret Sprinkle
Anne Devine
Richard McKeown
Cindy Dykes
Holly Anderson
Stephen Evangelisti, M.D.
Anesthesia Care Associates
Wendy Ford
Linda Ballard
Marilyn Fox
Susan Fox
Linda Gaylord
Pat Grover
Jennifer Griggs, M.D.
Suzanne Demers
Debbie Hevers
Mark Roos
Kristen Hurbutt
Mark Peterson
Dorrie Iaculli
Kathrine Iaculli
Lisa Ivers
Joan Alberti
Susan Ingram
Maureen Kingston
Carolyn Sheild
Diana Kohlbrener
Karen Arcara
Myra Jean Koster
Sallie Parsons
Jean Lazeroff
Valerie Tahan
Rose Leonard
Juliette & Forrest Cummings
Dr. Neal Levitt & Dr. William Zugner
Dental Office Staff Members

Marriage of Patricia Robinson & Brian Fleming
Evelyn & Tom Fender
Niki MacIntyre
Holly Anderson
Sandy Manahan
Sharon Lauffer
Margaret McGrath
Anonymous
Sandra Al-Ubaidi
Mary Louise Basile
Kathleen Colliflower
Donna & Sandro Detre
Barbara Fernaays
Pamela Harper
Celeste & Joe Mercury
Gloria Mercury
Marge Mercury
Bonnie & Michael Mongeon
Diane O’Brien
Laurie & Mike
Mary Paiz
Mary Ellen Perry
Kathleen & Rick Wessman
Marge McGuckin
Thomas Kinslow
Judy McMahon
Katharine McMahon
Susan Meynadasy
Holly Anderson
Betty Miller
Connie Schmeer
Jennifer & David Nicoletti
Kathleen Thomas
Dara Petersen
Barbara Arnold
Dr. Saul Presberg
Martin Presberg
Barbara Rosen
Kaleen Litvak
Marianne Sargent
Anonymous
Karen Scarbrough & John Chaffer
Mary Ann Charno
Nancy Schlinger
Vera Gramlich
Jean Sobraske  
Holly Anderson  

Dr. Alex Solky  
Henra Briskin  
Hannah Solky  

Susie Smith  
Anne Smith  

Mary Steinbugler  
Jane Steinbugler  

Anne DaSilva-Tella  
Margot Garcia  

Jerry Valentine  
Teresa Kennelly  

Viola Family  
Tyler Spencer  

Debra Vogler  
Anonymous  

Dennise Webster  
Doug Dupree  

Ann White  
Jennifer Collins  

Ellen White-Harrington  
Carol White-Llewellyn  

Nancie Williams  
Sallie Parsons  

Connie Zeller  
Holly Anderson  

In Memory of:  
Janice Sinnott-Allen  
Maura Allen & Jay Stetzer  

Sue Bailey  
Dr. Mary Ciranni-Callon  

Catherine Barchello  
Corinne Cino  

Lisa Bariga  
Pauline & Len Ofswitz  

Jean Batz  
Cindy Gibson  
Judith & Gregory Graham  
Neurology Associates of Rochester, P.C.  
Mary Ann & James Rall  
Rochester Fire Department - ENGINE 2  
Rochester Fire Department - ENGINE 6, Group 3  
Donna & Patrick Trobia  

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Arlyn Grossman  
Robert Grossman  

Patricia Haralambides  
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Carol Pittinaro  

Barbara Healey  
Thursday Night Swing-In Dance Company - Pink Pig Piggy Bank  

Gail Heidt  
Richard Heidt  

Theresa Keenan  
Tracey Ingerick  

Syd Krauss  
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Lisa Kubby  
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Founder’s Circle $5,000 +
Parkleigh - ARTrageous Affair Sponsorship
Women’s Council of Realtors

Visionary Circle $1,000-$4999
Richard Bell Foundation
Big Oak Driving Range & Golf Shop
Bishop Kearney High School
Broads Regional Arm Wrestling League - BOOBRRAWL
Canandaigua Girls Hockey 16U
Crossfit Boomtown
Cycle Stop - 4th Annual Dice & Bust Run
Generation Capital Management, LLC - ARTrageous Affair Silver Sponsorship
HAC Girls Volleyball - “Dig Pink”
John D. & Seana L. Holz Foundation
Kick the Cure - RIT student group Zeta Tau Alpha
Marek Krasicki, Bill Shearer, & Stuart Ward
Heidi McIntosh - Zumba Fundraiser at Studio 413
Newark Reds Cheerleading Boosters - October Cheerleading Competition
Nightmare Manor
Pluta Cancer Center - ARTrageous Affair Silver Sponsorship
Salvatore’s Old Fashioned Pizzeria - October Pink Box Promotion
Risa & Dan Saltzman
to the dance center’ - Shop for Hope
Town of Victor - Fat Tire Festival
Warm 101.3 - Melissa Etheridge Tickets, Guitar, & Meet and Greet
Western Regional Off Track Betting Corporation - Batavia Downs
Xerox - Chili & Dog
Yellow Jacket Racing - Pumpkins in the Park
Yellow Jacket Running & Fitness/Fleet Feet Sports - October Awareness

Dr. Wende W. Young - Mt Hope Enterprises

Advocate’s Circle $500-$999
Allstate Foundation - Employee Volunteer Ann Breen
Artistic Designs Hair Salon - October Cut-a-thon
Campus Auxiliary Services & The Big Tree Inn
Pam Cooper
Jodi & Lucas Cullen
Frontier - ARTrageous Affair Pink Sponsorship
Cynthia & Douglas Jack
Angela Martin
Brittany Mechler - Sweet 16 Birthday Party
Megan Mendolera - 2nd Annual October Zumba Class
Mary Micket
Stephanie Partridge
Pluta Family Foundation - ARTrageous Affair Pink Sponsorship
School of the Arts - JV & Varsity Girls Volleyball
Tyler Spencer - RIT Student
Van Borrel Ford
Hannah Walpole - Songs for a Cure
West Webster Volunteer Firemen’s Association
The Westport Fund

Pink Ribbon Circle $100-$499
ADT - Bake Sale
American Legion - Sons of the American Legion Post 367
Anonymous (2)
Karen Ashbaugh
Jeanette & Benjamin Atkinson
Bell and Howell - Jeans Day
Pam & Allan Bernstein
Blades for Life - PinkKniff Shelf
Jennifer Bowen
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Mary Ellen Derry
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Erwins Cleaners - October Pink Promos
EZ Bottle & Can Return
Tricia Fagan - Sipadha Designs Party with a Purpose
Mike Finegan
Gates Chili Federal Credit Union - October Fundraising
Gear Resource Technologies, Inc.
Greece Arcadia High School - Class of 2013
Greece Public Library - Dress Down Denim Day
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IDI Billing Solutions - Halloween Coffee Fundraiser  
Makayla Impallaria  
Insurance Auto Auctions - Nancy Wiley  
Jade Enterprises Media  
Michelle Jaromin  
Debra Kaczmarek & Wendy Koch - Modified Yard Sale  
Pam Kindig  
Chris Klem  
Deborah Leary  
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School for the Deaf - Denim Day  
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Jack Underwood  
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Joanne & Tony Ventura - Everything Free Garage Sale  
Jeanne Vehuls  
Wegmans Food Markets  
Sue Weisler  
Robert Westlake  
Hans Witte  
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Zion Episcopal Church - The Lucy Wardlaw Committee  

**Contributor’s Circle $1-$49**  
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The Sisters of Rochester NY Zeta Tau Alpha Alumnae Chapter
only imagined in medical school. Delivering babies, working with severe illness, and working across language and cultural differences—here were the patients for whom I had trained! Challenging stories compelled me to reflect and to process what I was seeing and learning. I again turned to writing, to help process experiences and to share the learning with others. I wrote from my perspective as a community physician, practicing in a setting where I knew something about the context of both tertiary care, having recently been a resident, and understanding the close connections among the migrant farm workers.

When one of my young patients was transferred to the tertiary university hospital and unexpectedly died, I soon noticed other young migrant patients coming in requesting unusual testing for seemingly benign symptoms. Writing about this experience helped solidify my understanding of the importance of the biopsychosocial model in health care.

Caring for a Mexican migrant farmworker couple during their pregnancy with an anencephalic baby gave me intense emotions: doubt in my own competence, anxiety about how the birth would go, and dreams, sometimes nightmares, of a difficult labor and birth. Writing about my emotions, doubts, worries, and particularly my fears, helped me tame the fear and realize that my emotions, although raw and real, didn’t need to define my experience with this difficult birth. This recognition allowed me to have my feelings and also put them aside while I worked with the family and the labor and delivery staff during this infant’s birth. Sharing this work took several years and ultimately helped me resolve the emotions I experienced.

My first several years of academic medicine found me writing more empiric than creative work. After returning to the same inner-city community health center as faculty where I’d trained as a resident, my patients’ stories captivated me, and I began to keep jotted notes in my clinic desk drawer. I happened upon 55-word stories in 2007 and was intrigued with the brevity and power they represented. I began to convert some of my scrawled notes into brief stories and became hooked. Several of these pieces remind me of the daily challenges of practice with real people, in contrast with the tidiness of clinical guidelines and evidence-based medicine. Writing brief stories of compelling moments in my practice helps me remember and honor my patients and our discipline.

Writing took on a whole new dimension when I was diagnosed with breast cancer in 2009. After a routine mammography revealed a lump, the biopsy came back showing ductal carcinoma in situ (DCIS). I can recall my terror, notwithstanding the radiologist’s statement that “This is the one to have.” As I called the Breast Cancer Coalition of Rochester (BCCR) soon after diagnosis, hoping that I could attend some of the programs, I remember how tentative I had felt. When Tracy, the program coordinator, returned my call, I told her, “Well, I only have DCIS, so I’m not sure I qualify.” Bless her for her unforgettable response, “Oh, honey, I’m so sorry, but you do qualify. Welcome to the club!”

BCCR hosts a regular writing group for women dealing with any stage of breast cancer. Writing in response to prompts, or just as often, ignoring the prompts and writing from my heart, was an amazing way for me to connect to my experience as a patient and to reflect on the challenges and downfalls of the health care system. Writing with this group helped channel the limited energy I had going through treatment toward listening to myself better.

As I experienced the fear of the pre-operative suite, the exhaustion and fatigue accompanying radiation, and the unexpected connections I felt with certain staff and even other patients, writing became a steady companion, a way to catalog and manage these new experiences. As I healed, I reviewed my writing and picked out pieces that I thought could be helpful to others working in health care. In this way, my own illness has become an important topic of my learning and writing, in addition to my role as a physician caring for others.

For me, writing has represented an important evolution in my work as a physician and person. Writing has helped me reflect on and understand life experiences far different from my own and has helped me reflect on my own family’s role in becoming a physician. Writing helps me to capture, honor, and share important moments of clinical care both from the vantage point of the physician and the patient.

Writing helps me to capture, honor, and share important moments of clinical care both from the vantage point of the physician and the patient.
**Thank you to our ROC the Day 2012 Donors**

The Coalition received $3,251 in donations!

Scott Adair
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**Gifts in Kind**

**Hug-a-bears “Sharing Some Love”**

We were thrilled by the donation of these soft, cuddly hand made bears and cats to use in our PALS packs for newly diagnosed women. A big thank you to Barbara Stetson of Real Things & Fanciful Thoughts. They will function beautifully as supportive pillows for use after surgery, and best of all, they were made with love.

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**Road Trip!**

We were pleasantly surprised on a recent Friday afternoon by a group of students from Charles Finney School, stopping by on their “Project Compassion Road Trip”. They had given careful thought to some small items that a woman diagnosed with breast cancer would find comforting and selected some cozy pink flannel pajamas and soft, thick socks to donate. We will share them gladly and know that this lovely gift will be enjoyed and appreciated. Apparently after visiting us, they were off to make similar stops at fourteen other agencies who serve folks having a tough time. It’s all part of Finney’s goal to “Do Something Greater”.

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“…to help people at all times…”

Girl Scout Troop 60716 from Webster met one afternoon to work on a very special project. With the help of five adult volunteers and working on five sewing machines, the girls, all third graders, pieced together two lovely quilts. The quilts were taken home and finished by troop leader and breast cancer survivor, Amy Weetman, and donated to the Coalition to be included in PALS Packs. These extra special quilts will go a long way toward uplifting the spirits of the women who receive them. Kudos to all involved in this project for their thoughtfulness!
Upcoming Events & Programs at the Coalition

Mother’s Day  
Sunday, May 12, 2013  
Pink Ribbon Run & Family Fitness Walk  
9:00am

Wednesday, May 22, 2013  
Marcia Krebs, M.D.  
Long-term Effects of Chemotherapy After Breast Cancer  
7:00 - 9:00pm

Wednesday, June 26, 2013  
Avice O’Connell, M.D.  
Breast Density  
7:00 - 9:00pm

Wednesday, July 24, 2013  
Katherine Streeter, R.D.  
Nutrition After Breast Cancer  
7:00 - 9:00pm

Wednesday, August 28, 2013  
Karin Cole, L.M.T.  
Massage Therapy & the Power of Touch  
Molly Branch  
Acupressure & Acupuncture  
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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PALS Coordinator  
Pat Battaglia  
Technical Support  
Alex Cheek
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

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)

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Breast Cancer Coalition of Rochester
840 University Avenue Rochester, NY 14607
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info@bccr.org • www.bccr.org

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

THE 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)
- Digital camera
- Blank CDs and DVDs (writable)
- Computer paper, white
- Large glass display case for merchandise
- 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
- Paper cutter
- Sleeping masks (lavender or unscented only)
- Thank you cards
- Electric pencil sharpener
- 3-hole punch (heavy duty)
- Paper products: napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam products)