Mother’s Day dawned with the promise of a clear, sunny day, as hundreds of volunteers and thousands of runners, walkers and supporters gathered at Genesee Valley Park for the 13th Annual Pink Ribbon Run and Family Fitness Walk. The perfect weather conditions drew near record crowds of participants and supporters to cheer them on.

Walkers and runners alike enjoyed scenic views of the Genesee River and Erie Canal. The park provided a beautiful...
On the very last day of the New York State legislative session, the State Senate and State Assembly passed a medical cannabis bill, making New York the twenty-third state to create legal access to this botanical for seriously ill patients. This includes cancer patients suffering from nausea, vomiting, loss of appetite and pain. After days of tense negotiations, the bill was passed in the final hours of the legislative session on Friday, June 20th. As we go to press, Governor Cuomo is scheduled to sign the bill into law this very day. Our Advocacy Chair, Marianne Sargent, is present for this historic and monumental moment (read her report p.5). The long-awaited law will also provide relief for thousands of New Yorkers suffering from other serious and debilitating conditions – such as multiple sclerosis and epilepsy – by allowing the use of medical cannabis under the supervision of their physician.

On that last day of session, patients, caregivers and providers watched from the gallery as the Senate debated and then voted 49 to 10 in favor of the bill. We were there and watched proudly as, one by one, Senators Grisanti, Maziarz, Robach, O’Brien and O’Mara - our own Upstate New York Senators and champions of the bill - voted in favor of the legislation. In the eleventh hour, we were appreciative that Senators Gallivan and Ranzenhofer joined their Senate colleagues in “aye” votes, but frustrated that they would only support the bill after smoking was removed as an option, essentially ignoring the role of physicians in determining how this botanical should be utilized by specific patients. (In a government-funded Institute of Medicine report, research demonstrated that there is a subset of patients who benefit from smoking cannabis for their illness. Why tie the hands of their doctors?) Though we missed the Assembly passage of the bill, we are grateful to our local Assemblymembers Bronson, Gantt and Morelle for wholeheartedly supporting the legislation as it evolved.

This has been a challenging piece of legislation for the Coalition. Though we have supported different versions of this bill throughout its history, it wasn’t until early last year, after meeting with Julie Netherland of Drug Policy Alliance and Anna Saini of Vocal NY, that our Advocacy Committee, followed by our Board of Directors, decided to push up our collective sleeves and put our all into it.

But why would a community-based breast cancer organization care so deeply about medical cannabis? Simply, too many patients are needlessly suffering from uncontrolled nausea. When we considered that the most feared side effect of cancer treatment is nausea and vomiting, and antiemetics are too often ineffective in reducing the nausea, we understood. As Luke Peppone, PhD (URMC/Wilmot Cancer Center) pointed out while chatting before a recent radio broadcast, two of their large nausea and vomiting studies, containing about 1,000 participants, demonstrated that while vomiting was well controlled (less than 20% reporting vomiting), nausea was much less controlled with approximately 60% of participants reporting nausea. That’s too high. Along with advocates at the Coalition, researchers at URMC were anxiously awaiting news that the Compassionate Care Act had passed so they could get to work. Utilizing the

Continued on page 28
The word “survivor” can mean different things to different people. It’s a rare individual – if such people exist at all – that has never lived through some adverse event; has never faced a seemingly insurmountable life challenge and moved forward with it. A breast cancer diagnosis ranks high among these traumatic events. The Coalition has been serving this special community of survivors since 1997, and recently we have opened our programs to include our sisters who have been diagnosed with gynecological cancers.

Expanding our reach has provided members of the Coalition's breast cancer community with the opportunity to meet some amazing women facing their own unique, upstream journeys; to learn of their struggles and challenges, but more importantly, to learn of their hopes and joys and support them as they find their way through the difficulties their diagnoses present.

Jacque Shatzel Ater was among the first to answer the invitation to those facing gynecological cancers, and has become a regular in our Monday evening yoga classes, where she has found acceptance, caring, and deep interest in her journey. “I appreciate the sisterhood in this camaraderie,” she says.

A speech pathologist in the Unity Health System as well as in private practice, Jacque is former Director of Speech Pathology at the now-closed Geneseo Hospital. She has also been an adjunct professor at Nazareth College. Jacque loves everything about her work; her patients and their families as well as her colleagues. But in September of 2012, her life took an unexpected turn.

“This diagnosis came out of nowhere,” Jacque recalls. Initial symptoms suggested gall bladder disease. Eventually, a pelvic CT scan was ordered, which showed suspicious areas on Jacque’s uterus and an ovary. Within 48 hours of that result, a transvaginal ultrasound was done, which showed uterine and ovarian lesions. A CA 125 blood test followed this discovery. CA 125 is a tumor marker that can become elevated in cases of ovarian cancer, among other conditions, and while it isn’t an accurate screening tool for the general population, it becomes part of the diagnostic picture when ovarian cancer is suspected. Together, these two tests are considered definitive for female reproductive cancers. In Jacque’s case, her blood work showed that her CA 125 level was, in her words, “barely outside of the normal range”.

Surgery followed ten days later. Jacque had a complete hysterectomy, which was performed laparoscopically, sparing her many of the discomforts of major abdominal surgery. Pathology results showed two separate cancers: a stage IIIB ovarian cancer and a stage IA endometrial cancer. Chemotherapy was begun, and for Jacque, that meant fifteen treatments of Taxol and Carboplatin. Eighteen rounds of chemo were originally scheduled, but as her blood counts fell precariously low, Jacque’s last three treatments were foregone. During this time, she also underwent four rounds of a short

Ovarian Cancer Facts*

- A woman’s lifetime risk of developing invasive ovarian cancer is 1 in 72.
- Women diagnosed at an early stage have a much higher five-year survival rate than those diagnosed at a later stage.
- Approximately 15 percent of ovarian cancer patients are diagnosed early.
- 22,000 new cases are diagnosed each year. 14,400 die from this disease each year.
- No screening test exists for ovarian cancer, but several tests are used to monitor those at high risk, such as those with:
  + BRCA mutations
  + A strong family history
  + Ovarian cancer symptoms
- A personal history of breast cancer may increase the risk for ovarian cancer, but that risk is still usually quite low.
- Symptoms can mimic nongynecologic conditions. Persistent symptoms that represent a change from normal should be reported to a doctor. They are:
  + Bloating
  + Pelvic/abdominal pain
  + Difficulty eating
  + Urinary frequency

*Source: The Ovarian Cancer National Alliance; www.ovariancancer.org
For further information and support: www.eyesonthelprice.org

Continued on page 29
By January 1, 2020, we will know how to end breast cancer. With that stated mission, the National Breast Cancer Coalition (NBCC) launched a campaign in summer 2010 known as Deadline 2020®, “a call to action for all stakeholders to focus efforts on knowing how to end the disease by the end of the decade”. The NBCC 2014 Leadership Summit and Lobby Day in Washington, DC on May 3rd – 6th focused on the knowledge, policies and strategies needed by advocates to carry that campaign forward.

On Tuesday, May 6th, NBCC Advocacy Day focused on two national legislative agenda items:

1. The Accelerating the End of Breast Cancer Act, S. 865 and H.R. 1830, the public policy piece of Deadline 2020, defines an important role the federal government must play in this effort by establishing the Commission to Accelerate the End of Breast Cancer to assess and strategize the ways in which breast cancer research is funded and conducted. In NBCC’s words, “The Commission [would be] comprised of representatives from biomedical research, business, breast cancer advocacy, and other related and unrelated disciplines [and would] be tasked with identifying promising opportunities, tools, technology and ideas not currently being prioritized …”

First introduced in the 112th Congress, the bill was re-introduced in the 113th Congress, our current Congress, and at the time of this writing has the support needed in the House to pass the bill, but still lacks the 50 Senate votes required for passage. The seven House members visited by Coalition advocates – Representatives Chris Collins, Richard Hanna, Brian Higgins, Dan Maffei, Bill Owens, Tom Reed, and Louise Slaughter – all co-sponsored H.R. 1830 early on; as did both New York Senators Gillibrand and Schumer, who signed onto S. 865. At this time, the entire New York State congressional delegation has signed on as cosponsors.

2. The $150 Million Re-Appropriation for the Department of Defense (DoD) Breast Cancer Research Program (BCRP) for Fiscal Year 2015. Widely viewed as a unique, innovative research model, the DoD BCRP was created in 1992 to “eradicate breast cancer by funding … high-impact research through a partnership of scientists and consumers.” Since 1992, over $3 billion have funded research projects, chosen by a much-admired two-tier peer-review process. Results include development of the drug Herceptin, clinical trials to establish the efficacy of digital mammography, and treatments that are now standards of care. With funding levels decreasing and the sequester threatening some programs, advocates from across the country have worked steadily with NBCC to ensure continued funding for this program on a yearly basis. This appropriation is scheduled to come to the floor for a vote in late summer or fall; given the reality of election year politics, however, the vote may not actually take place until after the November election. More information at http://cdmrp.army.mil/bcrp/

While the above measures address policy, other aspects of the Deadline 2020 campaign involve catalytic research projects currently underway (known collectively as the Artemis Project) and seed grants for future catalytic projects, strategic summits now being planned, and a global grassroots campaign being developed in workshops like the ones that took place in May in Washington.

What is the take-home lesson for all of us who are passionate about, first, finding a cure and, ultimately, knowing how to prevent breast cancer? Advocacy drives research and public policy, and in a world of shrinking dollars and growing demands, grassroots calls, emails and visits by citizen advocates – all of us – can inspire and sustain interest, provide answers, and help make allies of policy makers who might not otherwise have a connection to the issues that are important to people affected by breast cancer. We work most effectively when we work through the lens of many diverse voices.

Rebecca Solomon is the Coalition’s Team Leader to NBCC. Questions on this article? Contact the Coalition at info@bccr.org

SAVE THE DATE: Eleventh Annual Terri Schmitt Legislative Reception. Wednesday, August 13, 2014, 5-7pm.
Over the past year, members of the Coalition’s Advocacy Committee have read, discussed and networked with like-minded groups to learn about and advocate for the Compassionate Care Act (CCA); more commonly known as the Medical Marijuana Bill. Hearing the personal experiences of the women and men we serve prompted us to explore this legislation more fully. In other countries, this botanical has been used for many years to address the nausea, fatigue and malaise that may accompany chemotherapy treatment. Learning how tightly regulated this product would be in our state motivated us to lend our time and voices in support of passage of the CCA into state law.

Currently in the United States, twenty two states and the District of Columbia have enacted medical marijuana laws. The proposed New York law has the benefit of learning from past versions as well as the experiences of the states that went before us. The New York State Breast Cancer Network has supported past versions of this bill since the late 1990s, and it is an issue that has been discussed by our group before. We believe this newest version would provide patients with safe access to a safe product. In the past six months, we have witnessed a large number of community health groups and individuals sign on in support of medical cannabis. This spring, the New York Academy of Medicine voted to support this legislation, adding their voices to more than six hundred individual doctors already supporting the CCA.

The Compassionate Care Act would create a “seed to sale” process, regulated by the state health department, of growing and dispensing cannabis to registered patients under the care of medical professionals. Individuals must be deemed to have a life threatening or debilitating medical condition such as cancer, multiple sclerosis, Dravet’s Syndrome, PTSD or HIV/AIDS. The medication may be administered as an oil, a patch, through a vaporizer or inhaled. Given the breadth of health conditions this plant will be addressing, decisions regarding how to administer it will be left in the hands of health care providers.

Advocating for this bill has given us many opportunities to have in-depth discussions with our local state legislators. We appreciate their time and the views they’ve expressed when meeting with us. They have asked tough questions and presented us with various scenarios and concerns. We left each gathering with homework; there was information to be found, verified and shared. We also left with a deeper urgency and increased understanding of the issues at hand. Our Coalition neighbor, Assemblyman Harry Bronson, was an early cosponsor of this bill, which was brought forward by Health Committee Chair Dick Gottfried. The Assembly has been a frequent supporter of past versions and they did not disappoint the Compassionate Care patients and advocates. On Tuesday, May 27, the New York State Assembly voted to accept the Compassionate Care Act by a margin of 91 to 34.

While the NY Senate has presented different challenges, we have also agreed to support this legislation and cosponsor the bill. Senator Tim O’Mara (Elmira) has become a supporter as well. All of these legislators invested a large amount of time and energy in reading the information provided as well as

Continued on page 7
Wednesday, May 7th marks one year since cancer entered my life. One year of the highest of emotional highs and the lowest of depressive lows. A roller coaster of scans and surgeries and infusions and injections and research and laughs and tears and fears and celebrations and joys and soul-searching. It's been a truly awesome year. I've learned so much about myself: my resilience, my strength, my pain tolerance, my body’s ability to heal. And I've learned so much about the goodness in others - loved ones and friends and strangers alike.

So as I celebrate my very first cancerversary - nearly 3 months since being declared “cancer-free,” I find myself living in a strange space in my head. Cancer had become a part of my identity. An identity I certainly didn’t ask for, but since it was handed to me, I decided to make the very best of it. And I found that the more I embraced my situation, the easier the whole process became. Petty worries fell away. My purpose and place in life became crystal clear. I was happier. I was calm. contentment that I had never felt the grace that is gifted upon you yourself right here right now.

But here I am three months out I've lost my identity. I am no longer girl who had cancer. And what does myself and not sure where to focus drifting out into this vast endless sea with no sail and no rudder and no anchor. Aimlessly drifting. No direction. Just floating away. When I had cancer, my only purpose in life was to do whatever I needed to get well. I was living each day moment to moment. Staying in the present moment is a heck of a lot easier when it’s all you have and it’s all you can handle mentally or physically.

But now that I am on this side of it, I feel like this wide open expanse of future opened up for me and I am feeling stuck and paralyzed, not sure what to do next but feeling this intense urgency to just do something. I’ve been given the gift of life; I better make the most of it and live, damnit!

But make sure you live right! Don’t waste it! Don’t make the wrong choices! Don’t waste time!

I am placing some seriously high expectations on myself. That little slave driver in my head is cracking the whip and pushing me hard once again. I find myself right back where I was before cancer. Negative self-talk which leads to feelings of inadequacy, sadness, depression, and anxiety. Self-abuse like this holds us back from enjoying life and truly living freely.

In May of 2013, Tiffany Staropoli was diagnosed with stage IV colon cancer. Nine months later, after several surgeries and rounds of chemotherapy, she was found to be cancer free. During those long months of treatment, Tiffany found an unconventional and inspiring way to cope with her situation. She danced whenever and wherever she could - joyful, exuberant dancing; the sillier, the better. Her husband posted a YouTube video of Tiffany dancing that went viral. She also shared her journey through a Caringbridge page and eventually her own personal blog, Loving Cancer, which can be found at tiffanystaropoli.com. In her latest blog entry, Tiffany speaks from the heart to survivors of any type of cancer, or any emotional trauma. We came to know and love Tiffany while advocating for the Compassionate Care Act. We are grateful to her for allowing us to reprint her words here. -Pat Battaglia
And it dawned on me…

Self-sabotaging behavior in itself is a certain type of cancer.

Let’s ponder that for a bit.

The definition of cancer according to dictionary.com is “any evil condition or thing that spreads destructively.” Miriam-Webster says that a cancer can be “a practice or phenomenon perceived to be evil or destructive and hard to contain or eradicate.”

Cancer, in a sense, can then be seen as something that can happen to you AND cancer can be something that you can create.

So am I making my body unwell (both emotionally and physically) by engaging in negative thinking? By feeding these ideas of not doing enough and not being enough, am I assisting in the destruction of my own body? At the very least, I know for a fact that when I am in a negative state of mind, I am holding myself back from engaging in life and I feel terrible.

We all have a CHOICE as to how we decide to handle life.

I can continue on this path and allow myself to indulge in the “stinking thinking” and “poor me” attitude. Or I can push through those feelings and take steps toward positivity. And if one tiny step is all I can handle right now, so be it. It’s better than heading backward. It’s better than disengaging from life and sitting on the couch in a paralyzed ball of anxiety.

Need help with those steps toward positivity? I’ve found Jodi Aman’s suggestions for natural anti-depressants* helpful. One of the suggestions I have recently taken? I’ve ditched coffee once again. After chemo ended, my taste for coffee came back with a vengeance. It quickly became a crutch and an obsession. And the caffeine was surely contributing to some serious hormonal swings of late. Hormonal swings = emotional swings. I am happy to let those go and I know my liver (and my husband) will thank me for it.

So I ask you, what is YOUR cancer?

Can you resolve to accept yourself and accept your position right here and right now just I was able to when I was going through treatment for biological cancer? The grace that I experienced last year is still there for the taking if I want it. I just need to find a harmonious way of working through my current bout of emotional cancer. And that grace is there for you too, if you only reach for it.

*http://jodiaman.com/get-off-anti-depressants/

Compassionate Care continued

listening to the concerns and objections of dissenting citizens.

The Senate version of this bill was led by Senator Diane Savino of Staten Island. For the first time ever, it was approved by the Senate Health Committee, another day of celebration for advocates. It will then be voted on by the Senate Finance Committee and if approved, will then go to the floor of the Senate for a vote. If the bill is passed, the Senate and Assembly will work on revising the two versions into one bill which would then go to Governor Cuomo for his signature. June 19 is the last day of this legislative session, so there is much to be done in a short amount of time. While it appears to be an overwhelming goal, it can be accomplished. By the time you are reading this article, patients, doctors and advocates may be filled with hope and joy. Hope for the ability to access an alternative medication to combat various diseases; hope for a pain free day, for the ability to live a normal life. Joy in knowing the many hours invested have enacted positive change.

CCA UPDATE

On Friday, June 20th the New York State Senate and Assembly agreed on a version of a medical marijuana bill that satisfied the guidelines put forth by Governor Cuomo. This final version narrowed the number of qualifying conditions and completely removed smoking as an ingestion option. This compromise is not the Compassionate Care Act but it will bring relief to thousands of New York residents. Cancer patients, through their medical providers, will have safe, legal access to cannabis in the form of oils or tinctures. Implementation is projected to take eighteen months but the bill still awaits the governor’s signature. For our friends dealing with chemotherapy, multiple sclerosis, AIDS, epilepsy, the clock is ticking and we’re watching. ✶
A pearl is the beautiful covering an oyster gradually forms around an irritant. In the same manner, we can, in time, shape adversity into something beautiful.

Carol Henretta is a beloved member of our survivor community at the Coalition. In her talk at our Advanced Breast Cancer Seminar in the early spring of this year, as she reflected on living with metastatic disease and revealed a pink “Tackle Breast Cancer” rugby shirt given to her by her grandson, she gifted her listeners with numerous pearls of wisdom. The following is taken from her notes for the day.

“Ride the horse in the direction it’s going.”

~Bette Midler

What is it like to live with advanced breast cancer? It’s scary. I’m always wondering what’s next. It’s invigorating. I enjoy and appreciate every day as a gift. It’s freeing. It has enabled me to reset my priorities. For me, it is about my relationships with my family and other people in my life, but also to remember the “ME”.

The challenges are many and they differ from person to person; from time to time; from season to season; from mood to mood and from situation to situation.

To deal with fatigue, listen to your body. Take a break or a nap. Stop to smell the flowers. But keep doing for others. For me, helping others helps me.

My metastatic breast cancer first made itself known in my stomach, so I had a full gastrectomy. I live with many digestive issues. Always one to carry a small purse, I now carry a large Vera Bradley bag, a gift from my granddaughter. I love it. It’s big enough to hold extra “Depends”, and no one has to know they’re there.

Address your challenges, whatever they may be. The Metastatic Support Group at the Coalition is a safe place to air your concerns and joys. Also try to attend the monthly evening lectures.

Multiple appointments can be a challenge. Book an appointment with a relative or friend if that’s helpful. Do something special for yourself that day. I always wear my pink watch. It was a gift from my grandchildren when they visited Florida. They bought it with their own money. It’s pink and sparkly, and not really my style. But I love it! My grandchildren say it has “sparkles” that always shine to let me know they are always thinking of me. And that IS my style!

Spirituality is an important part of this process for me. I pray often. Prayer doesn’t have to be loud or long. Never underestimate the value of silent prayer. One of my favorite prayers begins “Father, when there is a big decision for me to make and everyone around me is telling me what they think I should do – but something within me is giving me pause – help me not to give in just because it seems like nine out of ten (friends) can’t possibly be wrong…”

“How do we know what we need if we don’t even know what we want?” ~Marc Natale

Making choices is difficult for everyone. My priorities now include getting my B12 shot and going to my cancer center. Going there keeps me in touch with my caregivers and allows me to learn more about them, and them about me. It increases the comfort level of everyone involved.

Let others help – let them do it! I am a caregiver and

Continued on page 9
receive pleasure from helping others.
Don’t deny others the opportunity to experience the joy of helping you.

“Don’t let what you can’t do interfere with what you can do.”
- John Wooden

The Coalition has become a new and important part of my life. I love the Healing Arts program and have participated in yoga, tai chi, and Qi Gong. The value of this organization and its availability are important to people like me.

Take the initiative to keep in touch with others. My Caring Bridge page set up by my son lets others know of my progress and allows them to send me good messages. As a result, I have reconnected with many former students.

Don’t underestimate the value of flowers. Even one fresh flower helps your mood.

To relieve stress, be willing to try new ways of doing things.

Find what floats your boat and don’t feel guilty.

What floats my boat? Holiday decorating all year. Sharing with my kids and others on facebook. Playing the piano, a gift from my daughter and son-in-law. I wear breast cancer pins on my jackets. And retail therapy; remember “Veni, vidi, visa - I came, I saw, I did a little shopping.”

Finally, I try to remember and live the words I heard from Father Bill Spilly:

ACT justly
WALK humbly
LOVE tenderly

*From A Woman’s Prayers From the Heart by Christine Dallman and Marie Jones.

For those who live with metastatic breast cancer, finding the needed resources, information, and support can be a challenge. To address the ongoing needs of this very special group, the annual Cindy L. Dertinger Advanced Breast Cancer Seminar was held at the Memorial Art Gallery on April 4 of this year. Attendees included those living with the disease as well as their family members, friends, supporters, and care providers.

Jennifer Griggs, M.D., M.P.H., moderated the afternoon’s events, which featured presentations by health care professionals and the words of those faced with this diagnosis. Jeffrey Haynes, M.D., offered updates on advancements in radiation therapy, Tarek Sousou, M.D., addressed the medical management of metastatic breast cancer, and Lesley James, M.D., provided information on the benefits of integrative medicine for those with metastatic disease. Carol Henretta and Mary Randall shared their hard-won wisdom as women who find meaning and joy in life while living with advanced breast cancer.

To provide a “breather” for participants, Susan Meynadasy, Registered Yoga Trainer and Raphaela McCormack, Qi Gong Therapist, led the gathering through some rejuvenating stretches and deep breathing.

An abundance of information was imparted, and the air of support and compassion in the room was palpable.

This yearly event is a means to let those who live with this diagnosis know that they can count on the solid foundation of a caring community as each forges a unique path through difficult terrain.

No one should have to walk this walk alone.

Kerry Quinn enjoying the delicious refreshments
Our Programs at the Breast Cancer Coalition of Rochester... all FREE of charge!

BC 101
These one-to-one sessions assist the newly diagnosed in managing the complex tasks and emotions of a breast cancer diagnosis, empowering them to be self-advocates as they proceed through treatment, recovery, and survivorship. Our professional facilitators provide a safe, comfortable atmosphere where information can be absorbed and assimilated while each individual formulates a personal strategy for coping with the diagnosis.

Tuesday Night Breast Cancer Support Group
This discussion-based group, led by Joan Mitchell, meets on the 2nd and 4th Tuesday evenings of each month from 5:30-7:00pm. Join others coping with breast cancer, share your experiences, and lend your support. No registration is required.

Thursday Night Breast Cancer Support Group
This discussion-based group, led by Peg DeBaise, LMFT, meets on the 1st and 3rd Thursday of the month from 5:30-7:00pm. This group is perfect for those who are newly diagnosed with breast cancer, or for those within the first two years following the end of treatment. No registration is required.

Brown Bag Fridays
Any given Friday at noon finds a group of survivors of breast or gynecologic cancer conversing over anything from making treatment decisions to hair loss and funky re-growth...from the latest clinical trials to our own locally-funded research initiative...from prosthetics to bathing suits...and on and on. Feel free to drop in for this non-traditional support group. Bring your lunch and we will provide delectable desserts.

Book Club
If a traditional support group isn’t for you but you still like the idea of participating in a supportive community following a breast or gynecologic cancer diagnosis, join our Book Club, led by: Carol Moldt, Jill Richards, Angelique Stevens and Karen VanMeenen which meets on the 4th Thursday of the month, from 6:00-8:00pm. Prior sign-up is required. Call us to reserve your seat, learn the next book selection, or to suggest a book.

Common Ground: Living with Metastatic Breast or GYN Cancers
For those living with metastatic breast or gynecologic cancers, we offer a support gathering on the 1st and 3rd Thursdays of the month at noon. Led by Peg DeBaise, LMFT, the discussion is topic-based, although all concerns of those present will be addressed. Bring your lunch, bring your questions, and we will provide beverages, dessert, and compassionate listening ears. No RSVP is needed.

The Lymphedema Awareness Network of Rochester
LANROC provides awareness, education, and peer support for anyone living with lymphedema. Caregivers, lymphedema therapists, medical personnel, and those at risk for developing lymphedema are also welcome. This group, facilitated by Karen Miltner, meets from 5:30 to 7:00pm on the second Wednesday of each month.
Voices & Vision: A Writing Workshop for People with Breast Cancer
This well-loved group gives people with breast or gynecologic cancer an opportunity to explore and express their feelings through writing. Led by professional instructors: Elizabeth Johnston, Pamela Emigh Murphy, Angelique Stevens and Karen VanMeenen, these workshops run in five week cycles on Tuesday evenings. Seating is limited, and advance registration is required.

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

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

Peer Advocates Lending Support: PALS
In this peer mentoring program, individual breast cancer survivors reach out to those who are new to the disease, providing the reassurance of one-to-one contact with someone who’s “been there”, helping them connect with needed resources, and instilling confidence during a difficult time. Please call to learn how to be enrolled in the program after your own diagnosis, or if you would like to become involved as a mentor.

Young Survivor Soiree
A young survivor may identify with those who have faced breast or gynecologic cancer in the midst of a career climb, or while raising children, or perhaps with those whose family plans have been derailed by treatment. Four times a year, we hold these soirees as an informal way to connect with others who have walked a similar path. The next soiree will be on July 25th. Please call to be added to the invitation list.
A Farewell and New Beginnings

We recently bid a fond farewell to Jean Sobraske, our Program Coordinator since 2012. Jean’s tenure at the Coalition was marked by her compassion, dedication, and energy as she steered our survivor programs. Hers was the kind voice on the phone for many of the newly diagnosed making their first call to the Coalition. As she moves on to new adventures in life, we will cherish warm memories of her cheerful presence. Adieu and happy travels through your new ventures, Jean!

While goodbyes are never easy, hellos are the opening of a door into new beginnings. In that spirit of happy anticipation, the Coalition welcomes our new Program Coordinator, Laura Albert. Laura carries with her the humanity and perspective she gained as an educator. Her first experience with us was at the Pink Ribbon Run last Mother’s Day. In her own words:

“On that gorgeous Sunday morning, it struck me that I was in the company of thousands of strong and loving survivors and volunteers. What great company! It was truly a splendid and joyful Mother’s Day. I felt honored to lead the walkers down the bike path, waving the orange flag proudly, with my mother and sister by my side.”

Welcome, Laura!

Starting a new job or entering into unknown territory brings on a set of learning experiences, challenges, and inspiring moments. I am a firm believer that inspiration is around every corner. Here at the Coalition, I find inspiration through a phone call with a newly diagnosed person, a warm greeting from a program participant, and an enlightening conversation with colleagues.

I have enjoyed learning about the wide variety of programs offered here at the Coalition. One of the highlights is observing the Art Therapy projects evolve. As a Healing Arts pilot program, participants in Art Therapy utilize a variety of mediums. The goal of the project is to find healing and stress relief through self-discovery. Similarly, Voices and Vision provides therapeutic healing through expressive writing. It is inspiring to see program participants support each other in managing the emotional and physical side effects of cancer.

As a former educator, I can testify as to how impactful art and writing are on impoverished young people, who are survivors in their own right. These children flourish emotionally, behaviorally, and socially when delving into their imaginative minds. Last summer one scholar, a native Spanish speaker, struggled for days to write a complete sentence. His fear of writing was so debilitating that his mantra was “I can’t!” After lots of practice and encouragement, he began to trust his potential. The words surged onto the page like a gust of wind through the trees. Absolutely magical!

Regardless of our stage in life, art and writing are two simple ways to find healing and maybe even discover our passions. Even when the odds are stacked against us, the potential to explore the depth of the mind and unleash hidden talents is boundless.

One of my goals as the Program Coordinator is to build upon and develop the strong network of Healing Arts Programs. It is my hope that even more survivors will be touched by the power of their own creative potential and moved by each other’s stories. I am thrilled to be on this journey with you. Please do not hesitate to attend a group or evening seminar, stop in and introduce yourself, or give me a call. My door is always open!
Everyone who walks through the door of the Coalition for a Breast Cancer 101 (BC101) session walks out with a PALS Pak in hand. What is BC101? What is a PALS Pak?

A breast cancer diagnosis is seldom expected; it is not the sort of life event one can prepare for. Because there are many nuances to the disease, each case is unique. So in the privacy and safety of a one-to-one BC101 session, the newly diagnosed person and a trained facilitator explore the complexities of the disease as it applies to her/his particular situation. The goal is empowerment; to impart the needed knowledge and resources to foster self-advocacy as those facing this diagnosis navigate a confusing and frightening experience. This is a very different process than the vital one that takes place in a doctor’s office. We are not here to make treatment decisions or affect the doctor/patient relationship in any way. In a similar vein, we are not here to replace the support of family and friends. We are here to complete the circle of support around an individual; to offer the solidarity of a survivor community because there is strength to be gained in shared experience. The PALS Pak is an outward sign of that support, the offering of a helping hand along the way from others who have walked this road; others who “get it.”

The Pak contains items designed to nurture and bolster the spirits of someone beginning a journey through this unfamiliar territory. The warm blankets, soft pillows, informative books, journals, and much more provided in these paks are our way of saying “We’re sorry you have to face this and we are here for you.”

Many who have taken these first steps accept our offer of a PALS mentor. Trained mentors are matched with newly diagnosed women and men based on many factors, which can vary from case to case. One person may have small children to care for, and the words of someone who has also faced that situation can be just the thing to reassure her that she can get through it. For another whose surgery is imminent, it may be more important to hear from someone who has undergone that same procedure. Still another may be facing an unusual diagnosis and talking with someone who has been similarly diagnosed can help ease feelings of isolation. Each person brings her or his own identity and history to the journey. PALS is designed to meet these individual needs as best we can.

From the first phone call to the Coalition after receiving a diagnosis, to a BC101 session, to talking with a PALS mentor, to becoming part of our survivor community, we are here each step of the way to listen, honor, and support each person affected by breast cancer. And until the day we all hope for – the day a cure is found - we will not stop!
Healthy YOU Healthy YOU Healthy YOU Healthy YOU Healthy YOU

Raise a Glass to Summer! -By Pat Battaglia

Summer isn’t just a season; it’s a state of mind. Picnics, camping, road trips, gardens in bloom, and sultry afternoons spent in a hammock are just a few hallmarks of the season. Long, hot days offer endless excuses for cool, refreshing beverages. And during the dog days of summer, these drinks are just what your body needs to stay hydrated.

Proper hydration prevents the body from overheating, and in warm weather, fluids can be lost quickly through perspiration. The best way to stay hydrated is to drink frequently and before thirst strikes. If you wait until you’re thirsty, you may already be dehydrated.*

During times of low or moderately intense activity, water is all you need. For a refreshing twist on plain water, place a few slices of cucumber and fresh lemon in the bottom of a large pitcher or jar. Fill with water and refrigerate several hours or overnight. Try this with different combinations of fruits such as berries, melon, pineapple, citrus fruits and more. Fresh herbs like basil, mint, or rosemary are another great addition and pair well with fruit. The possible flavor combinations are endless – experiment and find your own personal favorite.

If you plan to be active for over an hour or are engaging in more intense physical activity, you will need to replace electrolytes that are lost during sweating. Electrolytes are minerals that carry an electric charge. They affect your

Rosemary-Infused Cucumber Lemonade

Recipe adapted from EatingWell, July/August 2009
http://www.eatingwell.com/recipes/rosemary_infused_cucumber_lemonade.html

Ingredients

- 3 large cucumbers
- 1 T. chopped fresh rosemary, plus 4 sprigs for garnish
- 1 cup water
- 1/2 cup lemon juice
- 3 T. agave syrup

• Cut 12 thin slices of cucumber for garnish.
• Peel and chop the rest of the cucumber; transfer to a food processor, add rosemary and puree. Pour the puree through a fine-mesh strainer set over a medium bowl or large measuring cup. Press on the solids to extract all the juice. Add water, lemon juice and agave syrup to the cucumber juice; stir until the agave is dissolved.
• Divide among 4 ice-filled glasses. Garnish with cucumber slices and rosemary sprigs.

4 servings

The Seven “No’s” of Sunscreen Use -From the Environmental Working Group

1. No spray sunscreens! Super-convenient, sure, but they may pose serious risks if inhaled and they make it too easy to apply too little or miss a spot

2. Super-high SPF’s (SPF 50 or higher) are not your friend. SPF – sun protection factor – refers only to protection against UVB radiation and has little to do with protecting you from UVA rays – the ones that accelerate skin aging and have been linked to skin cancer.

3. Oxybenzone can mimic estrogen. That’s right, estrogen. A number of sunscreens contain the chemical oxybenzone, which penetrates skin, gets into the bloodstream and may act like estrogen in the body! It can also trigger allergic reactions.

4. Retinyl palmitate may harm your skin. On sun-exposed skin, the retinyl palmitate found in some sunscreens has been shown to speed development of skin tumors and lesions.

5. Skip sunscreen/bug repellent combos. Studies suggest that in some cases chemicals that filter harmful ultraviolet rays can interact with insect repelling chemicals in ways that decrease sunburn protection. Also, if you apply these products every two hours (as you should for proper sun protection!), you may be overexposed to the repellent chemicals.

6. Keep away from sunscreen powders and towelettes. Even the FDA’s weak sunscreen rules bar these products! Their level of protection is quite dubious.

7. Seriously – no tanning oils! Tanning oils are just a bad idea. They barely – if at all – protect you from the sun.

To access the EWG’s 2014 Guide to Sunscreens, go to http://www.ewg.org/2014sunsceen. Stay safe in the sun this summer!


Photo source: www.freeimages.com/photo/391771

1. No spray sunscreens! Super-convenient, sure, but they may pose serious risks if inhaled and they make it too easy to apply too little or miss a spot

2. Super-high SPF’s (SPF 50 or higher) are not your friend. SPF – sun protection factor – refers only to protection against UVB radiation and has little to do with protecting you from UVA rays – the ones that accelerate skin aging and have been linked to skin cancer.

3. Oxybenzone can mimic estrogen. That’s right, estrogen. A number of sunscreens contain the chemical oxybenzone, which penetrates skin, gets into the bloodstream and may act like estrogen in the body! It can also trigger allergic reactions.

4. Retinyl palmitate may harm your skin. On sun-exposed skin, the retinyl palmitate found in some sunscreens has been shown to speed development of skin tumors and lesions.

5. Skip sunscreen/bug repellent combos. Studies suggest that in some cases chemicals that filter harmful ultraviolet rays can interact with insect repelling chemicals in ways that decrease sunburn protection. Also, if you apply these products every two hours (as you should for proper sun protection!), you may be overexposed to the repellent chemicals.

6. Keep away from sunscreen powders and towelettes. Even the FDA’s weak sunscreen rules bar these products! Their level of protection is quite dubious.

7. Seriously – no tanning oils! Tanning oils are just a bad idea. They barely – if at all – protect you from the sun.

To access the EWG’s 2014 Guide to Sunscreens, go to http://www.ewg.org/2014sunsceen. Stay safe in the sun this summer!

Healthy YOU

Healthy YOU

Healthy YOU

Healthy YOU

Healthy YOU

Healthy YOU

Healthy YOU

Healthy YOU

Hydration levels and regulate important body processes. Commercially available sports drinks contain electrolytes. Many are also high in sugar and contain chemicals you may want to avoid. There are a number of recipes to make your own electrolyte replacement drink. Among the simplest: in a jar or pitcher, combine ½ cup of orange juice, 1/4 cup lemon juice, 2 cups water, 2 tablespoons natural sugar or honey, and 1/8 teaspoon of sea salt. Shake or stir well and refrigerate.**

Healthy eating is a great way maintain your electrolyte levels. Whole, unprocessed food such as fruits and vegetables, whole grains, legumes, nuts, and dairy products contain an array of electrolyte-replenishing minerals. To replace sodium, an important electrolyte, skip the salty chips and reach for a pickle or a few cured olives instead.

Alcoholic and caffeinated beverages should be consumed in limited quantities, as they tend to pull water from the body. Fruit juice may be a healthier choice, but contains high levels of carbohydrates that can cause stomach upset when consumed in large quantities. Diluting your juice with equal amounts of clear or sparkling water is a refreshing option.

Signs of dehydration include dry lips and tongue, flushed skin, dizziness, infrequent urination and/or dark urine color, and low energy. Heat illness can develop quickly once dehydration occurs. Chills, clammy skin, muscle pains or spasms, and nausea are signs that should be taken seriously. Move to a cool area, remove excess clothing, and consume cool liquids. If symptoms don’t improve quickly, seek medical attention.

Good hydration is important to your well-being. So raise a glass of your favorite summer libation in a toast to summer. And drink deeply! *\n
*my.clevelandclinic.org/disorders/dehydration/hic_avoiding_dehydration.aspx
**Adapted from www.mnn.com/food/healthy-eating/blogs/a-simple-homemade-electrolyte-drink

Additional sources:
cals.arizona.edu/backyards/articles/summer08/p14.pdf
www.mayoclinic.org/diseases-conditions/dehydration/basics/prevention/con-20030056
www.52kitchenadventures.com/2012/09/17/fifty-awesome-flavored-water-recipes
http://www.mnn.com/food/healthy-eating/blogs/a-simple-homemade-electrolyte-drink

Summer Internships with Community Impact

-By Victoria Koukoulas and Asia Wang

This summer, the Coalition has hired two interns: Victoria Koukoulas and Asia Wang. They are here to work on a grant-funded project called “Chemical Education for Cancer Prevention” and will conduct outreach and evaluation of educational materials about connections between toxic chemical exposure and breast cancer. Both interns are studying public health at the University of Rochester; their unique specializations ensure a well-rounded approach to community outreach and population health intervention. Victoria is a recent graduate with major in Health, Behavior, and Society and Asia is a rising junior with major in Epidemiology.

For the first part of this summer project, we will be evaluating the effectiveness of the Breast Cancer and Environmental Research Program’s (BCERP) chemical exposure brochure on phthalates and BPA in the Rochester community. We are adapting the BCERP brochure, which was designed for a North Carolina audience, to the Rochester population. To do so, we have created a survey for our target audience, women of childbearing age (ages 15-49), to gauge their comprehension of the brochure. We hope to get honest feedback from these evaluations to improve and customize the BCERP brochure for Rochester women.

The second part of the project involves conducting initial mapping of nail salon workers in Rochester. Nail salon workers are under high exposure to harmful chemicals such as phthalates, formaldehyde, and DBP. We will create a survey to collect data on workers’ demographics, healthcare utilization and satisfaction, medical history, medical concerns, length of employment, and perception of chemical exposures in the workplace. From this data, we will be assembling a “workplace atlas” for future research and outreach. Ultimately we are using this data to determine the efficacy of Coalition educational materials for the nail salon community. We hope our sample size will be an accurate representation of the Rochester community and that our findings can be used for future outreach and research.

Note: Victoria is off to India for another internship.

To view this brochure, please visit:
backdrop for the sea of pink t-shirts and other accessories donned by women, men, and children, all drawn together to do their part to fight breast cancer and support those who have traveled this road.

As people gathered at the park, they were treated to the lovely voices of the ladies from Vocal Point, a University of Rochester a cappella 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 and Naiaides Oncology Rowing group cheered them on from the river. Walkers were also entertained on both sides of the river by the Flower City Pride Band and a drumming group from Brockport.

Organizing an event of this size is a great undertaking and it would not be possible without the hard work and dedication of many volunteers who helped 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. A special shout out to long-time volunteers Scott Simkins and Colleen Joseph, who stepped up to serve as Race Director and Volunteer Check-In Team leader in the absence of Bix and Peg DeBaise, who have filled those positions for years but were unable to attend the event due to their daughter Chelsea’s graduation from Syracuse University that day.

A big “thank you” goes out to our generous sponsors: Wegmans, a gold sponsor who provides the refreshments and prizes, WROC Channel 8, WARM-FM 101.3, WFKL-FM 93.3 (Fickle), The ZONE 94.1, Towpath Bike, Yellow Page City, Bounce Aerobics, Christian Flooring, Dunkin’ Donuts, Freetime Magazine, Clark Moving and Storage, UR Medicine Breast Imaging, Fleet Feet Sports, Barefoot Sportswear, Rochester Woman Magazine, Cycle Stop, Marketplace Mall, Ashby Madison Salon, Tom and Maria Cook, Rockcastle Florist, Brothers Collision, and Morgenstern DeVoesick, PLLC.

Cover story continued

WINNER AND RECORD BREAKER!

Sarah Loerch, Age 28, 17:45.6
$300 Cash - Sponsored by Wegmans
$200 Cash - Record Breaker!

SECOND

Karen Blodgett, Age 37, 18:08.9
$100 Wegmans Gift Card

THIRD

Trisha Byler, Age 30, 18:23.0
$75 Wegmans Gift Card

Sarah Loerch accepts her prize for breaking the course record from Cindy Dykes
All race winners also received free coffee coupons generously donated by Gold Sponsor Dunkin’ Donuts.

Shown here are a few of the happy memories of our participants enjoying the lovely day and festivities at Genesee Valley Park!

**BREAST CANCER SURVIVOR CATEGORY**

**WINNER**

Jean Weber, Age 47, 24:38.1
Pharoah’s Hairum Spa Rejuvenation Package &
Jim Dalberth Sporting Goods $30 Gift Certificate

**SECOND**

Jenna Sallome, Age 23, 25:14.6
Woodcliff 50-minute Spa Treatment &
Jim Dalberth Sporting Goods $30 Gift Certificate

**THIRD**

Karen Luce, Age 53, 26:11.8
Park Avenue Salon & Spa 1-hour Massage Certificate &
Jim Dalberth Sporting Goods Gift Certificate

**FOURTH**

Mary Kummer, Age 59, 26:20.3
Bollé Sunglasses

Event photos taken by Mike Bradley, Rod Dietz, Jared Dietz, Lisa Gresens and Jenna Kuperberg
THANK YOU... TO OUR GENEROUS RACE SPONSORS! more sponsors pg.27

GOLD SPONSORS

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

BCCR Race Committee
Holly Anderson
Tom Anderson
Stacey Bershod
Mel & Richard Bianchi
Richard Bianchi
Dick Cataldi
Patti Cataldi
Marj Cunningham
John Frazier
David Harris
Mrs. Roberta Johnson
The Kruppenbacher Family
Debra Kusse
Michelle Mann & Steve Atterbury
Joe Miano
John & Nancy Owens
Debbie Rivera & friends
Wendy Rockcastle, Cindy Dykes, Amy Jones

We couldn’t do it without our hardworking volunteers!

The drummers above were a welcome treat to walkers!

Left, event director, Debra Bonsignore

Enjoying the ride!
19

19

Continued on page 20

Outreach Coordinators' Update

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

- Marianne Williamson

Lori Meath

As I write this article, Summer has finally arrived, and the Lilac Festival that truly defines our city is in the history books. The Breast Cancer Coalition of Rochester experiences the Lilac Festival as our largest opportunity to bring our resources to the community. Tens of thousands of area people flock to Highland Park to enjoy the flowers, the music, and incredible food. Perhaps surprisingly, several hundred also visit our informational booth to purchase something for a family member or friend, pick up literature, ask questions, and quite often to simply share their own story of a life touched by breast cancer. It is a priceless outreach, and is only accomplished with the help of a small army of volunteers.

I give a hearty “thank you!” to these wonderful volunteers who come, rain or shine, wind or whatever to greet our booth visitors for a few hours. You made my ten days fun and interesting, and as always, taught me a lot through your own experiences.

Linda Gaylord, Betty Miller, Connie Schmeer, Maria Mendicino, Jeanne VerHulst, Becky Simmons and John Rudy (we almost blew away!); Lynn Jones, Janice Barnum, Mindy Sammon, Amanda Ryan and her wonderful children Dymond and Victory (the champion raffle ticket seller); Michael Meath, Brenda Tartaglia, Mary Jo and Chuck Deichmiller (SPECIAL thanks for covering Mother’s Day morning!), Rebecca Solomon, Anne Bishop, Joann Morreale, Betty Digby, Nancy Weinmann, Jen de Ryke Henry, Ayanna Jackson, Bev Levy, Pat Foucht, Judy Wood, Dennise Webster, Karen Destino, Ro Jouen; Anna Young, Lori Kemp-Schneider, Marianne Sargent, Kathy Wurzel, Carol Rossi, Traci Cahill, Linda Brenner, The Lancers Dancers ladies, and Mike and Paula Petix. Thanks also to the ones who got “rained out” but were ready to get wet if necessary: Miriam Steinberg and Rachel Spezio, Marcy Lazio, Nancy Germond.

We also welcomed our two Summer interns, Asia Wang and Victoria Koukoulas, who worked many days, giving

Volunteer SPOTLIGHT

LuAnn Weinstein

- By Pat Battaglia

It is a daunting task to register the thousands of runners and walkers for our Pink Ribbon Run and Family Fitness Walk, which takes place every Mother’s Day. For the past two years, a bright, dedicated woman has traveled from her home in Florida to direct the massive undertaking of ensuring that each runner and walker is entered into our registry. LuAnn Weinstein, who has so capably filled the role of Registration Team Captain since 2002, is a former Rochester resident who moved to Poinciana, Florida after her retirement from Kodak. She didn’t let retirement and relocation stand in the way of her work for the Coalition, which she has continued with her characteristic spunk and “can-do” attitude.

LuAnn has appeared on the bustling registration scene with pink sparkles in her beautiful, spiky silver hair to direct the entire operation, training and overseeing the many volunteers who greet participants and process forms, answering the questions of runners, walkers, and volunteers, and interacting with everyone in a light, friendly manner. Her energy, dedication, and thorough understanding of the task at hand, as well as her willingness to travel a great distance to work long hours and see the entire process through from beginning to end have made Luann a beloved figure at the Coalition. “I adore her,” says Debra Bonsignore, Event Director. “She’s one of my favorite people on the planet. There is no one more dedicated or involved. She never says ‘never.’”

Though retired, LuAnn has recently taken a job at Disney World, a fitting position for one who exudes such youth and fun. Her arrival at the Coalition these past two years has felt like the arrival of our own personal pink fairy; one who manages a complex task with competence and energy while leaving a smile on the faces of those she works with. It may seem like magic, but we at the Coalition know how hard she works to make it all happen, and the stamina it takes to put the registration details in place. We are endlessly grateful to LuAnn, the sparkling dynamo who makes it all happen.
The Coalition’s 2013-2014 research grant recipients, Gokul M. Das PhD, Associate Professor in the Department of Pharmacology & Therapeutics at Roswell Park Cancer Institute and Helene R. McMurray PhD Assistant Professor in cooperation with Mark D. Noble PhD Professor of the Biomedical Genetics Department School of Medicine and Dentistry have begun their Coalition funded projects. The Research Committee will be visiting their laboratories in September and October respectively. These visits keep committee members updated on the progress of the research as well as putting the scientists face to face with the human component behind their work. These visits have had a positive impact on many of our researchers and their graduate students.

Dr. Ashwani Sood’s research on the “Immunologic Targeting of PDEF Oncogene in Breast Cancer” and Ryan Dawes investigation of “Breast Cancer Exosomes, Novel Intermediaries in Psychosocial Stress-Induced Tumor Pathogenesis” were funded by the Coalition’s 2012-2013 research initiative. Their work was completed in April 2014 and final reports submitted to the Coalition. The Research Committee has invited both of them to the Coalition this summer to present their findings and the potential impact on the Coalition’s research priorities of cause, prevention, prevention of metastasis and cure. In addition, we’ve asked them to outline their plans for furthering the Coalition funded research. Look for a follow-up report in the next newsletter.

Outreach Coordinator’s Update continued

them great on-the-job training and the chance to meet and learn from so many volunteers.

Nothing else we do is such an intense commitment of time and energy. But there are MANY festivals and health fairs, community fundraisers and speaking opportunities to attend and help is needed. Consider volunteering with a friend or family member. Join the fun!

As always, we CANNOT DO WHAT WE DO WITHOUT YOU!

Lilac Festival Raffle Winner:
Karen Destino

Karen Destino with Laura Albert
$250 Wegmans Gift Card
A Tribute to Tyler Davis - By Pat Battaglia

There are many friends of the Coalition who generously give their time to assist with the multi-faceted work we do, and they hold a special place in our hearts.

Tyler Davis, only nineteen years of age when we had to say a reluctant good-bye, was one of those big-hearted volunteers. For his contribution to community service while attending Bishop Kearney High School, Tyler worked for the Coalition, assisting in the office and acting as a road marshal for the Pink Ribbon Run and Family Fitness Walk. I was touched that he chose this avenue for his service, knowing that he did so because, as a family friend, he had been deeply affected by my diagnosis and treatment.

The warmhearted, spirited Tyler was a fixture in my household from the time he was six, and formed special bonds with each of my three sons as they grew up together. Through years of Little League Baseball, accompanying us on family outings, the countless sleepovers and the day-to-day adventures of growing up as buddies, the boys forged a bond that kept them close through their teens. They felt and acted as brothers. When Tyler left for college, he was missed. It became the welcome sign of a holiday when he would appear at our door, greet me cheerfully, and chat a bit before continuing on into the house to find my sons. The sounds of talking and laughter would quickly reach my ears.

When we learned of his sudden passing, my family and I were shaken to the core. We have lost one of our own. Tyler left behind his mom, Lynn, and father, Stephen, as well as a large extended family and countless friends. Through the months that have passed since that difficult farewell, it has become increasingly clear that this young man with a big heart and a keen sense of humor has had a big impact on many lives, and he will never be forgotten.

Would you like to write about someone you have lost to breast cancer? We welcome submissions from friends and family members and are particularly interested in stories about how they touched and changed your lives.

Please send your submission (300-500 words) with a digital photograph to Pat Battaglia, Voices of the Ribbon Newsletter Editor, at pat@bccr.org. We would be happy to honor your loved ones.

Remembering Kym Cardamone (Casciani) - By Sue Callan-Harris

The first thing I noticed about you, Kym, and the image that remains whenever someone mentions your name, is your beauty. It seemed to emanate from your very soul. You were a seeker and a lover of all things beautiful, and you coached everyone around you to have the pleasure of beauty. You were so attentive to having delicious treats available at your salon, and always asked my staff if they wanted a tasty Starbucks treat when you visited. Throughout your journey of surgery, chemotherapy, radiation therapy, and recovery, you dressed up (I remember the sound of those heels at work) with exquisite make-up and hair. You sought out safe cosmetics and hair products for other women who were on the journey and offered special spa days so that women could have the experience of pleasure in the midst of all the offensive aspects of dealing with cancer. Your salon was decorated by local artists; your voice was soft and soothing; your touch was delicate and your smell was fresh and uplifting. You were a treat for the senses, and you understood how vital that was for health.

Continued on page 26
Our Fundraising Friends

Bald Amidst the Blossoms

“I don’t know how many guys will actually do it…”

Organizer Mike Rich of the Williamson Fire Department was hopeful, but perhaps dubious. How many of the firefighters in the three town cluster would actually have their heads shaved in public with him?

Mike needn’t have wondered. In fact, not only did 25 firefighters go bald for the Coalition, so did 10 women including the Wayne County Fair Queen runner up, another 15 onlookers, and finally the hairdresser who had shaved so many of those heads!

Mike’s beloved sister, recently diagnosed with breast cancer, was his inspiration. Many others told touching stories of the impact of breast cancer on their families and friends’ lives.

Apparently roused to action by the Williamson Apple Blossom Parade and gorgeous weather, the throngs gathered on the Parade grandstand, lining up for a new Summer ‘do. A bucket was passed, supplementing the efforts of those who had collected pledges, and this fun and laughter resulted in a donation of $543!

Many thanks not only to Mike and the Firefighters of the Williamson area departments, but also to Wende of Wende’s Mane Attraction and three of her razor toting friends for their work. And of course, thanks to the over 50 brave souls now feeling the Summer sunshine a little brighter on their hairless heads.

Faith Community Focus on Health

The Congregation of Restoration of Church of God in the 19th Ward is a place of not only spiritual support, but community commitment, and ongoing efforts to support healthy lifestyles and practices. To that end Darnell and Gail Garland arrange speakers on topics of health, and are working to facilitate easy access to mammograms for their neighborhood community. The Coalition has received a donation of over $430. from Restoration Church, and hopes to make their dream of a “mammogram field trip” a reality this Summer.

Simply Kind

Simply Crepes is a Rochester-area treasure with heart. The raffle of a beautiful hand made pink ribbon afghan raised $250 which was kindly given to the Coalition. Thanks to our friends at Simply Crepes!

Pittsford Event “Went Swimmingly!”

The end of December was not a time most of us were thinking of spending hours in the pool. For Sam Randall and the rest of the Pittsford Swimming and Diving Club, it was the perfect time to put their hard training to work raising money that they donated in honor of Sam’s Mom Mary and other loved ones dealing with breast cancer.

As the year 2013 came to a chilly close, the swimmers sold T shirts and collected donations, and ultimately swam and dove their way to collecting an incredible $3437!

As Sam said so well thanking his team, “I hope you always know that you have helped support your community, and the loving people who live within it.”
Under the guidance of Celeste Frohm and an incredible crew of experienced volunteers, Pittsford Youth Hockey has once again orchestrated a wildly successful fundraiser benefiting the Coalition.

The Bill Gray’s Arena was packed as Pittsford met their rival McQuaid in two thrilling contests. Students in Pittsford Panther costumes fueled the crowd frenzy and were also on hand to supervise the Chuck-a-Puck contest. Attired in their traditional pink gear for this annual event, the players dedicated the evening’s efforts to friends and loved ones dealing with breast cancer.

The teams’ rivalry was clear, but it was the chance to donate $8150 to the Breast Cancer Coalition that motivated BOTH teams to play with determination, stunning speed, and great sportsmanship.

Generosity Begets More Generosity

How do you get some 800 local contractors and their workers to open their wallets and give generously? The Duke Company KNOWS how!

Each early Spring, the dynamos at the Duke Company thank their vendors and customers with a truly impressive charcoal grilled steak meal with all the trimmings. Duke company “closet cooks” prepared all of the side dishes, and promotional items from the previous year are offered at bargain prices, with all proceeds kept by the Coalition. Donations directed to the Coalition are encouraged, and the fed and happy contractors are more than willing to oblige! This festive annual event raised $1743.

Just two weeks later, the Duke Company holds an Open House at their Jefferson Road location. Once again, donations are directed to the Coalition, and we were thrilled to receive a check for $450 from this event.

Striving for “Saint” hood

The Churchville-Chili “Saints” traditionally don their flashy black and orange uniforms when they head for the ice. But on a frigid Friday evening in January, the players sported pink once again and honored the memory of “Hockey Mom” Elfie Chapman.

Elfie’s efforts on behalf of the fledgling team many years ago inspired the team’s annual effort to contribute to the fight against breast cancer in their community. The Coalition is so proud to be the recipient of this year’s donation of $2372.

Elfie left a legacy of a true zest for life and amazing resilience. She would be proud indeed of these wonderful players and their dedication and hard work.

Pink the PAC

Once again, the American Association of Women in Community Colleges has honored us with a generous donation from their annual Pink the PAC events. This year’s festivities brought the usual sea of pink decorations and attire to the MCC atrium and fitness facility affectionately known as the PAC, and resulted in a gift of $615. We appreciate the support of this group of community minded young women.

Gift from Grande Ville

Kudos to the residents at the Grande Ville Senior Living Community in Greece. These community minded folks designated the funds from an Easter basket raffle to the Breast Cancer Coalition.

We appreciate the gift of $109.
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 autumn newsletter.) We apologize for any errors and/or omissions on our donor pages.

**In Honor of:**

- **Kate Bishop**
  - Robin Vavrina
- **Andrea Borrelli**
  - Rebecca Wilson
- **Bruce Brannon**
  - Daphne Futerman
  - Thomas Hinterman
  - Monika & Les Katzel
- **Sylvia Cappellino**
  - Adeline Bruno
- **Alissa Huston, MD & Luke Peppone, PhD**
  - Carol Ford
- **Marilyn Manis**
  - Linda Cooper
- **Teresa Meunram**
  - David & Beannie Tomasso
- **Elizabeth Osta**
  - Annarose Sullivan
- **Joyce Paley**
  - Judy Dell
- **Lori Jeanne Peloquin**
  - Tracey Boccia
  - Drs. Nancy & Russell Cain, MD
  - Stephanie Foran
  - Catherine Flannery
  - Miriam Gale
  - Jane Gogan
  - Rita Izzo
  - Jane Lange
  - Danica Miller Eskind
  - Sandra Mitzner, MD
  - Ronni Monsky
  - Roberta Pasternack
  - Mary Jo Provenzano, RN
  - Jane & Carl Ruoff
  - Molly Witten
- **Mary & Sam Randall**
  - Scott Lazeroff
- **Andrea Reynolds**
  - Emily Piper
- **Richard Roxin**
  - Amy Roxin
- **Connie Schmeer**
  - James Chatterton

**Wendy Spong**
- Deb Roskowski

**Sherrie Valentino**
- Diane Campoli
- Jill Edd
- Deborah Wagner

**Stephen Vega, MD & Staff**
- Sue Cupolo

**Dennise Webster**
- Ogden Presbyterian Church - Deacon’s Fund

**Bess Whittacker**
- Shirley Gordon

**In Memory of:**

- **Jeannette L. Benson**
  - Janet & George Wolf
- **Mary Ann Borrelli**
  - Rebecca Wilson
- **Judy Buchanan**
  - Meredith Walker
- **Carol G. Campbell**
  - Susan Worboys
- **Alberta DeRue**
  - Sharon Bade
- **Robert Funkhouser**
  - Kathleen Wurzer
- **Dianne M. Gerew**
  - Marilyn & Sam Falzone
- **Danielle Kunzwiler Guistina**
  - Jaime Bartholomew
  - James Guistina
- **Sue Henkel**
  - Diane Campoli
  - Jill Edd
  - Deborah Wagner
  - Sybil Young & Family
- **Madeline Howell**
  - Mary VandeLogt
- **Faith Keller**
  - Judy Zelin
- **Irene Lewis**
  - Nancy & Peter Chesterton
  - Carol & Jerry Leichtner
  - Neal Levitt, DDS
  - Bobbi Rubens
  - Ida Siegel
- **Roberta Monachino**
  - Judy & Harry Wood
- **Emily O’Malley**
  - Kate Flanagan
- **Marie Frances Panella**
  - Mr. & Mrs. Calabrese
  - Mr. & Mrs. R. Colilli
- **Maureen Piccione**
  - Wendy Bolton
- **Kathy Reaside**
  - Holly Anderson
  - Patricia Andolina Persia
  - Pat Battaglia
  - Alice Begley
  - Carol & Paul Begley
  - Patricia & David Borisenok
  - Joanne & Frederick Burnash
  - Camp Stella Maris of Livonia
  - Pam Carty
  - Deborah, Larry, & Bryan Clark
  - Gabriele & Eugene Coburn
  - Eileen Collins
  - Phyllis Connelly
  - Cretoked Realty Associates
  - Ann & Jon Desormeau
  - Mr. & Mrs. William Diberardino
  - Cathy & David Dieter
  - Kathleen & David Drew
  - Susan Dunton
  - Mary Ellis
  - Sally & Dick Ewell
  - Carrie Fazio
  - Margaret Ferrarone
  - Margaret Fiset
  - Shelli Fitzsimmons
  - Paula Fitzpatrick
  - Patricia Flanigan
  - The Garrison family
  - Linda Gaylord
  - Deinis Gordinier
  - Theresa Geen
  - Eileen & Ron Guiry
  - Jeanne & Kevin Harris
  - Carol & Elmer Henretta
  - Sharon & Mark Holbrook
  - Penny Infererra
  - Teresa Johnston

Donations ending March 31, 2014
Helene Kibler
Catherine Laruffa
Jean Lazeroff & Cinthia Garcia
Chris Leone
Margaret & Bruce Lombard
Julie & John Lombardo
Judy & Bob Loughlin
Mary & Tony Lauzze
Colin McCready
Betty Miller
Jayne Miller
Ann & Mike Morris
Charles V. Munier III
Mary Beth Musto
Mary & Owen Shevlin
Mary Pavone
Rod Potter
Kathleen Reilly
Thomas Reuning
Eugenie Rives
Rochester Squash Racquets Association
Donna Roth
Christine Sayles
Mary Beth & Mike Schluter
Mary & Owen Shevlin
Pat & Bill Smith
Randy Sparrazza
Kathleen Spitz
Marjorie Spitz
Kristinia & Jeffrey Swan
Caren Weaver
Sara & Lawrence Wiest
Bill Whitwood
Jane Woolston

Lawrence Shinebarger
Breast Cancer Coalition - Board of Directors

Anadolfa "Del" Shyhalla
Nona & James Maurer

Jan Skuse
Sharon Peck Silvio
Ron Skuse

Donald J. Weeks
Point Pleasant Fireman's Ladies Auxiliary

Kenneth Wood
Kathleen Betlem
Elizabeth Clark
Barb & Ron Dunadee
Carol & Michael Eagan
Wendy Frank
Doug Good
Nancy & Barry Gombert
Bernice Kneller
Julie & Gary Marks
Margaret McMahon
Carol Mills
Tracie Moore
Carolyn & John Roberts

Karen Destino
Ellen Eber
Extra Credit, Inc
Bonnie Guon
Vicky Wood

Founder’s Circle $5,000 +

Excellus Blue Cross Blue Shield - ARTrageous Affair Gold Sponsor
Friends of Pittsford Hockey - Pink the Rink
Kathy O’Neill - 12th Annual Bowl for the Cure
Subaru - Share the Love

Visionary Circle $1,000-$4,999

Burlesque for Breast
Chrys Charno
Highland Hospital - Silver Ribbon Sponsor - Pink Ribbon Run & Family Fitness Walk
Paychex
Pittsford Diving Booster’s - Paint the Pool Pink
Saints Hockey - Elfie Chapin Pink the Rink
Salvatore’s Old Fashioned Pizzeria - Pink Boxes
Stephen J. Vega, MD
Women’s Council of Realtors - Annual Fall Fashion Show

Advocate’s Circle $500-$999

The Baker Foundation
Radka & Chris Chapin
Maria & Tom Cook - Pink Ribbon Sponsor - Pink Ribbon Run & Family Fitness Walk
PUSH Fitness Center
RIT - Kick for the Cure
Vision One Management
Wells Fargo Advisors, LLC

Pink Ribbon Circle $100-$499

The Karen Carson Crane Foundation
Deaf Rochester BBQ
Dan Deutsch - Abilene Dry Goods
Beth Doane
Naomi Erdmann
Marilyn & Sam Falzone
Denis Gordinier
Maryann Platania
QCI Asset Management
Johanna Ringwood
Debra Roach
Irene Saeva
Sophie Seus & Kara Janes - Friday Bake Sale
Simply Crepes
Nancy Wiley

Friend’s Circle $50-$99

Linda Alex
Ellen Alhart
Allen Carey

Thank you to the Webster Quilt Guild for the beautiful quilts they created for our PALS Paks!
Our Fundraising Friends

**Mighty Mustang Owners**

The ROC City Mustangz Car Club is a group of Mustang enthusiasts with heart. Throughout the year, they host many social and fundraising events such as a Euchre tournament, bowling night, and this May’s car show. As many members including President Christopher Washington have family members dealing with cancer, they have directed their efforts this year to raising awareness and money for the Breast Cancer Coalition. We are honored to receive their recent donation for $500. Thanks, Mustangz!

**Pitching the puck for our Coalition**

The theme was “Our blood, our sweat, and cancer’s tears” when the young women of the Canandaigua Knights Hockey team skated for three days in the Great Lakes Girls Hockey League tournament. The team chose to honor the women in their lives by directing the tournament proceeds to the Breast Cancer Coalition of Rochester. Their efforts made a donation of $1668. a reality. Nice job, ladies!

Friends remembered continued

I remember how proud you were of all the people who came to your salon, how you loved their stories and how you always made connections among your friends. You introduced me to so many people. You surrounded yourself with some truly amazing women, yet you were so very humble. You sought out, and found, the beauty in all of us, paying close attention to eye color, eyebrow shape, the natural wave in our hair, skin tone, body shape, or a piece of jewelry. We all left you feeling gorgeous and ready for what was next in our day, even if it was returning to work. You never missed an opportunity to say ”I love you”.

In one of your last texts, you wrote that you were baffling all the doctors at Duke University Medical Center because you were looking and feeling so fine in the midst of extensive disease. You sought out ways to boost your own immune system and trusted your feminine power to live your life true to your calling right up to your last breath.

Rest assured, beloved Kym, that I will always cherish and delight in the lacy, sparkly, soft, sensual, tasty, melodic treats in everyday life, and think of you with love and gratitude.

---

**THE COALITION’S CURRENT WISH LIST**

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

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

- Hand knit caps
- Scarves or bandanas
- Fleece throws/blankets
- Journals
- Note cards
- Satin sleep masks (lavender or unscented only)
- Thank you cards
- Foam ear plugs
- Lanyards (preferably plain)
THANK YOU... TO OUR GENEROUS RACE SPONSORS & DONORS!

DONORS
Jim Dalberth Sporting Goods
Dunkin Donuts
Gallea’s Tropical Greenhouse
Lisa Fiorentino-Levy
Fleet Feet Sports
Jack 'n Jill Childcare
Park Avenue Salon & Day Spa
Pharaoh’s Hairum Salon and Spa
Rockcastle Florist
Woodcliff Hotel & Spa

The Flower City Pride Band above added to the festive mood!

iPad Raffle Winner: Patricia DeJoy, D.C.

Dr. Pat DeJoy with Cindy Dykes
An Award for a Healthcare Pioneer

March 25, 2014 was a special day for the Coalition. At a luncheon that took place at the Hyatt Regency Rochester, our own Executive Director, Holly Anderson, was among the twenty-two individuals and two organizations that were recipients of the Rochester Business Journal’s 2014 Health Care Achievement Awards. These awards recognize excellence, promote innovation, and honor the efforts of organizations and individuals making a significant impact on the quality of health care in our area. Holly’s well deserved award was in the Management category. Joining members of her family on hand to celebrate the occasion were members of the Board of Directors and staff of the Coalition.

Nominating Holly for this honor was a group effort among Coalition Board members, staff, and area health care providers who are aware of her long standing commitment to those affected by a breast cancer diagnosis. Testimonials and other supporting information were provided to the Health Care Achievement Awards Committee, which responded quite favorably to the outpouring of support from those Holly has served so well.

A survivor herself, Holly is keenly tuned to the needs of those who face breast cancer. She has steered the Coalition in the development of innovative programs that address all areas of concern from the time of diagnosis onward into long years of healthy, purposeful living. She has been a vocal advocate at the local, state, and national levels for those affected by breast cancer, and maintains a high level of education on current issues and research that affect the broad-based community of breast cancer survivors.

Those who saw this nomination process through to its happy conclusion are acutely aware of Holly’s contribution to this community and the number of lives she has touched, and were overjoyed to see the RBJ recognize this compassionate trailblazer.

Executive Director continued

whole plant, they were designing trials that would look at the entourage effect of all components of the plant, not just oils, tinctures, ointments and selected compounds.

When Governor Cuomo announced a series of last-minute changes that he wanted made to the bill, its sponsors, Assemblyman Dick Gottfried and Senator Diane Savino, worked tirelessly to accommodate the Governor’s concerns so they could get the bill to the Senate floor, finally, for a vote. While less comprehensive than the legislation many advocates had fought for, the modified bill would allow many with serious illnesses or debilitating conditions legal access to medical marijuana for the first time. Patients with the following conditions will qualify for the program: cancer, HIV, ALS, Parkinson’s, multiple sclerosis, certain spinal cord injuries, irritable bowel syndrome, epilepsy, neuropathy, and Huntington’s disease. The newly signed law allows the Governor’s administration the ability to add conditions, and includes a deadline of 18 months for the Governor to determine whether or not to add Alzheimer’s, PTSD, muscular dystrophy and dystonia, and rheumatoid arthritis.

It’s a step. Working alongside so many patients, family members, friends and advocates, we came to understand their conditions/disease processes as well. It is hard to believe some of these were excluded. The law also places restrictions on healthcare providers, such as a requiring that all recommendations for medical marijuana be made by physicians (excluding nurse practitioners or physician assistants who can prescribe many other medications) and mandating that participating physicians take a training course — a requirement for which there is only one other precedent in all of U.S. medicine.

So while we celebrate this beginning, we are keeping our shirtsleeves rolled up. As long as people are suffering from diseases or side effects of treatment, we have farther to go. After all, patients can’t quit, so we won’t quit either. And stay tuned, we’ll be supporting other legislation as well.

SAVE THE DATE:
LUKE PEPPONE, PhD will speak about medical cannabis at the Coalition on Wednesday, August 27, 2014
A Personal Journey continued

but intense type of radiation therapy called high dose brachytherapy, which ended in February of 2013. Jacque’s treatment for this phase of her illness was over.

Accompanied by her two adult children, Kelly and Ian, Jacque took a celebratory trip to Puerto Rico in mid-April, 2013. After her return, as her CA 125 level had risen slightly, a CT scan was done. Although there were a couple of unidentifiable shadows in the image, Jacque’s doctor was cautiously optimistic and declared that there was no evidence of disease (NED), although close monitoring would, of course, occur.

“I started back with my life full force. I’m an active person,” Jacque recalls, and she went back to the career she found so fulfilling. “It was within 6 weeks of going back to work that I thought something was wrong.” She called her doctor, who ordered another CA 125. The results showed an increase over the previous test, which raised concern. Subsequent imaging showed a noticeable difference from the prior scan, and Jacque was prescribed tamoxifen in the hope of arresting any further progression.

Life went on, and during the ensuing summer months, Jacque spent time at her son’s farm in the Adirondacks, visiting with her beloved granddaughter there. She also spent time with her daughter and two equally beloved granddaughters who live on Long Island, and she began taking yoga classes at a local studio. But maintaining an active lifestyle was beginning to become a strain. “I felt I was struggling, going uphill,” Jacque says, and soon colon-related symptoms began to appear.

By late October, based on imaging results, a colon resection was recommended. But the insuppressible Jacque, with her surgeon’s blessing, decided to wait until after she had attended a professional meeting in Chicago. The surgery took place in November, and this time the procedure could not be performed laparoscopically. Jacque’s oncological surgeon and a general surgeon worked together, and during the surgery, they discovered cancer in different places throughout the abdominal cavity.

Afterwards, having carefully considered several chemotherapy options, Jacque and her doctor opted for an aggressive regimen, consisting of the drugs Gemzar and Cisplatin. By late May of this year, Jacque completed eight of the twelve proposed rounds of this treatment when PET and CT scans showed the ovarian cancer had metastasized further. After a six-week break in treatment, Jacque will begin a new chemotherapy regimen in July.

Living with advanced stage disease has forced some major readjustments in Jacque’s life. Despite her love for her career, she was advised to retire in December of 2013. “At 61, I was not ready to retire,” she says. While she is no longer employed, Jacque is still educating people. “I’m hoping to join a small group of local women who go out and teach medical practitioners and medical residents about the disease process.” And she is opening up to new experiences. In February of this year, she was welcomed as a member of the survivor community here at the Coalition.

Jacque holds her medical care providers in high regard. “We are very fortunate in this area to have such a strong gynecological oncology group,” she asserts, and has maintained a high level of mutual trust and cooperative decision-making throughout her journey. To address the overall effects of treatment on the quality of her life, Jacque has added a palliative care specialist to her health care team. And she advocates for others to become empowered members of their own health care teams. “I think that one needs to be as in charge of their health as they absolutely can be. By that, I mean to do what’s necessary to take in the information carefully and thoroughly. Have one or two people with you during visits. Have your notebook; generate the kinds of questions that you need to feel a trust and partnership with your physician.”

Along with the difficulties of living with advanced ovarian cancer, there are everyday struggles. A caregiver by profession, Jacque finds it challenging to ask for help from others. Still, she often counsels others to ask for help. By allowing others to step in and assist when and where they can, she has shared the journey with family and friends in a meaningful way. She notes, “I’ve been receiving ongoing support since September 2012 from all avenues of my life. But I recognize how others are struggling.”

Jacque has faced pain, uncertainty, and the loss of her career while dealing with her disease. But cancer has not altered the essence of who she is. In allowing herself to grow and learn through this process, in continuing to reach out to educate others, in being a full participant in her care, and in practicing what author Anne Lamott calls “radical self-care”, Jacque has not only remained true to her authentic self; she has grown as an individual. She has also become a much loved and respected member of the survivor community here at the Coalition.

Since Jacque will remain in active treatment for the duration of her life, she is hesitant to call herself a survivor. There are many levels of survivorship, and although she didn’t choose this particular path, she has chosen the terminology she uses to describe herself. “Survivor” is just a word. Whatever word or words you may choose in speaking of her, Jacque is an original. She has not stopped living, growing, learning, or becoming. As she so simply and honestly states, “Who you are in this – in the cancer – is who you were before.”

*http://www.mayoclinic.org/tests-procedures/ca-125-test/basics/definition/or-20009524
Upcoming Events & Programs at the Coalition

Wednesday, July 23, 2014
Howard Langstein, M.D.
Updates in Reconstruction
7:00pm

Wednesday, August 13, 2014
Eleventh Annual Terri Schmitt
Legislative Reception
5:00pm - 7:00pm

Wednesday, August 27, 2014
Luke Peppone, PhD
Medical Cannabis
7:00pm

Wednesday, September 24, 2014
Posy J. Seifert, D.O.
Digital Mammography
7:00pm

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

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

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

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

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

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

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

OTHER:
☐ I am bi-lingual in ____________________________

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

Other ways I would like to volunteer: ______________________
___________________________________________________

Take Action!

Become a Supporter of the Breast Cancer Coalition of Rochester by making a gift today!

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

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

☐ $5000 Founder’s Circle
☐ $1000 Visionary Circle
☐ $500 Advocate’s Circle
☐ $100 Pink Ribbon Circle
☐ $50 Friend’s Circle
☐ $25 Contributor’s Circle
☐ $ Other

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

I would like to make a gift of $ __________

In ☐ Honor of
☐ Memory of

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

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

Amount Enclosed $ __________

Credit Card No.
Expiration
Signature
Name on Card

Gifts of $100 + receive a complimentary Comfort Heart.

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

Breast Cancer Coalition of Rochester
840 University Avenue Rochester, New York 14607
(585) 473-8177; www.bccr.org
Calling all artists!

HOW DO you REDEFINE PINK?

Show us by donating an ARTrageous piece of artwork to the ARTrageous Affair Breast Cancer Gala!

Please submit art by Friday, August 22, 2014

BREAST CANCER GALA - SATURDAY, SEPTEMBER 27, 2014
ROCHESTER PLAZA HOTEL