Tee’d Off at Breast Cancer and Doing Something About It

When the 13th annual Tee’d Off at Breast Cancer Golf Tournament returned to Brook-Lea Country Club on July 27th, unlike last year, no rain date was required! We were blessed with a warm, sunny day for the 165 golfers who participated in this sold out and highly successful fundraising event. Three teams played an early morning round with the rest of the golfers taking off at the noon shotgun start.

Continued on page 16

12th Annual Terri Schmitt Legislative Reception

During our 12th Annual Terri Schmitt Legislative Reception, Senator Michael Nozzolio and others from the NYS Finger Lakes/Western New York Senate Delegation, recognizing the astounding regional impact our organization had had, announced they had secured $200,000 in funding from the 2015-2016 New York State Legislative Budget! These funds will provide the Coalition with the means to push further into our eleven-county region. Read the Executive Director column (p. 2), Advocacy column (p. 5) and Regional Outreach Director column (p. 20).
We hear it far too often from those outside our immediate area: “Is there any organization like the Coalition near me?” Most often, the answer is no. Calls come from the east, west, and south; some even cross state lines. Though breast cancer awareness campaigns have been extremely effective for many years, those newly diagnosed with the disease are often shocked to discover that organizations focusing on the aftermath of the diagnosis – survivorship - are few and far between. Our organization has primarily served the immediate Monroe County area with a gentle push into the six surrounding counties and a clumsier attempt to serve all eleven regional counties, including Erie and Niagara. We have simply lacked the capacity and resources to do a better job.

This is about to change.

Members of the New York State Senate, Finger Lakes and Western New York Delegation, Senators Mike Nozzolio, Rich Funke, Patrick Gallivan, Tom O’Mara, Robert Ortt, Michael Ranzenhofer, Joseph Robach, and Catharine Young, recently announced they have secured state funding for the Breast Cancer Coalition of Rochester as part of the 2015-2016 New York State Budget. The $200,000 state grant, administered by the New York State Department of Health, will assist the Coalition with outreach to individuals impacted by breast cancer and help us provide our services throughout the region.

This funding could not come at a more critical time. As baby boomers move into their sixth and seventh decades, and with aging as the highest risk factor for many diseases, our healthcare system is undergoing significant change as provider practices address the growing number of people under their care. The number of cancer survivors in our country has steadily climbed to more than 10 million since the 1980s, secondary to advances in detection and treatment protocols. This reality has drawn the attention of the entire community to meet the needs of this population. Cancer care providers are being called to develop survivorship programs for patients with curable disease. Both the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) have developed guidelines to help the growing numbers of healthcare professionals struggling to create survivorship programs for their patients. Our organization is already a resource for practices in our immediate area. We have enjoyed all of our collaborations, but we know we can do more.

Continued on page 25
Patty Bellohusen didn’t have time for cancer. At 38 years of age, this busy registered nurse was working part time and taking classes that would lead to her Master’s degree. Life was hectic and her schedule chaotic, and Patty began to notice her clothes didn’t fit right. The high level of stress she was under had manifested itself in weight gain, and while examining this change in her body, she noticed a lump in her breast. “It was at the end of May 2012 when I found this lump and told the doctor,” Patty remembers. Her doctor suggested she follow up promptly and make an appointment at a breast imaging center. So, at an age when this is not in the picture for most women, Patty scheduled her first mammogram.

Sitting in the waiting area of the imaging center, Patty spotted a copy of Voices of the Ribbon, picked it up, and began thumbing through it. Noting the name of our organization but not wanting to think further about breast cancer, she set the publication down and went to get herself some tea. While preparing her brew, she struck up a conversation with a woman who shared that she was a five-year survivor of breast cancer, she set the publication down and went to get herself some tea. While preparing her brew, she struck up a conversation with a woman who shared that she was a five-year survivor of breast cancer. “It was this weird, out-of-body experience,” Patty recalls. It seemed like breast cancer was everywhere she turned. After a long day of imaging and a biopsy, she was finally able to leave and await the pathology results.

The phone call came a few days later. “Are you driving? Are you sitting down?” were the first questions Patty heard, and she knew that the news she hoped for was not likely to be delivered. As she listened to the words “You have breast cancer,” all sorts of emotions began to fight for her attention. Facing this diagnosis, especially at such a young age, was hard to comprehend. “It was shocking, to say the least,” Patty observes. Equally difficult, in their own way, were the next steps she needed to take. “[The diagnosis] revved up my anxiety and I was moving ahead of the game, not focusing on one thing right here and right now.”

Her husband, Mike, her family and friends, and the Coalition, which she turned to shortly after her diagnosis, bolstered Patty through this time. “It was very helpful telling people what was going on because it gave me such support,” she remembers. In reaching out to the Coalition’s survivor community, Patty was able to connect with others who had faced their own diagnoses and found their way through. She joined the group that meets every Friday at the Brown Bag table when she was able, and connected with a couple of PALS mentors: young women like herself who had faced the same treatment decisions she was facing. With her support system to uphold her, Patty put together her medical team and made the decisions that enabled her to move forward.

After careful consultation with her doctors, Patty came to the conclusion that her best surgical option was a bilateral mastectomy with TUG (transverse upper gracilis) flap reconstruction, in which the tissue needed to build her reconstructed breasts was taken from her inner thigh area. One of Patty’s PALS mentors had gone through the same procedure and shared her experience, along with some practical tips that had helped during the post-operative time.

With her surgical decision made and the date set, there was now some time to reflect on what had happened so far. And Patty came to a realization: looking back on how frenetic the days since her diagnosis had been, she now observed it would have been best to take little sanity breaks here and there. “You have some time to breathe and think things over. You have time to make a phone call or an appointment. Just take a little time and some deep breaths and sleep on something overnight if you need to.”

Facing a diagnosis of breast cancer—or any kind of cancer—is an emotionally charged experience; a time of uncertainty, difficult questions, and life-altering decisions to make in a relatively short time. Through her experience, Patty learned to pause and remember who she was and what she needed in this; to stop and just breathe sometimes. And that enabled her to move forward with less stress and more clarity.

With her newfound perspective in place, Patty underwent her surgery. Six weeks afterward, she began a three-month course of chemotherapy. She found the evening support groups at the Coalition invaluable as she struggled with some physical and emotional side effects of this treatment that challenged but did not defeat her.

When chemo was finished, it

Continued on page 27

Breath is the bridge which connects life to consciousness, which unites your body to your thoughts. -Thích Nhất Hạnh
There are moments that change our lives forever. One such moment is finding out that we or someone we love has cancer. For me, it was September 14th, 1987, around 7:00pm. After a long day of teaching and coaching soccer, I sat down in my tiny studio apartment to call Mom and say "Happy Birthday!" I could tell from her voice that something was wrong. After a few minutes of hedging, Mom told me she had been diagnosed with brain cancer and would need emergency surgery that night. I jumped in my car, went to Aunt Marilyn’s for gas money, drove to Geneseo to pick up my brother, then sped across the Thruway toward Albany with one thought in mind: please let me see Mom just one more time so I can tell her how much I love her.

And in that moment when fear and hope are fighting for control, when perhaps for the first time we recognize our own mortality, one thing becomes apparent: it doesn’t matter if one is black or white, Democrat or Republican, gay or straight; we are all just visitors on this planet for a relatively short time and it would behoove us to spread a little more love along the journey.

My Mom survived her surgery and radiation with a few deficits, but mostly okay. And she is one of those people whose life is defined by helping others. Both in her cancer diagnosis and in her altruism, she reminds me of Terri Schmitt.

I first met Terri at a political fundraiser - I honestly don’t remember who the candidate was. Terri’s ubiquitous smile and joyful laugh made her hard to resist. Over time, I got to meet her family: Bix/Kevin/Rob, her handsome, multi-named husband; and Dan, MaryBeth, Tom, Tim, and Chelsea, her amazing kids. Terri and her family had a way of making all

Continued on page 8
August 5th, 2015 marked the twelfth year of the annual Terri Schmitt Legislative Reception, and was the first to take place in our new location. Held to recognize and honor the inspiration of Terri Schmitt, who was a former Town Supervisor of Rush, breast cancer advocate, and co-chair of the Coalition’s Board of Directors, the reception was very well attended by many local and state elected officials, their representatives, advocates, survivors, members of Terri’s family, and other friends of the Coalition. It was a very exciting evening filled with great conversation and great food.

A brief program began with a warm welcome, after which our Director, Holly Anderson, shared the good news about a significant grant that the Coalition has just received from the New York State Department of Health. Members of the New York State Senate Central and Western New York Delegation secured the funding that will allow the Coalition to extend its reach in the Upstate New York region.

The guest speaker of the night was one of Terri’s dear friends and a recent inductee into the National Teacher’s Hall of Fame, Rich Ognibene. He shared the story of meeting Terri at a political fundraiser and recalled how her joyful presence captivated him and many others. She was the Town Supervisor of Rush, and Rich spoke with deep respect of those who choose a life of public service, calling Terri a champion for all. Putting on his best ‘teacher voice’, he spoke of the responsibility we have to be more compassionate and to pay it forward. He concluded by saying that those whose lives are guided by a giving spirit and acts of kindness, as Terri’s was, live on in those who loved them.

Members of our advocacy committee, survivors, family and friends had the opportunity to speak with some of our local and state elected officials and their representatives about breast cancer related bills and public policy, and to thank them for the support they’ve shown to the Coalition over the past year.

The Advocacy Committee meets at the Coalition on the first Wednesday of every month at 4:30 pm. We are always looking for new members. If you are interested about learning more, please contact the Coalition at 585-473-8177. We would love to have you join us.

---

Advocacy Chair's Update

Twelfth Annual Terri Schmitt Legislative Reception

-August 5th, 2015 marked the twelfth year of the annual Terri Schmitt Legislative Reception, and was the first to take place in our new location. Held to recognize and honor the inspiration of Terri Schmitt, who was a former Town Supervisor of Rush, breast cancer advocate, and co-chair of the Coalition’s Board of Directors, the reception was very well attended by many local and state elected officials, their representatives, advocates, survivors, members of Terri’s family, and other friends of the Coalition. It was a very exciting evening filled with great conversation and great food.

A brief program began with a warm welcome, after which our Director, Holly Anderson, shared the good news about a significant grant that the Coalition has just received from the New York State Department of Health. Members of the New York State Senate Central and Western New York Delegation secured the funding that will allow the Coalition to extend its reach in the Upstate New York region.

The guest speaker of the night was one of Terri’s dear friends and a recent inductee into the National Teacher’s Hall of Fame, Rich Ognibene. He shared the story of meeting Terri at a political fundraiser and recalled how her joyful presence captivated him and many others. She was the Town Supervisor of Rush, and Rich spoke with deep respect of those who choose a life of public service, calling Terri a champion for all. Putting on his best ‘teacher voice’, he spoke of the responsibility we have to be more compassionate and to pay it forward. He concluded by saying that those whose lives are guided by a giving spirit and acts of kindness, as Terri’s was, live on in those who loved them.

Members of our advocacy committee, survivors, family and friends had the opportunity to speak with some of our local and state elected officials and their representatives about breast cancer related bills and public policy, and to thank them for the support they’ve shown to the Coalition over the past year.

The Advocacy Committee meets at the Coalition on the first Wednesday of every month at 4:30 pm. We are always looking for new members. If you are interested about learning more, please contact the Coalition at 585-473-8177. We would love to have you join us.
My name is Mary Jane Weed. No, my parents were not hippies; they were strict, church-going Methodists. I am a 60 year old lesbian, a recovering alcoholic of 29 years, a skilled mechanic, and a breast cancer survivor of 19 years.

I grew up with 2 older brothers and one sister. One brother died of a heart attack in 2011. In 2013, my other brother and his wife died tragically in a car accident. My sister faced breast cancer in 2007. Thankfully, she is doing very well today.

I was one of five female apprentices at Kodak in 1978, working in a previously all-male mechanics department. The stress was unbelievable. But I was determined to make a difference and forge a path for the next generation.

In 1990, I joined a non-denominational church and wed my wife. In 1995, we moved into a ranch house on five acres. We were thankful to know we would always have a roof over our heads.

In 1996, I was taking a shower at work and felt a lump. I remember crying after I told my wife, while she tried to reassure me that things would be fine. The next day I had a biopsy and the surgeon knew right away it was cancer. I looked my wife in eyes told her our lives would never be the same.

I had to wait one agonizing month for my lumpectomy and afterwards, would need chemo, radiation, and five years of tamoxifen. When I felt lonely and down, I would drive to my best friend’s place to sleep on her back porch and snuggle with her cat, Yanya, who was such a comfort. I remember watching the turkey, deer, and squirrels and it made me feel more alive. Just being in nature helped me to cope.

I was the first person in our church to have cancer. The phone rang off the hook. My wife started getting mad from all the calls and people constantly coming over. We decided to leave the church. The phone stopped ringing and no one came over. Some folks did come to my head shaving party, which really was fun. I was excited to see what my head looked like as a newborn. Thank God it was perfectly shaped!

I went back to work seven months after my surgery. One of my biggest challenges was that people at work expected me to be exactly the same as I was before my breast cancer. Unfortunately, I wasn’t the same. I struggled to carry my tool pouch. I now had asthma and had difficulty walking from the parking lot to our building. I worked with my arm wrapped due to lymphedema. Sometimes I was so exhausted I would go into the ladies’ bathroom and sleep on the floor. Finally, in 2003, Kodak let me go.

In 2005, I got my Commercial Driver License and started driving a bus for the Churchville-Chili school district. Shortly afterward, I found that, once again, I could not walk far without difficulty breathing. I was rushed to the hospital because my lungs were collapsing and it was discovered I had metastatic breast cancer in the pleural cavity. My mobility was limited now and pain medication became part of my life. It was during this time that my wife decided to leave me. The stress over this was just too much for me to bear and I ended up in a two-week outpatient mental health program to work on accepting this loss.

I am still here.

In 2006, my oncologist suggested that I go to Gilda’s Club, and Gilda’s led me to the Coalition. I attend a metastatic group that meets twice a month.
**October 13 is Metastatic Breast Cancer Awareness Day**
*By Pat Battaglia*

Amid the noise and attention devoted to breast cancer awareness during the month of October, one day is set aside for those who live with the disease on a daily basis. In 2009, the United States Senate and the House of Representatives agreed to pass a resolution designating October 13 as Metastatic Breast Cancer Awareness Day.

In 2014, the Pfizer Company completed a study of the public perception of metastatic breast cancer (MBC), and the results were eye-opening. More than sixty percent of participants reported knowing little or nothing about MBC. Seventy two percent believed that advanced disease is curable if it is detected early. And fifty percent believe that breast cancer progresses because people did not take the right treatment or preventative measures.*

During a month when much of the public conversation centers on early detection, those who will live with advanced disease for the duration of their lives, as well as those who care for and advocate for them, have heard too many stories about people who “did everything right”, including taking prescribed treatments for early stage diagnoses and engaging in health-promoting practices such as regular exercise and healthy eating, and are living with metastatic breast cancer. The message of early detection and culture of self-blame do not apply here.

While much has been learned in recent years about treating the disease, we are still a long way from understanding what causes breast cancer to metastasize. This is the reason our Research Initiative at the Coalition focuses on understanding metastasis, as well as dealing with primary prevention.

To honor those who live with advanced disease 365 days a year, every year, learn the facts about metastatic breast cancer. You can begin here: [http://mbcn.org/developing-awareness/category/13-things-everyone-should-know-about-metastatic-breast-cancer](http://mbcn.org/developing-awareness/category/13-things-everyone-should-know-about-metastatic-breast-cancer). Donate to our Research Initiative in honor of someone you know or love. Get to know those who are living with this disease; they are not defined by their diagnosis.

For those living with MBC, know you are not alone. Become part of the Coalition’s support community, join others on a similar path, and meet even more who understand and care. We’re here for you on October 13 and every other day of the year.

*I am still Here continued*

I am trying to accept the fact that I have gone from having a skip in my step to using a cane and a walker. I am now going to a pain clinic and Strong Palliative Care. I was frightened to go there in the beginning but am so glad I finally accepted that I need help.

Through all of this, I have received many blessings. I have friends who have taught me to how to live and teach me to keep living. I have time now to spend with my 90 year old mother; we are making a quilt together. I have a cat that brings me great joy. I bought a reliable truck with the money from sale of my house. I have a new apartment and can let my creative side show; old fashioned sewing machine treadles with glass tops are my end tables, a post office clerk’s desk is my TV stand, and the top where letters once were now holds my precious collectibles. I am working toward my dream of fixing my blacksmith barn built in 1891 and setting up my woodworking shop.

*How blessed are they
Who know the art
Of living for each other,
For all life’s joys are doubled
When you share them
With another.
~Anonymous*

SAVE THE DATE:
The 13th Annual Advanced Breast Cancer Seminar

Friday, April 8, 2016
at the Memorial Art Gallery

---

*I Am still Here continued*

And my hope for you and me is that the cure is around the next bend.

---

**SAVE THE DATE:**
The 13th Annual Advanced Breast Cancer Seminar

Friday, April 8, 2016
at the Memorial Art Gallery
Research Administrator’s Update

Coalition Awards
2014-2015
Grant for Breast Cancer Research
By Jennifer Gaylord

On July 23, 2015, many Coalition Board members, Committee members, Coalition supporters and former grant recipients attended a summary presentation by one of our 2013-2014 research grant recipients Gokul M. Das, PhD, Associate Professor in the Department of Pharmacology and Therapeutics at Roswell Park Cancer Institute in Buffalo, New York. Having completed his Coalition supported research, Dr. Das outlined his findings regarding the “Role of Estrogen Receptor Beta and Tumor Suppressor p53 Signaling in Triple Negative Breast Cancer.” We were excited to learn of his discoveries concerning the connection or “cross talk” that occurs between the Estrogen Receptor Beta and p53 gene. Dr. Das sees the potential that this connection can be exploited for therapeutic intervention in breast cancer, especially triple negative breast cancer. He and his research team have several pending and planned grant applications to potentially fund the continuation of his research efforts. His next steps will involve the implantation of previously collected human cancerous tissue into mice, utilizing a tran-species process known as xenotransplantation to investigate the action of new drugs on tumor growth and metastasis. Dr. Das anticipates that the results will lead to new clinical trials with breast cancer patients. Well done Dr. Das!

Look for a summary of the Coalition’s second 2013-2014 research grant recipients, Drs. Helene McMurray and Mark Noble to be reported in the next newsletter.

Legislative Reception/Our True Purpose continued

their friends feel special, like we were part of their clan. And as our friendship evolved, I became more aware of Terri’s altruism.

She was the Town Supervisor of Rush. Anyone who chooses a life of public service is working for the greater good.

She was the proud mom of five wonderful kids. Like all moms, she sacrificed so her kids could have what they needed.

She was one of the first elected officials to speak loudly about the need for gay rights. She welcomed gay friends into her home and made us feel valued at a time when others were less willing to do so.

She was on the Board of Directors for the Association of Battered Women and AIDS Rochester, giving her time and effort to help the most vulnerable among us.

She was a champion for all of us. And then our lives changed forever when we found out that Terri had breast cancer. In typical Terri style, she didn’t want pity. She immediately immersed herself in helping others with this disease. As we watched her endure the various procedures and treatments, with all their side effects, it became clear, especially toward the end, that she endured them not so much for herself, but for those of us who depended on her.

Whenever we lose a friend, particularly someone as young and vibrant as Terri, it causes us to reflect on existential questions. Why are we here? What happens when we die? What is our purpose? I am neither a philosopher nor a cleric, but here’s what I believe: the main reason we are here – the purpose that makes us feel most fully human – is to help others. And if we live a life dedicated to that noble goal, then when our physical form disappears, our spirit still lives on in the lives of the people we loved.

Terri knew her purpose. She gave love to others unabashedly and unconditionally. That love lives on in all of us. But we cannot be selfish with that gift. We have a responsibility to pay it forward in the way we love our family and friends, in the way we treat the most vulnerable among us, in the way we help people fighting cancer. If we can all find a way to be just a little more compassionate, then through those myriad acts of kindness, the spirit of Terri Schmitt will live on. And I can think of no greater legacy than that.
Difficult life events of all sorts have created survivors of all sorts. They all have at least one thing in common: each has overcome daunting obstacles, and their stories resonate with tenacity and hope. Beverly (Bev) Levy has two such stories.

In 1999, Bev found the Coalition to be a source of support and inspiration as she faced a diagnosis of breast cancer. After finishing chemotherapy and radiation, she went on to become one of the Coalition’s beloved and diligent advocates, doing meaningful work in support of legislation important to those affected by breast cancer.

In 2006, she and her husband, Gail, made plans for a trip to the west coast to visit their daughter. A week before their departure, Bev began to notice urinary symptoms. During the two-week trip, her symptoms steadily increased in severity. Upon her return, she quickly scheduled a visit with her primary care doctor, who was able to feel a mass in her lower abdomen and referred her to her gynecologist for a transvaginal ultrasound. This confirmed that there was a sizeable mass, but didn’t give any information regarding its nature. When Bev’s CA-125 level proved to be elevated, she was referred on to a gynecological oncologist, who recommended a hysterectomy as the best means to a definitive diagnosis. Bev awoke from her surgery to learn that she had been diagnosed with a rare form of fallopian tube cancer: a stage IIIB carcinosarcoma, also called a mixed Mullerian tumor, that had moved beyond the fallopian tubes and involved her uterus.

Once again undergoing chemotherapy, Bev had a good response to the six rounds of carboplatin she was prescribed. Genetic testing did not find any known link between the two cancers. Ever the advocate, she sought second opinions regarding her extremely unusual diagnosis at both Memorial Sloan Kettering and Dana Farber, and both agreed to the basic regimen recommended by her local doctor, but with variations on how the drugs would be administered. Grateful for the perspective she gained during this process, Bev chose to remain with her local oncologist for the duration of her treatment.

After treatment, life went on relatively uneventfully for this tenacious advocate until four years ago, when Bev’s CA-125 levels, which had been carefully monitored since her 2006 diagnosis, began to rise. Her oncologist decided to try the estrogen-blocking drug, tamoxifen, at twice the dosage normally prescribed to breast cancer patients, despite the fact that Bev’s breast cancer pathology had shown her tumor to be estrogen receptor negative, indicating that tamoxifen might not be an effective treatment for her. But this doctor’s instincts proved sound; Bev’s CA-125 counts have returned to normal and have stayed that way.

Gynecological cancers have been called “silent cancers” because the signs and symptoms can be easy to miss. But self advocacy is high on Bev’s list of priorities, and she is living proof of its effectiveness. “Be aware of your body,” she advises, “and when you notice something different, act.”

Through her experience with both cancers, Bev found support, encouragement, and compassionate listening ears at the Coalition. A former member of the Advocacy Committee, a volunteer for our ARTrageous Affair and community events, and a PALS mentor to those with both breast and gynecological cancers, she has found numerous ways to give back to the community that has been there for her. “There is always hope,” she says. “Never give up.”

“Be aware of your body.”

“Hope” is the thing with feathers
-Emily Dickenson

“Hope” is the thing with feathers -
That perches in the soul -
And sings the tune without the words -
And never stops - at all -

And sweetest - in the Gale - is heard -
And sore must be the storm -
That could abash the little Bird
That kept so many warm -

I’ve heard it in the chillest land -
And on the strangest Sea -
Yet - never - in Extremity,
It asked a crumb - of me.
Our Programs at the Breast Cancer Coalition of Rochester... all FREE of charge!

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

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

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

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

Book Club
If a traditional support group isn’t for you but you still like the idea of participating in a supportive community following a breast or gynecologic cancer diagnosis, join our Book Club, led by Pamela Emigh-Murphy, Carol Moldt, Jill Richards, Angelique Stevens or Karen VanMeenen, which meets on the 4th Thursday of the month, from 6:00-8:00pm. Prior sign-up is encouraged. Call us or visit us at www.bccr.org for details and latest book selections.

Common Ground:
Living with Metastatic Cancer Discussion Group
For those living with metastatic breast or gynecologic cancers, we offer a discussion group on the 1st and 3rd Thursdays of the month at noon. Led by Peg DeBaise, LMFT, the discussion is topic-based, although all concerns of those present will be addressed. Lunch and beverages are provided so RSVP is needed.

The Lymphedema Awareness Network
LANROC provides awareness, education, and peer support for anyone living with lymphedema. Caregivers, lymphedema therapists, medical personnel, and those at risk for developing lymphedema are also welcome. This group, facilitated by Karen Miltner, meets from 5:30 to 7:00pm on the second Wednesday of each month.
For information or to register, please call the Coalition at 585-473-8177 or e-mail info@bccr.org

Peer Advocates Lending Support: PALS SM

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

See page 13 for PALS Program updates.

Young Survivor Soiree

A young survivor may identify with those who have faced breast or gynecologic cancer in the midst of a career climb, or while raising children, or perhaps with those whose family plans have been derailed by treatment. Four times a year, we hold these soirees as an informal way to connect with others who have walked a similar path.

The next soiree will be Friday, November 20th. Please call to be added to the attendee list.

Voices & Vision: A Writing Workshop

This well-loved group gives people with breast or gynecologic cancer an opportunity to explore and express their feelings through writing. Led by professional instructors from local colleges, Elizabeth Johnston, Pamela Emigh Murphy, Angelique Stevens and Karen VanMeenen, these workshops run in five week cycles on Tuesday evenings. Seating is limited, and advance registration is required.

The Healing Arts Initiative

This initiative is an opportunity to learn a new modality or practice a complimentary healing course to relax, de-stress, and exercise.

Gentle Yoga

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

Qi Gong

Now offered on Wednesday afternoons in six week sessions throughout the year. Qi Gong is facilitated by certified instructor, Raphaela McCormack. This class is limited to 14 survivors of breast or gynecologic cancer. Advance registration is required.

Ongoing Healing Arts Sessions

Courses run in four-week sessions and are open to 14 survivors of breast or gynecologic cancer. Advance registration is required.

Saturdays:
- Gentle Yoga with Raksha Elmer
- Nia Movement with Jane Pagano
- Fluid Motion with Tracey Boccia
- Tai Chi with Nancy Gillespie
- Art Therapy with Joyce Kliman NEW!

Thursdays: NEW!
- Mindfulness & Meditation with Estalyn Walcoff

Please visit www.bccr.org for the 2015 Healing Arts Program Schedule and Registration Guidelines.

The expansion of the Healing Arts Initiative was made possible by The Greater Rochester Health Foundation
Support groups bring together people who are facing similar life experiences and encourage networking within an expanded circle. Ample research documents the benefits of support groups for women going through breast cancer. Two main reasons women attend support groups are to provide mutual support and help one another navigate the various phases of cancer care.

One study reported that the benefits of support groups included both emotional support and practical support. The women in the study who connected with other breast cancer survivors felt understood, offered hope and shared experiences, and laughed alongside each other. These participants were able to address their emotional needs. In addition to the observable emotional benefits, the participants received practical and informational support. This was evident in the exchange of important medical information and learning how to ask for help, or “get what you need.” Advocating for oneself can be muddy territory to meander through, especially for those who have never gone through a health crisis. The ongoing support from a small group of women who have “been there” is immensely beneficial.

At the Coalition, a few different support and networking groups are offered consistently throughout the year. Our calendar remains constant so that our community of survivors - both familiar faces to us and those who are newly diagnosed - can easily access our resources. Our two traditional support groups are offered on the first and third Thursday of the month and the second and fourth Tuesday. The non-traditional networking group, Brown Bag Friday, is offered weekly. Finally, the Lymphedema Awareness Network of Rochester (LANROC) always meets on the second Wednesday of the month. We understand that dealing with a cancer diagnosis can be an incredibly overwhelming time. This is why the above-mentioned groups operate on a drop-in basis, so no RSVP is required. Please refer to pages 10 and 11 for a full description of our support programs. We will continue to provide regular, high quality support and networking groups for anyone in our community living with breast or gynecologic cancer.

To learn more about our support programs and the information available at the Coalition, please contact Laura at 585-473-8177 or laura@bccr.org

Are you on our mailing list?
Is your e-mail address and/or phone number a part of our listing? Please send us your information for our mailing list so that we can offer e-mail news as well as print news. Send your information (full address or just your other details) to Laura Albert at laura@bccr.org

Thanks!

JOIN US
Lives Touched, Lives Celebrated
10.28.15
Along with some much-needed support and perspective, everyone who attends a Breast Cancer 101 session receives a PALS pak: a canvas tote bag filled with comfort items tailored to the needs of those newly diagnosed with breast cancer. These canvas tote bags typically include such items as blankets, surgical pillows, reading materials both informative and inspirational, lotions, teas, and much more. We choose these things carefully, based on feedback we’ve received from survivors. Many items are donated, and a good number are handmade. Thanks to the generosity of so many, our PALS paks are filled to the brim with items that say “We get where you’re coming from, and we’re here for you.”

PALS paks are also a great introduction to the PALS Program, which matches those who are newly diagnosed with breast cancer - or in treatment for the disease, or, in some cases, living in the aftermath of active treatment - with a trained PALS mentor. A mentor can be helpful at many points along the way. Most, but not all, of those who receive a pak decide to accept this one-to-one connection with someone who’s faced a similar situation. But all receive the message that the option is open to them; they know there are others who’ve “been there” and are willing to offer the voice of experience in dealing with the day-to-day reality of living with this diagnosis.

This kind of human connection surpasses any type of material goodies we may offer in a PALS pak. Still, the power of the message implicit in the contents of the bag can’t be underestimated. Small gestures can have great meaning, and small items can have great value to those in need. If you have been through a breast cancer diagnosis and treatment, is there something that was particularly comforting or useful to you? Or something you wish you had known about when you were going through it? Something that is relatively easy and inexpensive to obtain or might be donated by caring community members? Something you feel would be appreciated by others who are new to this experience?

Although I am not solely responsible for deciding what goes into PALS paks, I am always open to suggestions that can be considered by the support staff at the Coalition.

Email your ideas to me at pat@bccr.org.

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

- Leo Buscaglia

"Scared and sacred are spelled with the same letters. Awful proceeds from the same root word as awesome. Terrify and terrific. Every negative experience holds the seed of transformation."

- Alan Cohen

* PALS - Peer Advocates Lending Support
People have used ginger and turmeric for thousands of years to season their food and to ease common ailments. Readily available in fresh and dried, ground form at affordable prices in supermarkets and specialty stores, both spices are obtained from the rhizome (a sort of modified underground stem) of their respective plants, and are members of the same plant family. Both have been studied by local researchers interested in certain properties they contain that can help ease some of the side effects of cancer treatment.

Two common side effects of treatment are nausea from chemotherapy and dermatitis from radiation therapy. Although antiemetics are routinely prescribed to help patients with nausea, over 70% of patients undergoing chemotherapy experience nausea.\(^1\) Radiation dermatitis occurs in approximately 95% of patients receiving radiotherapy,\(^2\) even though enhanced skin care measures are often suggested to prevent or ease the condition.

Ginger is one of the most commonly used condiments in the world and many medicinal properties have been attributed to it throughout the ages. Its mechanism of action isn’t entirely understood, but both ginger and its cousin, turmeric, are generally regarded as safe by the US Food and Drug Administration.\(^3\) Among other uses, ginger is a traditional remedy for nausea such as morning sickness in pregnancy or motion sickness. In order to study its anti-nausea characteristics under carefully controlled conditions, the University of Rochester was the home base of a phase II/III clinical trial that drew participants from private practice oncology groups throughout the country to investigate the effects of ginger supplementation on cancer patients undergoing chemotherapy and receiving standard antiemetic medication. Headed by Julie L. Ryan, PhD, MPH, an Assistant Professor in the Departments of Dermatology and Radiation Oncology and member of the Community Clinical Oncology Program (CCOP) Research Base at the University of Rochester Medical Center, ginger supplements were taken by patients three days before...
Roasted Butternut Squash and Navy Bean Soup with Ginger and Turmeric

**Ingredients**
- 2 tablespoons olive oil, divided
- 4 cups cubed butternut squash
- 1/2 cup diced white onion
- 1 tablespoon fresh minced ginger or 1/4 teaspoon ground dried ginger
- 1 tablespoon fresh grated turmeric or 1 teaspoon ground dried turmeric
- 4 cups vegetable broth
- 1 cup navy beans, rinsed and drained (If using canned beans, look for BPA free cans)
- 1/2 teaspoon black pepper
- 1/4 teaspoon salt

**For Serving (optional)**
- Soy sauce or tamari
- Chopped fresh cilantro
- Toasted sesame seeds
- Cooked brown rice

Makes 2-4 servings.

*Adapted from Naturally Ella*

http://naturallyella.com/ginger-butternut-squash-soup/

- Heat oven to 400 degrees.
- Toss the squash cubes with 1 tablespoon of the olive oil and spread in a single layer on a large, lightly oiled baking sheet (or line with parchment paper). Roast 30-45 minute, until fork tender and lightly browned.
- In a pot, heat olive oil over medium-low heat.
- Add onions and cook until soft.
- Stir in ginger and turmeric; cook for 30-60 seconds, just until fragrant.
- Add squash, broth, beans, salt, and pepper. Bring to a boil, reduce to a simmer, and cook until squash is extremely soft.
- Puree soup using an immersion or regular blender. Return to pot (if using regular blender).
- If using rice, place about ½ cup in bowls. Pour soup into bowls. If using, top with a swirl of soy sauce and sprinkle with cilantro and sesame seeds.

Sun Tea

In our last issue, we offered directions on making sun tea. An alert reader pointed out to us that the Centers for Disease Control advises against brewing tea in the sun, as the water does not reach a temperature sufficient to kill pathogens that may be in the water or in the tea leaves themselves. This is of particular concern to those in treatment, whose immune systems may be compromised. Brewing your tea the usual way with boiling water will kill any pathogens. Another safer alternative is refrigerator tea. Fill a pitcher or other container with cold water, add four to six tea bags, and refrigerate at least six hours or overnight.

We live and learn, and are grateful for our knowledgeable readers.

Golden Milk

**Ingredients**
- 1 tsp turmeric paste (see recipe below)
- 1 cup hot milk (cow, goat, soy, rice, almond or coconut)
- 1/2 tsp almond or sesame oil
- Maple syrup or honey to taste
- a pinch of cinnamon (optional)

- Combine all ingredients
- Gently heat, stirring occasionally, enjoy!

**Turmeric Paste**

Combine 1/4 cup turmeric powder with 1/2 cup water (filtered if possible) and simmer over medium-high heat for at least 7 minutes, stirring constantly, until a thick paste forms. If the mixture gets too dry while cooking, add a little additional water. Remove from heat, cool and store in a glass jar in the refrigerator for up to 1 month.

*Adapted from http://drarjan.com/turmeric-paste-golden-milk/*

Chemotherapy and continued for three days afterward, for a total of six days. It was found that ginger reduced the severity of acute nausea in these patients. Interestingly, lower doses of ginger seemed most effective. While prior studies had not found ginger beneficial in this setting, researchers for this latest study theorize that beginning ginger supplements before chemo, which had not been done previously, was an important element of their success.

Lesley James, M.D., a board certified family physician who is also certified by the American Board of Integrative Medicine and offers integrative oncology services, recommends her patients in chemotherapy begin using low doses of ginger three days before their treatments, usually in combination with prescription antiemetics. “I find that it is not as effective if taken as needed, which is how many people tend to use it,” she says, and continues, “I always advise my patients to call me with any side effects or nausea. I rarely get calls.” Dr. James prefers lower doses of ginger, as higher doses were shown to be less effective and can cause heartburn and worsening of GI symptoms in those undergoing chemotherapy.

Turmeric, the warm and peppery spice commonly included in curries, contains an active compound called...
High spirits on the course throughout the afternoon continued inside the clubhouse as the golfers returned to enjoy dinner and prizes. The highlight of this year's raffle was a pair of luxury suite tickets to the Buffalo Bills home opener on September 13 against the Indianapolis Colts. Congratulations to John Costello, the lucky winner! The generous donation of this special prize by Jim Herbst at Manning & Napier is deeply appreciated, as are the many people who purchased raffle tickets in the weeks leading up to the tournament and at the event. We also extend our heartfelt gratitude to the many sponsors and donors whose support made this event possible.

Special thanks go to the extraordinary planning committee, led by co-chairs Sean Patton and Lee Cordero, and joined by Holly Anderson, Sylvia Cappellino, Cindy Dykes, Kay Kolb, Sandy Monahan, Brigid Ryan and Susie Smith, whose unflagging efforts ensured an enjoyable day for all involved. Of course, we could not host a successful event like this without the volunteers and Coalition staff members who were there that day to help: Janey Harper, Marcy Lazio, Colette McConnell, Lori Meath, Margie Micca, Betty Podlesh, Brenda Tartaglia, Connie Zeller and Jake Zembiec.

We hope you will join us next year for the 14th Annual Tee’d Off at Breast Cancer Golf Tournament on Monday, July 25, 2016, at Brook-Lea Country Club.规划建设

### OUR GENEROUS SPONSORS

**EAGLE SPONSORS - $2,500**
- The Richard T. Bell Foundation
- Ron & Kelly Ricotta
- Towpath Bike, Inc.

**LUNCH SPONSOR - $1,000**
- JP Morgan Asset Management

**GREEN TEE SPONSORS - $1,000**
- C.M. Armitage Electrical Contracting, Inc.; The Cabot Group; Jeffrey Ellis Carl Cabinet Makers, Inc.; Kenron Industrial Air Conditioning, Inc.
- The Duke Company
- Envisage Information Systems
- Fidelity Investments
- Paul W. Harris Funeral Home
- PIMCO
- Prudential Retirement
- Ria Tafani Photography
- Shapiro, DiCaro & Barak, LLC
- The Standard Insurance Company
- Transamerica Retirement Solutions
- Westminster Consulting, LLC
- The Weybrecht Family
- Zeller Corporation

**PINK TEE SPONSORS - $500**
- American Century Investments
- New York Life
- PNC Capital Advisors, LLC
- Rizzo DiGiacco Herr Baniewicz Accounting & CPA Services
- Visiting Nurse Service of Rochester & Monroe County, Inc.
- T. Rowe Price Retirement Plan Service, Inc.

**HOLE SPONSORS - $175**
- Jim and Sylvia Cappellino
- Colony Dry Cleaners
- Design Inspirations Studio
- C. Dennis Beaver; Hill Creek Consulting, LLC
- Tony and Kathy Iacovangelo (In Memory of Mary Jane Patella)
- Interlakes Oncology and Hematology, PC
- Lincoln Financial Group
- The Maggio and Monahan Families
- MFS Investment Management
- C.H. Morse Stamp Co.

**RECOGNITION SPONSORS - $125**
- Dawson Law Firm, PC
- Gallina Development Corporation
- C. Dennis Beaver; Hill Creek Consulting, LLC
- Upstate Niagara Cooperative, Inc.

Please visit our website, www.bccr.org for 2015 Tournament results.
Hoping for a win!  Going for the putt!  Volunteer Brenda Tartaglia enjoying the weather

Hoping for a win!

Committee Co-Chair, Sean Patton congratulates Bills raffle winner, John Costello

Triumphant Lori Betlem-Lytle!

Leader of the pack, Chair of the Board, Patti Cataldi

Gallea’s Tropical Greenhouse
Genesee Valley Penny Saver
Georgetown Liquor
Grinnell’s Restaurant
Gruttadaria Bakery
Hedonist Chocolates and Ice Cream
Izzo Golf
Brian Jessen
Joe’s Pasta House
KLR Landscape, Inc., Robin Vavrina
Kay Kolb
Lake Beverage Corp.
Margie LaTourette
MFS Investment Management
Manning & Napier (Jim Herbst)
Marketview Liquor
Sandra Monahan
Jim Mrva, Monroe Golf Club
North American Breweries
Pane Vino on the River
Pharaoh’s Hairum
Scott’s Hallmark Shop
The Pittsford Pub

Pomodoro Grill & Wine Bar
Preferred Plants
Rockcastle Florist
Saha Med Grill
Salon Brio
Salon Europa
Savoia Pastry Shoppe
Lisa Scally, Locust Hill Country Club
Shark’s Ice Cream

Skin Topic Spa
Anne Smith
Susie Smith
Texas Roadhouse
Wambach Garden Centers
Webster Golf Club
Westminster Consulting, LLC
Wild Wood Country Club
J. William Jewelers
Windsor Cottage
Carolyn Yackel

Event photos included here taken by Ria Tafani, official photographer of the Coalition. Thanks, Ria!

Leader of the pack, Chair of the Board, Patti Cataldi
Survivorship: 
-By Pat Battaglia

The word “survivor” holds as many different meanings as there are people who use it to describe themselves. Some who have faced a cancer diagnosis feel survivorship is a goal that’s reached when a certain phase of treatment, such as surgery, radiation, or chemotherapy, is over. Others may feel that from the moment of their cancer diagnosis, they have begun to fight their disease, and every small triumph that moves them from day to day marks them as a survivor. And some do not care to use the word at all, preferring an alternate expression such as “thrivor” or recoiling at the thought of any label whatsoever.

In truth, there is no right or wrong term you might use to identify yourself once you’ve faced a cancer diagnosis; this is one part of the process that is entirely under your control. Unless a person is living with metastatic disease and approaching cancer as a chronic illness (and those in this category are indeed considered survivors), a day will come when active treatment has ended and the transition into life beyond cancer begins. This can be an emotionally charged time full of uncertainty and questions such as: What comes next? How do I deal with my fears about recurrence? What are long term effects of the treatment I’ve had? Will I have ongoing physical limitations? Who will be monitoring my health? How can I incorporate this experience into my way of being as I move forward in my life?

For the remainder of this article, the word “survivor” will be used to refer to those who have completed active treatment, in full acknowledgement of the inadequacies of the word and individual preferences regarding its use.

A Large and Growing Group

There are currently about 14.5 million cancer survivors in the United States today and their numbers are expected to increase to 18.9 million by 2024.1 The questions they face are innumerable and the needs of this growing group are a major concern to health care providers.

In 2005, the Institute of Medicine (IOM) issued a report, From Cancer Patient to Cancer Survivor: Lost in Transition², which recommended that cancer patients receive a written survivorship care plan and outlined four components of quality survivorship care: prevention and detection of new cancers and recurrent cancer; surveillance for recurrence or new primaries; interventions for long-term and late effects from cancer and its therapies; and coordination between specialists and primary care providers to ensure that all of the survivor’s needs are met.

To fulfill the goals of these four components, some specific survivorship care needs were identified:

- **Providing referrals** to specialists and resources as indicated
- **Familial genetic risk assessment** as appropriate
- **Guidance** about diet, exercise and health promotion activities
- **Providing resources** to assist with financial and insurance issues
- **Empowering survivors** to advocate for their own healthcare needs³

Fast forward to 2011, when the Essential Elements of Survivorship Care Meeting was convened by LIVESTRONG in response to the IOM report. Over 150 community leaders, stakeholders, cancer survivors and advocates reached a consensus on the basic components of quality survivorship care. Based on this consensus, the Commission on Cancer issued Standard 3.3, which requires that all cancer programs provide a written summary of treatment and a follow-up care plan to all patients completing cancer treatments. This is to be phased in over a four year period beginning in January 2015, with 100% of eligible patients enrolled in these plans by January 2019.⁴

To meet this new standard of care, cancer centers throughout the country are using a variety of approaches. Local facilities are developing and implementing programs, and patients interested in

Continued on page 28
Summer is now a fading, glorious memory. It was a season when the Coalition spent a lot of time on the road offering Lunch and Learn sessions, speaking to church groups, talking with people at health fairs, and making our presence known and felt at many Rochester area summer festivals.

As the arms of our area health systems reach into more Upstate New York communities, an increasing number of people are able to receive their cancer care close to their homes. This is great news for so many - the fatigue and expense of traveling 20 to 50 miles for treatment can be burdensome. But with this expansion of services, it has become clear that there is a growing need for the Coalition’s programs and services in places outside the Greater Rochester area.

Letting these folks know we are here is a great start. For example, a newly diagnosed woman from the Brockport area may come to the Coalition for a Breast Cancer 101 session. Even if she is unable to attend Brown Bag in those early days, she can be carefully matched with a PALS mentor for support nearby or on the phone. Perhaps during her treatment, she might meet others experiencing breast or GYN cancer and decide to carpool to an especially pertinent Evening Seminar. Intrigued by what she hears and sees, she may find that driving into the city once a week for Brown Bag or a Healing Arts class is feasible. And as she experiences the camaraderie and support of the amazing women of the Coalition, she may decide to share that knowledge with women in her home town.

The people who make up the Breast Cancer Coalition are a caring, sharing, and inspirational lot. It is a joy to share this message about our ever-expanding community of survivors throughout the greater Rochester area and beyond. There are so many ways to be a part of this mission. It takes many, many hands and open hearts. It takes a lot of volunteers.

It takes YOU.

When Betty Miller was first diagnosed with breast cancer in 2000, she was quickly drawn into the Coalition by her niece, Terri Schmitt, a leader of the fledgling organization. Sadly, Terri was eventually lost to the disease. Betty faced a second diagnosis in 2002 and continued to embrace the Coalition’s survivor community with her niece close in heart.

With her passion for life, deep empathy, and willingness to go the extra mile for each person who walks through the Coalition’s door, Betty has become a familiar and beloved presence in our survivor community. She has welcomed countless newcomers to the Brown Bag table with a warm hug, presenting each with a prayer shawl handmade by women from her church. She has listened to their stories, offered words of wisdom, and demonstrated her unmatched ability to offer humor that uplifts without diminishing the situation. Laughter truly is the best medicine, and Betty has administered many doses of her own special brand.

A spirited presence at many of our tables and booths at summer festivals, health fairs, and other community events, Betty has also volunteered at our Pink Ribbon Run/Walk and the ARTrageous Affair. Her ineffable energy is genuinely appreciated. When Monroe County Cancer Services partnered with Highland Breast Imaging and the Coalition to offer free mammogram days for those without insurance coverage, Betty was one of the first to sign on as a volunteer. She showed up with jars of homemade jam for those receiving screenings. Her warmth and enthusiasm made her a sought-after volunteer for subsequent screening days, and she gladly signed up again and again.

Continued on page 27
The pictures and stories can be so compelling: the TV commercials, the letters in the mail, and more recently the social media and fundraising sites. There are more and more charities reaching out to you each year, asking for a donation. How many times have you received a solicitation in the mail and wondered how the organization got your name? What about the organizations that send you a gift with the appeal letter? I know people who feel compelled to donate to organizations that send them address labels.

Before you know it, October (Breast Cancer Awareness Month) and the end of the calendar year will be upon us. The solicitations by many organizations will increase in hopes of riding the coat tails of recognition, or end of year donations for tax deductions. While most charities are legitimate and a percentage of your donation does support the cause, you might want to investigate just how much supports the cause and how much supports fundraising efforts, advertising, and the gifts that come in the mail.

If you fear where your money might be going, ASK!

If you support the same charities year after year, do you know what impact your gift has? ASK!

With national organizations, does all the money go to one place, or does it help your friends and neighbors in your community? ASK!

We have all received the dreaded dinner time telemarking call. It can feel very awkward and rude to decline, but the best thing you can do is say “No thank you,” and hang up – even if the call is on behalf of a charity you wish to support. Then send your gift directly instead of donating through the telemarking company. By sending your check or donating through the organization’s website, you are ensuring that 100% of your gift is going to the charity and is not parceled out to the tele-funding company.

If you need help researching charities, there are several websites that can help you. Some of the most comprehensive are Charity Navigator, Charity Watch, the BBB Wise Giving Alliance and GuideStar.

Thank you for your continued support!

—I slept and I dreamed that life is all joy. I woke and I saw that life is all service. I served and I saw that service is joy."

—Kahlil Gibran

While we have gently served breast and gynecological cancer survivors from Monroe, Erie, Genesee, Livingston, Ontario, Orleans, Seneca, Wayne, Wyoming, and Yates counties, we’ve dreamed of extending our outreach efforts further into the Finger Lakes region of Western and Central New York in a more meaningful way.

We’ve dreamed of connecting with those who have received a breast or gynecological cancer diagnosis, who might not be aware of the Coalition’s work, who might not know about local resources available to them right now, and who might not be finding the support that is so crucial when navigating through surgery, recovery, and treatment.

In September, those dreams became a reality and our regional outreach initiative launched. We have already begun community assessments to learn about the programs and services existing in the areas we’re exploring. Community round tables are planned for October so that we may engage breast cancer survivors and their families to learn their stories and to hear in their own words what resources they found - or didn’t find - when they needed these most.

To where did they turn? What did they wish they had access to at any point following diagnosis? This critical information will help shape our regional outreach.

The Coalition has engaged six New York State senators to host these events in their districts. At the time of this writing, locations are being finalized, with Geneva, Bath, Dansville, Warsaw, Batavia, and Medina as potential sites.

It’s not unusual for a newly diagnosed woman to call our office after finding us on Google. She might live two hours away, with plans for surgery and treatment at her local hospital or treatment center. She is looking for help. She might not be able to come to weekly Brown Bag Friday gatherings, or to a six-week session of Gentle Yoga, but we can let her know about existing resources closer to her. We can offer Breast Cancer 101 over the phone. We can connect her to another survivor with similar experiences; someone who has “been there” and can lend support.

As we move through the fall season, we invite survivors of breast and gynecological cancers living in our regional communities to add their voices to our network. Call us. Email us. Tell us your stories. We’re here. We’re listening.

Please call (585) 473-8177 x310 or e-mail tracy@bccr.org for more information.
A Tribute to Dennis Bateman  - By Pat Battaglia

When Dennis Bateman was diagnosed with breast cancer in 2006, his wife, Lynn, was by his side throughout the journey to come. And what a journey it was! Together since they had begun dating shortly after Lynn's graduation from high school, the couple had built their own home and a good life on the farm run by Dennis's parents. Their two children, Jared and Justine, thrived on country life and close contact with their grandparents, eventually growing up and moving out on their own. In time, grandchildren entered the picture.

It was Lynn who found the lump in Dennis's breast and it was at her urging that he underwent a mammogram and subsequent testing that confirmed the diagnosis. Shortly afterward, he turned to the Coalition. Holly Anderson, recalling her interactions with Dennis, remembers him as “…an outspoken, gregarious self-advocate.”

Beginning their long trek through the complexities of this diagnosis, Lynn recalls that “We took the first step. And then the next step. And then the next.” Dennis underwent a mastectomy, followed by radiation and chemotherapy. When the inevitable hair loss from chemo became imminent, the South Byron Volunteer Fire Company, of which Dennis was a decades-long member, held a head-shaving party in his honor. The firefighters were joined by members of the Red Knights motorcycle club – another group that included Dennis among its longtime members – and friends and family as well. Many heads were shaved that day in support of one man who was clearly beloved by his community.

Treatment left Dennis considerably weakened and weighing less than when he started, but with a determination to move forward and help others affected by this disease. He, Lynn, and other family members and friends participated in a breast cancer awareness walk at Watts Farms in Albion. Among the many proudly sporting pink “survivor” sashes, Dennis was the lone male, openly welcoming the opportunity to educate others that this disease affects men too.

Although less than one percent of all breast cancers occur in men*, when a self-advocate like Dennis Bateman is affected, his voice will be heard. He and Lynn used every opportunity to spread the word that male breast cancer is a real and life-altering diagnosis. When Life Magazine published a cover story on breast cancer that did not include any reference to males, Lynn wrote them a letter. As Dennis returned to his job at Kodak, through his layoff from that position and into a new employment situation for both him and Lynn at Lapp Insulator in LeRoy, the couple kept up their advocacy efforts and added to their ever-widening circle of friends. Co-workers at Lapp quickly became like a second family, and when Dennis’ cancer was

Continued on page 27
Our Fundraising Friends

**Done With Duct Tape**

Flowers come in a multitude of beautiful hues; so does duct tape! Jean Hendrick’s sixth grade students at McQuaid Jesuit School made dozens of gorgeous pen-stem blossoms to raise money for the Breast Cancer Coalition’s Research Fund just in time for Mother’s Day. Sales were brisk, and the young men were pleased to present us with a check for $1136. What a lovely way to honor the moms in your lives, boys.

**Ladies On the Links**

The sun shone brightly on this year’s Midvale Golf Tournament. Nearly seventy ladies and a few gentlemen enjoyed a lovely June evening of golf followed by a delicious dinner and a dazzling assortment of raffle items and door prizes. The Tournament has become a well-oiled machine over several with the guidance of the Coalition’s dedicated Marcy Lazio, her friend Betty Podlesh, and Marcy’s own family. This year’s tournament raised an impressive and appreciated $4,480.

**Saying Thanks, Raising Funds**

In conjunction with the spring time appreciation steak roast lunch the Duke Company offers for its vendors and contractors, the company has once again made a generous donation to the Coalition. Under a massive tent, Duke welcomes hundreds of area contractors with perfectly grilled steak, chicken, sausage and hamburgers, homemade salads and vegetable dishes. Duke branded promotional merchandise from the previous year is sold at bargain prices and all proceeds are given to the Coalition. In a dizzying two hour luncheon Duke raised $1,433 for us with the help of their generous and appreciative customers.

**Farewell to Old Friends**

For several years the Rochester Lancers soccer have been great supporters of the Coalition, not only donating money, but also providing cheerleaders and players to help us out at festivals. We are grateful for their last gift of $196, the result of a February 50/50 raffle at one of the games of their last season in Rochester. Changing economics have forced the dissolution of this community team, and they will be missed.

**A Tradition of Churchville Caring**

The dynamic Elfie Chapin was a one-woman whirlwind of energy and dedication whose efforts brought about the birth of Churchville-Chili Saints Hockey club in the late 1990s. Since she lead the effort of the fledgling Churchville-Chili Flames to become a high school sanctioned team, the group has honored her dedication with an annual Pink the Rink tournament. Though Elfie succumbed to her breast cancer many years ago, each year the players and a hardy group of dedicated parents fill the hockey barn in Scottsville with an enthusiastic crowd, capping off several months of fundraising efforts. This year, the team proudly presented a check for $1,746.80, with an additional $500 donated by her son Chris Chapin, for a total of $2,246.80 in Elfie’s honor! Though the players today were infants when Elfie’s son Chris played on that early team, Chris is gratified to see his mother’s dream team carry on this fifteen-plus year tradition.

**“ROC”king the Hobbies for Charity**

Chris Washington and his friends work hard and they also play hard. Chris led the charge to raise money for us through a weekend filled with friends, bowling, and his beloved Mustang car. On May 15 Chris hosted a breast cancer awareness bowling tournament at Bowl-A-Roll Lanes, followed by a car show and picnic, the next day, put on by the ROC City Mustangz. This weekend of good times raised $750 for the Coalition which was delivered by club members to our new offices.

**Camping Capers**

Campers are a fun loving lot and those who park camping vehicles in permanent grounds often form close-knit communities. This year one of the community activities at Wolcott’s Lake Bluff Campground was a 5K race for cancer. We received several donations in loving memory of Lake Bluff friend Lori DeCarlo totaling $450. Lori, well known to the Coalition, ran in our 5K year after year. What a great way to honor Lori’s memory!
Ninety Years and Counting

Terry Marino has a long and lively life of ninety years to celebrate. To honor this lovely lady, her daughter Kathy Mangione and family invited friends and family to a gathering of laughter and memories. In lieu of gifts, Terry and Kathy suggested that donations to the Breast Cancer Coalition would be most appreciated. Many were happy to oblige and to date $190 has been received in recognition of Terry’s happy occasion. Happy Birthday Terry!

For the love of Sweet Stephanie

Breast cancer is at its cruelest when it strikes a young woman, particularly as she is raising her small children. Stephanie Lagree Gebo, a founding member of our Angel Bag Project that became the PALS Project, was just thirty-seven when she died from her disease, leaving behind her husband and three children.

In honor of their much-loved and missed daughter, Bob and Linda Lagree began Stephanie’s Memorial Golf Tournament in 2007. This year, the Lagrees chose the Breast Cancer Coalition to receive the proceeds of the June 6 tournament as well as those raised through the raffle of a custom golf cart!

Those who participated honored the cherished memories of a wife, mother, daughter and friend. Thanks to Stephanie’s family, golfers, sponsors, and Timber Ridge Golf Course for the wonderful gift of $1605.

Kudos for Kindness

Bravo to BCC Software, who implemented a Charity Choice program back in 1997. Employees are able to submit names of favorite charities throughout the year and donations are held by “Pickles” the (pink) charity piggy bank. Each quarter, one submission is drawn to receive that quarter’s contributions. We are so pleased to receive a gift of $244 in honor of Will and Cheryl Gardner.

Gifts in Kind

Thirty Ways To Celebrate

Isaiah Tyler is celebrating a big birthday in a big way. In honor of his 30 years, he is offering 30 good deeds to area agencies. Isaiah and his friends gathered a basket of items found on our Wish List set about delivering them with a smile. Happy birthday, Isaiah! You really brightened this day for us.

A Piece of Their Hearts

Each piece is stitched with love and care. The beautiful quilt masterpieces given to our PALS program by the amazing ladies of the Webster Quilt Guild are given with that same spirit.

The quilts begin their journey to us in the minds and hearts of the quilters, who design patterns and carefully choose the right fabric. Baggies containing quilt “kits” were distributed to individuals who then gathered on a Saturday in October to piece the squares together into colorful tops. The long dark days of Winter were spent battting and backing and at last, as Spring arrived, Coordinator Michele Sanderson sat at her long arm machine to quilt 29 lovingly created gifts for women newly diagnosed with breast cancer.

This is the second year of this project, and the third year that Michele and her mom Jennifer Martin have created larger quilts for our Artrageous Affair.

Signs for the Busy Times

This year the Coalition has been present at more fairs, festivals and community events than ever before. But increased presence meant we were often short of the signs that would bring people to our booths. Jeff Sherwood of Premier Signs in Rochester was made aware of our dilemma by busy volunteer Margie Micca and quickly created and donated four beautiful versions with our logo including a banner, a table cloth and two lawn posters. Thank you Premier!
Donations ending June 30, 2015

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 June 30th will be included in the winter newsletter.) We apologize for any errors and/or omissions on our donor pages. Please notify us if a correction is in order.

In Honor of:

Margaret Brongo
Churchville - Chili SHS CTE Department

Mary Carafos
Frank & Norma Riedman Family Fund

Phyllis Connelly
Barb Pifer

Elijah Dietz
Michelle & Sean Caron

Blaine Egan
Holly & Tom Anderson

Friends & Family
Sandra Watts

Corinne Heh
Dawn Lindboom

Maureen Kingston
Carolyn Sheild

Susan Meynadasy
Holly & Tom Anderson

Karen Miltner
Lara Liu

Leni Rayburn
Lida Riedlinger

Susie Smith
Ann McCarthy

Luann Weinstein
Clarice Speier

Connie Zeller
Holly & Tom Anderson

Dominica Margaret Mary Brugger
Margaret McCaughey

Nicholas L. Cummings
Mary Beth Brendel
Darlene & Roger Magrin
Rochester Lead Works, Inc.
Deborah & Donald Taft

Phyllis Fiorica
Carole DeMauro & Family
Patti & Bernard J. Iacobangelo
Bonita & Michael Lindberg
Susan Nicolais
Grace Piperni
Richard Ricci
Cheryl & Tom Rogers
Patricia Stuver
Joan & Thomas Wamp

Denise Graver
Cathy & Tom Vajentic

Cheryl Hinz
Barbara Peachey
Ruby Red Elegant Dames (Red Hats)

Americo LiButti
Julie & James Bovitz

Marla Jean Kelly
Judith English

Max Maisel
Dr. Carol & Elmer Henretta

Mrs. Llewellyn
Carol White-Llewellyn

Ellen Marple
We-Mo-Co-Retirees

Caroline Mirrione
Gia Allen

Mrs. Pacana
Carol White-Llewellyn

Madeline Pasquirella
Laima Gallo

Sarah Perlman
Eileen Goldman

Victoria Ranno
Bonita & Michael Lindberg
Susan Nicolais
Patricia Stuver

Betty Remillard
Barbara Peachey
Ruby Red Elegant Dames (Red Hats)

Mrs. Salisbury
Carol White-Llewellyn

Jennie Scavulli
Nancy & Richard Adamus
Gloria Carabelli
Mary & John Conlon
Gary Dean
Elmer Family
Jamy Ferguson
Mary Giuffre
Gloria & Ronald Hope
Michele Lostracco
Marion & Angelo Nichele
Theresa Passero
David Pelizzari
Sharon & Raymond Perkins
Karen Stanton
Zulla Family

Christine Shanto
Renee Wright

Kathy Skeval
Janet Dalke
Marianne Greco

Thelma Slate
Barbara Haller

Mrs. White
Carol White-Llewellyn

Mrs. Whitford
Carol White-Llewellyn

Helen Zavodny
Laurie Laugeman
Brian Valint
Dan Valint

In Memory of:

Catherine Anderson
Lorraine Pellegrino

Harvey Anderson
Holly & Tom Anderson
Christine & Robert Baker
Mel & Richard Bianchi

Mary Benfonte
Allen Creek Teachers Association

Lorraine Pellegrino

Mel & Richard Bianchi

Madeline Pasquirella
Laima Gallo

Sarah Perlman
Eileen Goldman

Victoria Ranno
Bonita & Michael Lindberg
Susan Nicolais
Patricia Stuver

Betty Remillard
Barbara Peachey
Ruby Red Elegant Dames (Red Hats)

Mrs. Salisbury
Carol White-Llewellyn

Jennie Scavulli
Nancy & Richard Adamus
Gloria Carabelli
Mary & John Conlon
Gary Dean
Elmer Family
Jamy Ferguson
Mary Giuffre
Gloria & Ronald Hope
Michele Lostracco
Marion & Angelo Nichele
Theresa Passero
David Pelizzari
Sharon & Raymond Perkins
Karen Stanton
Zulla Family

Christine Shanto
Renee Wright

Kathy Skeval
Janet Dalke
Marianne Greco

Thelma Slate
Barbara Haller

Mrs. White
Carol White-Llewellyn

Mrs. Whitford
Carol White-Llewellyn

Helen Zavodny
Laurie Laugeman
Brian Valint
Dan Valint

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 June 30th will be included in the winter newsletter.) We apologize for any errors and/or omissions on our donor pages. Please notify us if a correction is in order.
Executive Director continued

To that end, we have welcomed back former Program Coordinator Tracy Brown to direct this push. Tracy brings a wealth of experience from her previous role, as well as abundant passion and enthusiasm for what we know must be done. See her column on page 20 to learn more. Plans for community forums and roundtables are already underway. We desperately want to hear survivor voices from around the region. So Geneva, Bath, Dansville, Warsaw, Batavia, Medina - and all the surrounding towns - here we come.

There are no words that could possibly convey our deep gratitude for this funding. To have a dedicated group of upstate senators fighting fiercely for families living in the aftermath of a breast cancer diagnosis, a disease that continues to take the lives of too many and impacts many more, is the stuff of wildest dreams. For those of us in the trenches, nothing is more frustrating to hear than “I wish I had known about you sooner” or “I wish you were closer.” This funding will provide the platform we need to reach those who have heard the life-changing words, “You have breast cancer,” at a time when our programs and services will provide the maximum benefit. Breast cancer strikes deeply into our families and communities. Please help us thank those Senators who helped secure these funds that will allow us to reach those affected by this disease and to support and empower them as they learn to navigate an often difficult journey. Contact info@bccr.org if we can assist you with finding contact information.
Anonymous (23)
Marianne Abraham
Michael Abraham
Christa Abugasea
Dale Adams
Ronald Alkin
Timothy Allyn
Sandra Almekinder
Louis Andolino
Taneesha Ashford
Jennifer Atseff
Glenda Ayers
Sharen Bassett
Braitman Family Foundation
Tammy Becker
William Bennett
Richard Bianchi
Tracy Birge
Loriann Boe
Tanya Brandenburg
Dawn Breen
Darlene Briggs
Jeff Brown
Teressa Brown
Tynisha Brown
Dawn Bruner
William Burnett
Jerome Butterbrodt
Wendy Caceci
Maria Larissa Cafer
Linda Cala
Susanne Callanan-Harris
Stephanie Campbell
Antoinette Capellupo
Kathryn Carson
Arnett Carter
Mary Cassidy
Susan Catalano
Halin Cebula
Lisa Cerro
Alissa Chaney
Jeffrey Childs
Patricia Clark
Lenora Colarouotolo
Cora Conklin
Kevin Conklin
Kristina Conklin
Susan Conrey
Kathleen Conroy
Michelle Cook
Nicole Cooper
Joyce Cordello
Karen Cosentino
Karen Cosmano
Michelle Cramer
Mary Crawford
Nancy Cross
John Currie
Jeff Currier
Adelina Davin
Melissa Davis
Paul Davis
Wendyv Day
Cassandra DeCari
Susan DeCaro
Mary Jo
Deichmiller
Melissa Dekedrun
Sue DeRose
Mary Ann DeVeto
Deeja Dewar
Keriie Diehl
Jody Dietz
Joseph DiFrancesco
Gena Dioguardi
Kristin Dioguardi
Patricia Dix
Cathy Dobrowal
Lynn Doescher
James Dolan
Kristina Dunoski
James Dykes
Christine Eldridge
Janet Elman
Willie Enge
Debra Enright
Ashley Fagan
Elizabeth Feier-Hauser
Mary Pat FitzGerald
Colleen Fogarty
Jonathan Fogg
Ruth Fogser
Jennifer French
Julie Fugle
Scott Gabbielli
Kathleen Gaesser
Cynthia Garza
Cynthia Gary
Janet Gawon
Cheryll Geer
Paul Geer
Shelley Gentile
Gulsah George
Linda Geraci
Andrea Giugno
H. Claire Gladwell
Arlene Gluchowicz
Lauren Goetz
Chaslara Greenfield
Lisa Greenwood
Lori Griffin
Rosemary Guccione
Rachel Gullo
Pamela Gurbakhi
Sonia Hahn
Debra Hall
Marla Hamilton
Laurie Hamlin
Carolyn Hanson
Mary Harper
Laurel Harrington
Max Harrington
John Hawkins
Lena Hayes
Rebecca Healey
Corinne Heh
Lisa Hendrikse
Carol Allen
Lena Henretta
Michael Henretta
Margaret Herman
Patricia Herman
Ticia Hess
Andreia Hicks
Deretha Hines
Jody Hirsh
Shelley Hodge
Susan Hollister
Julie House
Marcia Hunsinger
Scott Ingall
Carolyn Insalaco
Steven Inzana
Charmaine Johnson
Kathi Johnson
Cynthia Jones
Kelly Jones
Stacy Kanaley
Helen Kashian
Ellen Keenan
Jeffrey Kelley
Gerald Kelly
Steven Kelly
Edison Kier
Doris Kirk
Tina Knapp
Theresa Krause
Michael Krug
Debra Kusse
Marta Laboy
Linda Laing
Judith Laing
Carla Langham
Vicki Lattimore
Deborah Lazio
Joanne Leduc
Martin Leeland
Duane Leisten
Ann Leonard
Gary Levy
John LiPari
Anida Litzenberger
Quyen Lui
Stephan MacIntyre
Darren Mack
Kevin Mack
Timothy Mahoney
Mary Maier
Laurie Malsegna
Cynthia Mandrycky
Glenda Mansfield
Lyne Manuel
Donna Marchand
Mary Maranzetti
Pamelia Marzolf
Michelle Mazor
Maureen McCulam
Michael McCartan
Mary McConnell
Brian McDonald
Thomas McJury
Jessica McWilliams
Thomas Meacher
Heidi Miller
Christina Moraza
Mark Mori
David Morris
Joan Morse
Thomas Mundung
James Munnings
Virginia Murn
Patti Murphy
Gretchen Myers
Diane Nau
Molly Nero
Lauren Nicoletti
Bonnie Niver
Nicholas Noce
Fran Norman
Michael Nudd
Carmella O’Brien
Steve Olufsen
Jennifer Oremus
Richard Orlando
Juliet Overbeck
Tramale Owens
Jeanne Paiko
Susan Pallucon
Dwayne Palmer
Pamela Parker
Joanne Parr
Sarah Partner
Michael Patane
Ann Pellman
Dina Petrone
John Pinkoski
Lauren Polito
Leo Porcelli
Carol Porras
Lena Pride-Stephenson
Judith Prinipe
Nicolai Rainbow
Mary Ann Rainh
Mary Randall
Charles Rankin
Shelia Rankin
Allan Rayburn
Julian Rayburn
Tammy Redding
Carol Reed
Judy Reed
Michele Reichelmayr
Thomas Reichelmayr
Christine
Remington
Paula Roberts
Jessica Rogers
Shelly Rogers
Richard Rohring
Marie Rolf
George Rosati
Lee Rosenthal
Charlot Rossi
Romualdo Rossi
Julia Rossiter
Phyliss Rotoli
Janice Rubsam
Susan Ruef-Statt
Philip Sabatka
Sandra Sabatka
Sheri Sage
Damir Saracevic
Theeu
Saviengyong
Isabelle Scalise
Patricia Scarlata
Norman Schaefer
Carol Schaubroec
Ashley Scheck
Nancyn Scheerens
Beth Schiano
Julie Schiff
MaryAnn Schifitto
Larry Scott
Jamie Scrips
Nicole Semo
Vicki Sfteko
Michelle Shaye
Josephine Sigoutin
Jennifer Simpson
Kelly Siofri
Ronald Skuse
Amanda Slack
Cody Smith
Doreen Smith
Justine Smith
Kurt Smith
Lisa Smith
Monica Smith
Matthew
Snyderman
Gregory Spacher
Linda Spath
Lori S. Pierre
Johnathan Stanton
Rachel Stanton
Kimberly Starken
Dawn Staub
Matthew Steele
Bonnie Stein
Annette Stenglein
Linda Stepanek
Judith Stewart
Tanya Strachan
Marilyn Sullivan
Kelley Swagler
Nancy Swanson
John Sweeney
Maria Tantillo
David Taylor
Jacqueline Taylor
Jill Taylor
Kathleen Taylor
Paul Om
Tori Toliver-Powers
Laurie Tschudi
Willie Tucker
Lisa Tydings
Bradley Upson
Maureen Valentine
Sheryl Valentino
Melissa Villafane
Kellirae Vonglis
Nicole Wahl
Stephen Wallman
Agnes Wallner
Lisa Wasser
Mark Watts
Sandra Watts
Deborah White
Amy Wilkinson
Lisa Wille
Rachel Williamson
Amy Winterberger
Edward Wolanski
Harry Wood
Lauren Woolston
Lisa Yankevich
Annmarie Young
Barbara Young
Scott Young
Adrienne
Youngblood
Karen Zuber-Roberts
Volunteer Spotlight continued

Betty has forged connections with many women newly diagnosed with breast cancer, both in her capacity as a PALS mentor and simply because she perceived a need and took the initiative to reach out. She has shared her listening ear, her own journey, and her home baked goodies with countless people. A trained actress and singer, Betty is a particularly effective communicator. But her caring and concern for those touched by breast cancer is no performance. These things clearly come from her heart and her selfless commitment to ease the suffering of others.

Due to family health issues, Betty has recently reduced her volunteer work at the Coalition for the time being. But we’re always delighted when she drops in to see us. The effervescent, compassionate Betty Miller holds a special place in our hearts, and in the hearts of so many whose lives she has touched for the better.

Thank you, Betty Boop!

Dennis Bateman continued

found to have metastasized a few months after he began working there, they organized a fundraiser to help the couple with insurance co-pays.

Through the overwhelming days that lay ahead, Lynn became her husband’s caretaker until assisting this larger-than-average-guy became more than she could do alone. Friends from the volunteer ambulance corps transported Dennis to the hospital, and a few days later, in a winding trip that included stops at his most beloved locations, they took him to Crossroads House in Batavia, where he spent his last days in peace and comfort.

Friends and family gladly endured two hour waits at his calling hours. A long procession of motorcycles honored one of their own and, as they attended the service, “the sky opened up” as Lynn says; loud thunder and lightning accompanied by a brief but drenching downpour had motorcyclists dumping water out of the helmets they left hanging upside-down on their handlebars while Lynn exclaimed, “He had to get you one last time!”

Life is forever changed and the tears still flow at times as Dennis’s family moves onward with him kept close in memory. One year to the day after Dennis’s passing, Justine gave birth to a son. Lynn has happily remarried, and when she discovered a lump in her second husband’s breast, she strongly urged him to seek the testing that ultimately revealed a benign condition, but one that warrants close surveillance. She continues to speak out and remind others that men are also diagnosed with breast cancer. Their stories may be fewer in number than those of women, but they are just as compelling and deserve to be heard.


A Personal Journey continued

was determined that radiation therapy was not needed in Patty’s case. As her particular cancer was found to be responsive to hormonal therapy, she began a course of tamoxifen. In addition, she underwent several procedures to revise and complete her reconstruction, including nipple reconstruction and tattooing, and this process was completed in March of this year. Patty now eyes her “new normal” with both trepidation and relief. “It took a while to get used to my new body image, my new ‘me,’” she concedes, but she is moving onward with aplomb and a renewed sense of who she is in this world.

Patty went back to school after her cancer experience and recently received her Master’s degree. She has taken a position of responsibility, and one that she loves, in a local health care facility. Her normally high energy level, which took a hit from her diagnosis and treatment, has returned, and she has become a beloved, smiling face in the Coalition’s community of survivors. She participates in yoga and other healing arts classes, is a trained PALS mentor, volunteered at our Pink Ribbon Run and Family Fitness Walk when her schedule allowed, and she and Mike have worked side-by-side as volunteers for the ARTrageous Affair.

Taking care of herself, body, mind, and spirit, has become a higher priority than ever for this effervescent, intrepid young woman. Whether she’s choosing nourishing foods, participating in yoga classes at the Coalition, gaining inspiration through reading, or connecting with family, friends, and her fellow survivors, Patty balances her own needs while connecting in meaningful, helpful ways with others.

She is a breath of fresh air.
learning about the specific offerings available to them can contact their treatment centers for more information.

Real Survivors, Real Questions

Returning to the list of specific survivorship care needs, of particular significance to many is the last item: empowerment. The vital skill of advocating for one’s health care needs is a tool many develop and/or refine when going through cancer treatment. But, just like the word “survivor”, “empower” carries more than one meaning. For many, it involves using the tools gained on this unwelcome journey to move into life beyond cancer in a more knowledgeable, and perhaps more self-aware manner.

Lucy Miraglia and Elizabeth Mercado, two program participants at the Coalition, have recently completed chemotherapy, and kindly agreed to share their perspectives in the form of answers to two questions.

Q., What does the word "survivor" mean to you?

Lucy: To me, it means the exiting of intense treatment and the big “now what?” Trying to move back to what my life was before my diagnosis is not an easy task. Do I need to pick up where I left off or move into a new challenge? I’m still struggling with how to proceed into a fulfilling, contented life.

Elizabeth: I want to use my experience to forge a new way of being in the world. I’d like to find a way to use it as an impetus to find new meaning for my life that I wasn’t able to find before. None of us asked for this diagnosis, but surviving it forced me to discover more strength in myself than I knew I had. I want to access and use that strength in other areas in my life, for the rest of my life.

Q., Now that you’re finished with the hardest part of your treatment, what would empower you as you move forward?

Lucy: Exercise is probably the biggest piece for me. I take yoga classes at the Y and at the Coalition, and seeing people there who’ve been through what I’ve been through is helpful. Throughout my life, I’ve been involved with artwork, and that’s something I want to get back into. Intense focus on a project takes me away from life and brings a sense of relief. Right now, I need the structure of a class, and I’m looking into that. And there’s reading - I don’t think I’ve ever read so much in my life!

Elizabeth: This is the $64,000 question! I’m actively seeking to answer this by trying new things. I’m gravitating more toward physically challenging activities, such as an Adirondack outing. I think meeting challenges that match or surpass those that were forced on me by my cancer diagnosis might give me that empowerment. But there’s the very real risk that I won’t be able to climb that Adirondack peak, and that means that I’ll have to be able to accept this without thinking of it as another setback. My comfort zone was blasted wide open at my diagnosis, and I feel the need to both to define a new one and then step out of that.

Many Stories, One Hope

Those facing cancer bring the totality of their being into the experience. For many, no part is left untouched by their diagnosis and treatment. Cancer centers are responding to this reality by developing survivorship programs. And the survivors themselves develop myriad ways to incorporate their experience based on their own interests, hopes, and dreams.

Emerging from this experience as an empowered individual looks different for each person. Ways of moving forward into a fulfilling, meaningful life are equally diverse. But there is strength in numbers and much to be learned from the stories of others who have been similarly challenged. The Coalition’s support programs offer a connection with a mutually supportive community to those diagnosed with breast and gynecological cancers, and the door is always open no matter how many weeks, months, or years have elapsed since the original diagnosis.

The road to survivorship is unique for each individual, but the common hope is to emerge from the experience with one’s essential selfhood intact; to see the unwritten page of the next chapter of life as one full of possibility, and to begin writing that chapter fearlessly.

curcumin that gives it its bright yellow color and has been studied for its uses in cancer patients. In another local research connection, the same Dr. Ryan, along with colleagues who included Marilyn Ling, M.D., a Radiation Oncologist at the University of Rochester Medical Center, conducted a randomized, double-blind, placebo-controlled clinical trial and found that breast cancer patients who took curcumin supplements during radiation experienced reduced severity of radiation dermatitis. The regimen was well tolerated and no significant adverse events were reported. The data obtained from this small study, which involved a sampling of thirty patients, established a positive safety profile for curcumin and will provide the basis for larger trials to confirm these results and determine the optimal form and dose of curcumin.

Having established its safety and efficacy, Dr. Ling currently uses curcumin in her patients who are undergoing radiation therapy. According to Dr. James, “Patients of mine who have used this protocol have told me that the techs note they have very little dermatitis during their treatments.”

Cancer treatments are, by necessity, strong. They can and do save lives, but their side effects can impact quality of life. While cancer patients should always advise their medical team of any food supplements they may take, as unwanted interactions can occur, the study of traditional healing modalities in the safe, effective management of the side effects of cancer treatment is seen as a welcome development by many, patients and health care providers alike.

**Know your chemicals**

Everyday products can contain harmful chemicals. Before you buy, find out what’s really inside!

**Flame retardants:** These chemicals are building up in our homes, bodies, and breast milk. Over time, they can get into the air, dust or on our hands where we breathe them in and ingest them in food and water.

**Look for them in:** electronics, padded furniture & baby products with foam.

**Bisphenol A:** BPA, the building block of polycarbonate plastic, can harm natural hormone systems. It can leach from the plastic, often labeled as number 7 with PC in the “recycled” logo.

**Look for it in:** sports water bottles, baby bottles, sippy cups, toys, ‘shatterproof’ cups, and food, drink and infant formula can linings.

**Phthalates:** Used in artificial fragrances or colorings. Since fragrance information is protected by trade secrets, phthalates are not listed on the label. Linked to hormone and reproductive problems.

**Look for them in:** products with fragrance on the label; phthalates won’t appear as an ingredient.

**Triclosan:** Studies show it doesn’t do a better job of preventing germs from spreading than ordinary soaps, and can lead to resistant bacteria. Triclosan can harm fish and other animals that live in lakes, streams, and oceans.

**Look for it in:** hand soap, dish detergent, hand sanitizer, and other antibacterial products.

**Parabens:** Used as a preservative to slow bacterial growth. Known to act like human hormones; linked to reproductive problems.

**Look for them in:** shampoo, conditioner or lotion, sometimes with a prefix like “methyl-” or “butyl-”

**Better Plastics**

If you use plastic, look for products with these labels. Be sure to recycle your 1s, 2s, 4s, and 5s where available.

---

**Holiday Open House Raffle!**

Jane Beamish, in honor of her 10th anniversary of survivorship of triple negative breast cancer, has made this beautiful quilt to be raffled off at our holiday open house. Materials for the quilt were donated by Pam Eberhardt, Marilyn Sottile, Quiltsbug.com Quilt Shop, and Jane! Jane is a wife and mother of two lovely girls and a teacher of the deaf and hard of hearing. She and her family live in Webster and Jane is a longtime friend and program participant here. Tickets for this lovely quilt are available now! $2 per ticket, $5 for 3 tickets, $10 for 10 tickets. Thank you and congratulations to our beautiful friend!
Upcoming Events & Programs at the Coalition

Wednesday, October 28, 2015
Lives Touched, Lives Celebrated
7:00pm

Thursday, December 3, 2015
Holiday Open House
5:00-7:00pm

Wednesday, January 27, 2016
Mind, Body, Spirit:
An Integrative Approach to Wellness
7:00pm

Friday, April 8, 2016
The 13th Annual
Cindy L. Dertinger
Advanced Breast Cancer: Tools For the Journey
Memorial Art Gallery
1:00pm

Board of Directors:

Chair
Patricia Cataldi
Past Chair
Joyce Wichie
Vice Chair
Pamela Bernstein
Treasurer
Debra Rivera, CPA
Secretary
Mary Carafos
Advocacy Chair
Miriam Steinberg
Major Fundraiser Chair
Patricia Cataldi
Community Friends Chair
Mary Carafos
Annual Fund Chair
Aria Camaione-Lind
Audit Chair
Debra Kusse
Chair Emeriti
Sylvia Cappellino
Phyllis Connelly
President, Ex Officio
Holly Anderson

Staff:

Executive Director
Holly Anderson
Office Manager
Connie Zeller
Program Coordinator
Laura Albert
PALS Coordinator
Pat Battaglia
Regional Outreach Director
Tracy Brown
Development Associate
Cindy Dykes
Research Administrator
Jennifer Gaylord
Outreach Coordinator
Lori Meath
Graphics Coordinator
Susan Meynadasy
Newsletter
Pat Battaglia & Susan Meynadasy

Questions? Contact the Coalition at (585) 473-8177
THE COALITION’S CURRENT WISH LIST

- A cure for breast cancer
- Books about breast cancer and lymphedema for women, men, children, families (2010 or later)
- Books about endometrial, ovarian, cervical, fallopian, or other GYN cancers (2010 or later)
- Books about prostate or testicular cancers (2010 or later)
- Copy paper, white
- Foam core (new)
- Gift cards: Wegmans, Tops, DiBella’s, Staples, Target, Barnes & Noble, Michaels, pizza, etc.
- Paper products: napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam products)
- Tablecloths 70x90 and 70x108 (white, sage green, pink)
- Batteries, D and AA
- Beverage pitchers, dish towels
- 8½ x 11 slant back clear acrylic sign holders, vertical and horizontal
- Plastic or glass Food storage containers

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

- Hand knit caps
- Scarves or bandanas
- Journals
- Soft socks
- Sleeping masks (unscented or lavender scented)
- Herbal or green teas (no loose tea please)

Let us know what you would like to see in the PALS Pack.

When You See Water
~Alice Walker

When you see water in a stream
you say: oh, this is stream water;

When you see water in the river
you say: oh, this is water of the river;

When you see ocean water
you say: This is the ocean’s water!

But actually water is always only itself
and does not belong to any of these containers
though it creates them.

And so it is with you.

Kicking off a great year!

For Diane Bretz, the second half of 2015 has begun with celebration. Celebration of a year of cancer treatment now behind her. Celebration of a twenty-fifth wedding anniversary, delayed due to that treatment. Celebration of their youngest child’s high school graduation and the start of college. A long-awaited vacation. And, returning to the news that Diane had purchased the winning raffle ticket at Park Ave Festival for a $250 Wegmans gift card!

Thanks for stopping at our booth, Diane. We wish you much happiness and good health as you start this next part of your life. ✨
Voices of the Ribbon is published quarterly by the Breast Cancer Coalition of Rochester for the purpose of providing encouragement and inspiration to those facing a breast cancer diagnosis, their supporters, and care providers. In addition, it is intended to impart accurate, science-based information to enlighten and empower its readership.

PLEASE JOIN US!

Wednesday, December 3rd, 5 - 7pm
Breast Cancer Coalition of Rochester
1048 University Avenue
Kindly respond by December 1st
585.473.8177 or laura@bccr.org

Refreshments, music, good cheer and all of our Good Friends!