For the tenth year in a row, elected officials, advocates and friends gathered at the Breast Cancer Coalition for the Terri Schmitt Legislative Reception. This year’s event was held on August 14th. As Executive Director, Holly Anderson, described it in her opening remarks, the work of eliminating breast cancer defies politics and brings people together in unique fashion from both sides of the aisle.

This annual event has become a mainstay on the Coalition calendar, involving brief comments from speakers, an array of refreshments, and an opportunity to discuss breast cancer and health-related policy with government representatives.

Named for Rush Town Supervisor (1999-2002) and co-chair of the Coalition’s Board of Directors, Terri

Continued on page 4

Tim Deckman, Terri Schmitt’s son, holding a pastel by step dad, Bix DeBaise, was the evening’s keynote speaker.
So have you heard the one about the New York State Breast Cancer Research Fund?

The one overseen by the New York State Department of Health and the Health Research Science Board? And the failure to dispense the nearly $9 million in earmarked funds that have accumulated? A fund that taxpayers have been contributing to through tax check-off and license plate sales since well before 2003, a date recently referenced in the Democrat & Chronicle? A fund we zealously promoted in our early days, and fought tooth and nail to provide oversight?

For those of you that have been following this story for the many years since our tiny (but mighty!) organization began fighting for breast cancer survivor seats on the Health Research Science Board, it will come as no surprise to learn that we were at the root of a recent front-page story in the Democrat & Chronicle. Frustrated by many years of attempts to obtain our rightful seat at the decision-making table, and after being repeatedly stonewalled by New York State Assembly Speaker Sheldon Silver, we began speaking out publically about our thwarted efforts. We spoke out here in our newsletter, as well as on local television and radio stations, regional magazines and, finally, after much prodding, in the Democrat & Chronicle.

It was over two years ago when we first spoke with Patti Singer, health reporter for the Democrat & Chronicle, and chewed her ear about the lack of transparency with the Health Research Science Board and the Breast Cancer Research and Education Fund. Most infuriating was our inability to gain a seat for a Western New York breast cancer survivor, even though it was written into the law we fought to have passed that there should be one. I applied for that seat FOUR times over three years and still it sat empty. Also infuriating was the inability to discern how much money was in the fund. Let me be clear. We did not WANT the funds. We wanted them utilized properly. We wanted to be sure they were going to deserving breast cancer research scientists. The funds would do no good sitting in a bank account while women were dying of this disease.

Periodically, usually around other breaking stories, we would rant about the issue. Ms. Singer listened carefully but wasn’t sure how to approach the story. This past spring, it came up once again and she promised to take the story to her editors. Weeks later, in early summer, we received a follow-up call from David Riley, a Democrat & Chronicle investigative reporter, who listened with fascination to the entire tale of woe. He promised he would do some digging. Stuningly, after many weeks of probing and requesting information under the Freedom of Information Act, he unearthed devastating news, not only for breast cancer survivors, but the prostate cancer community as well. In a top-notch piece of investigative journalism, he exposed the problems to the world as the story was promoted in our early days, and fought tooth and nail to provide oversight?

And stay tuned. This is far from over. ☹
She was 33 years old and the mother of two young daughters when Rachel Burke noticed a strange sensation – a heaviness in her chest similar to the way it felt when she was pregnant. She remarked on this at her annual checkup with her OBGYN. The doctor spoke of tissue changes that occur naturally over time, as well as the effects of monthly hormonal fluctuations, and felt these were likely explanations for what Rachel was feeling. But to err on the side of caution, she ordered a mammogram.

Because Rachel has dense tissue, an ultrasound was done after the mammogram, and the results of both tests brought good news: all looked normal.

Fast forward two years. Rachel went for another checkup with the same OBGYN, who wondered why she hadn’t gone for a follow-up mammogram after the original one. “I didn’t think I needed to go until I was 40,” Rachel answered. The doctor replied that since a baseline had been established, it would be a good idea to continue with yearly screenings.

Because Rachel has dense tissue, an ultrasound was done after the mammogram, and the results of both tests brought good news: all looked normal.

As she reeled from the news, Rachel’s family rallied behind her. Her husband has two cousins and an aunt who have had breast cancer, and his aunt not only knew of a good surgeon, she accompanied Rachel and her husband to the initial consultation. Rachel felt she was in good, compassionate medical hands and, together with her surgeon, weighed her options carefully. It became clear that a lumpectomy was an excellent choice for her, and the surgery was scheduled for early October.

The same aunt who had guided Rachel to her surgeon suggested that Rachel contact the Coalition. Rachel made the call, met with Holly Anderson for a Breast Cancer 101 session, and was matched with a PALS mentor. “It helped hearing her story because she was at the same stage of her life,” Rachel remembers of talking with her mentor. She also sought support at one of the Coalition’s evening support groups. Meeting others who had faced this diagnosis showed Rachel that “there’s light at the end of the tunnel.”

After her surgery, Rachel consulted a medical oncologist and found that the next step in the journey would be chemotherapy; four rounds of chemo, to be exact, spaced over the next few months. While the prospect of losing her hair was out of her control, she decided to take charge of the things that were within her power.

With her daughters accompanying her, Rachel went to her hairdresser and had her long hair cut short. In a show of solidarity, the girls had their hair cut short, too. Because they were at the tender ages of 8 and 6, Rachel decided not to use the word “cancer” with them. She didn’t want them to hear scary stories from others who knew of cancer experiences that ended sadly. The girls knew Mom was sick and were by her side all way through to healing. Afterwards, they were given the full story. Each mother knows what is best for her children, and Rachel followed her instincts. She and her daughters remain closely bonded.

Before long, there came a day when Rachel knew it was time for the rest of her hair to go. Her sister-in-law did the honors, shaving Rachel’s head as they sipped wine together. Rachel found it empowering to have

Little things seem nothing, but they give peace, like those meadow flowers which individually seem odorless but all together perfume the air. ~Georges Bernanos

Continued on page 28
Schmitt, the gathering’s deliberate theme of cooperative advocacy fits its namesake well. In delivering remarks and remembrances about his Mom, Terri’s son, Tim Deckman, spoke of her “ability to connect with people, which permeated her career in politics.” Tim went on to describe his Mom, who died in 2002 at the age of 43, saying, “Her involvement, I believe, was a direct result of caring so much about the people around her.”

Many area legislators and their representatives were in attendance, including those from federal, state, county, city, and other local levels. Friends and members of the Advocacy Committee ensured that conversation around the room centered on highlighting the Coalition’s work through personal contact, sharing of critical information, and discussion of pressing legislative issues affecting the fight against breast cancer.

With the presence of so many survivors, family members, and others touched by breast cancer (including Terri’s children and the grandchildren she hoped so much to meet someday), it was difficult to escape the importance of the Coalition’s purpose and the causes it supports. As Tim Deckman remarked, we still look forward to the day “when daughters, sisters, wives, nieces, grandmothers, and aunts no longer worry about the ‘c’ word.” With the bipartisan and combined forces of all concerned advocates, we will get there.

The Coalition’s Advocacy Committee meets the first Thursday of each month at 4pm. Among their many activities, Committee members make periodic visits to local legislators’ offices in the greater Rochester area and Albany. All interested members of the community are welcome to get involved. Please call 473-8177 for more information.
Thank you for inviting me to speak today. It is an honor to speak on behalf of my mom.

Terri Schmitt passed away eleven years ago this past April. A lot has happened since 2002: iPods, smartphones, another war in Iraq, and still no Bills playoff appearances.

My mom chased her dreams. She had a deep desire to serve. She lived only 43 years, but she worked hard to make a positive impact on the world in the time she had. She did this because she understood and cared about the people around her. That’s why she spent parts of her life as a librarian, as a politician, and volunteering at numerous not-for-profit organizations around the Rochester community.

One of my favorite childhood memories with my mom involved the stupid games we used to play. I remember sitting with her at Marketplace Mall when I was younger, making up full life stories about people we saw walking by. (Something like: “I bet that guy’s name is Leonard and he’s a banker with a pet shark at home that he calls Mario. I bet her name is Molly and she is a card dealer in Vegas who is here for the weekend to attend the wedding of her childhood friend, Patsy.”) Her stories were, admittedly, always more fun and interesting than my own. But mom knew people - that’s why she was so good at this game. She knew what made people tick and how to really connect with them. She was the kind of person who looked you in the eyes and could see your soul.

I believe that my siblings and I each got a piece of that. How people work and connecting with others permeates each of our careers.

Mom’s ability to connect with people infused her career in politics. Her involvement, I believe, was a direct result of caring so much about the people around her. When she connected with people, she very literally could feel the pain of others - you could see it on her face. She genuinely wanted to help, and wanted to improve conditions for everyone; that was her platform. Sometimes improvements were small, like the beautification committees in Rush, which hung flower baskets along the hamlet. Sometimes they were bigger things, like fighting to keep a munitions testing tire house out of a residential area. Mom liked to say she was a public servant, and she always backed that up. She answered the phone (even in the middle of the night), and she made more pots of chili for the snow plow drivers in Rush than I can count.

Mom was an inspiration to all, and she still inspires me today. She still talks to me, sometimes in the weirdest ways. She actually came to me in the form of an anxiety dream last week, which reminded me to get going on this speech.

Her example to the world was that courage and hard work are the only necessities for making a difference.

She taught me courage (OK, so setting aside her own fears of airplanes and thunderstorms, of course), but she had life courage. Mom never let the uncertainty of taking a risk keep her from making the jump. She was never paralyzed by her own fear. Whether moving out to the country, embarking on a political campaign, or volunteering for a new cause, mom always dove in with both feet. An unapologetic optimist and extrovert, not only did she want to make a positive difference in the world, she usually wasn’t receptive to any other outcome.

She taught me to work hard. She was able to accomplish so much because she worked so hard, or because she drank so much tea; either one. I remember all the mugs; you couldn’t open a vehicle door without a mug falling out.

I’m joking, of course. Mom worked so hard because she believed so deeply in everything she did. She was unable to refuse any new opportunity to volunteer for one of her many causes. I have so many memories of fund raisers at our house in Rush on school nights, a parade every weekend some summers, and of course, all the time she spent on the phone. Believe me when I
On July 11, 2013, members of the Coalition's Advocacy Committee visited the local offices of some elected officials who represent our area in Albany. This was an opportunity to introduce new committee members to our own Advocacy Day as we reminded the officials of the important services provided to their constituents by this organization. We also had the opportunity to discuss two areas of interest to our committee: hydrofracking in New York State and the upcoming health insurance exchanges.

For several years, our Advocacy Committee has been paying attention to the issues surrounding hydraulic fracturing, (also known as hydrofracking or fracking), a technique to extract natural gas from deep within shale rock formations. We care because at least 25% of the 600-plus chemicals used in the process are connected to cancer. An additional 37% are hormone interrupters identified as impacting cancers of the breast, prostate, pituitary, testicle and ovary. While many of the specific chemicals in use are protected as trade secrets, benzene, traces of which can be found in fracking formulas, is a known link to breast cancer. In addition, drilling may release radioactive substances, vapors and toxic metals into the air, water and soil. The Coalition has joined with several other health-related and environmental groups in requesting a thorough health impact assessment of hydrofracking. The review should be conducted by an independent team, without ties to the industry or state government, following scientific standards. We recognize that this technology represents an opportunity for economic growth for our state. Natural gas is an important energy resource. However, we feel it would be short-sighted to make an uninformed decision. While our representatives understood our concerns, their responses stated that any decision is in the governor’s hands at this point.

Beginning in October, New York State began to offer health care enrollment for the uninsured through a Health Care Benefit Exchange. The goal of this program is to offer access to quality health care for the one million uninsured New Yorkers beginning in January of 2014. A lack of insurance can result in delayed diagnosis and decreased quality of life, as well as unnecessary deaths. By providing timely treatment, those with cancer will spend less time being patients and return to their families and livelihoods. Lives can be saved. The elected officials we saw have concerns about the affordability of the program, and they question whether or not individuals will sign on for health coverage. We all agreed that not having insurance does impact our state’s economy and well-being on many fronts. We at the Coalition have too often seen the impact of a breast cancer diagnosis on the uninsured and under-insured.

We wish to thank Senator Joseph Robach and Assemblymen Mark Johns, Bill Reilich and Harry Bronson for their time. We also met with Brian Van Grol of Assemblyman David Gantt’s office and Jim Nasso in Assemblyman Joe Morelle’s office. Each meeting provided us with the opportunity to discuss the issues, gather information and to reflect on the bigger picture. Thank you to Mary Gross for scheduling these meetings and to Rebecca Solomon for providing us with the needed background information. Committee members Mary Beth Allyn, Dominique Boller, Dan Deckman, Eileen McConville, Cynthia Nelson and Miriam Steinberg attended the meetings along with Mary, Rebecca and myself. To all who participated, the gift of your time and effort is appreciated as we continue to advocate for those affected by breast cancer.

A bill to legalize the use of medical marijuana has been introduced in the New York State legislature every year since 1997. It has passed the State Assembly four times; it has never made it to the floor of the Senate for a vote. At this time, 20 states, including several surrounding New York, have bills in place allowing the medicinal use of marijuana. Members of the Coalition’s Advocacy Committee met on September 12th with Anna Saini of VOCAL-NY, an HIV/AIDS advocacy organization, and Julie Netherland from the Drug Policy Alliance of New York. Both organizations are working toward passage of the Compassionate Care Act to allow New York State providers to certify the medicinal use of cannabis to patients. We are seeking people willing to tell their personal stories publicly in regard to the use of marijuana. Did you use it? Was it helpful, or not? Did you want to use it and couldn’t get it?

If you are willing to speak about your experiences, contact the Coalition at 585-473-8177 or email info@bccr.org

“Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it’s the only thing that ever has.”

-Margaret Mead
Like most people, a cancer diagnosis was never on my radar. But in May of 2012, I found out I had endometrial cancer. I was 48.

At my first meeting with the gynecologic oncologist, I asked what the risk factors were for the surgery she would be performing, which involved removing the uterus, cervix, fallopian tubes, ovaries and a few lymph nodes.

“Lymphedema,” she said.

“What’s that?” I asked.

“Oh, it’s just some swelling. You manage it,” she replied.

It didn’t sound that serious, and at the time, I was preoccupied with more pressing questions. How far did she think my cancer had progressed? Would I need further treatment after surgery? Could this shorten my life?

The surgery went well and the tumor was staged 1A, which meant I could skip chemo and radiation and celebrate a very promising prognosis. Now all I had to do was stay at home for the next six weeks and recover from the surgery. Easy, I thought.

Things started out well, but increasingly my groin and upper thigh seemed kind of puffy, and my legs and buttocks ached and felt heavy. As the days progressed, standing or sitting for long periods became painful; sometimes excruciatingly so. Instead of feeling better the farther out I got from surgery, I felt worse. And anxious.

I started reading about lymphedema.

When lymph nodes are damaged or removed, lymph fluid cannot drain properly and accumulates in the tissue, leading to swelling in the affected limb or body part. This is lymphedema, a progressive condition that affects an estimated 10 million Americans, according to a 2009 lecture by Dr. Stanley Rockson, director of the Stanford Center for Lymphatic and Venous Disorders.

There are two types of lymphedema. Primary lymphedema is a congenital condition where lymphatic vessels are impaired or not fully developed. Secondary
Living With Advanced Breast Cancer

Exercise and Advanced Breast Cancer
Yes You Can

-By Pat Battaglia

At a recent evening seminar at the Coalition, Karen Mustian, Ph.D., M.P.H., spoke on The Benefits of Exercise During and After Breast Cancer. Dr. Mustian is the Director of the Physical Exercise and Kinesiology (PEAK) Lab at the University of Rochester and has studied the effects of exercise on those facing breast cancer at all ages and all stages of the disease. Having witnessed suffering and loss due to cancer in her own family, Dr. Mustian has dedicated herself to improving the quality of life for those in all levels of cancer treatment through the use of movement and exercise.

In studying the effects of exercise on women with metastatic breast cancer, this compassionate researcher found that many needed the exercises to be modified to accommodate individual needs. Working within the limitations that were presented to her, Dr. Mustian learned along with the patients which particular modifications worked best. Women with advanced breast cancer fared well with a gentle exercise program designed to fit their needs. They soon began to see improvements in their fatigue levels, cardio-pulmonary function, muscle function, balance, flexibility, and body composition. It all adds up to an improved overall sense of well-being, and can optimize quality of life for those living with this disease.

When considering beginning an exercise program, Dr. Mustian recommends that you start by talking with the doctor in charge of your care about possible contraindications to exercise, or to particular forms of exercise. This applies to everyone, and is especially important for those with advanced breast cancer. Once you are ready to begin, learn about community resources and work with professionals qualified in dealing with cancer patients. Start slowly. Any exercise is better than none, and the benefits of a single exercise session—which can be as simple as a ten-minute walk—will last for days. With consistent activity, you will see improvement.

Those recovering from or living with breast and/or any GYN cancer have access to our Healing Arts Initiative and Gentle Yoga classes. For more information about these and other community resources, call the Coalition at 473-8177. To learn more about the PEAK Lab, visit http://www.urmc.rochester.edu/physiology-exercise-lab.

“There is no exercise better for the heart than reaching down and lifting someone up.”

- John Andrew Holmes
Those who live with metastatic breast cancer encounter ongoing challenges that can be overwhelming and isolating. The emotional impact of the diagnosis is often, in and of itself, staggering. While undergoing medical treatments designed to keep the cancer at bay, both the effects of the disease and side effects of treatment raise health and wellness concerns that are as individual as each person who faces this diagnosis.

In working to develop quality programming to fit the emotional and physical needs of those who walk this particular path, Holly Anderson, our Director, submitted a successful grant proposal to the New York State Department of Health that focuses on the specific concerns of those with metastatic disease. The Coalition gratefully acknowledges these funds that enable us to enrich our offerings to this very special group of survivors.

Living with advanced breast cancer can be extremely challenging. Complex issues arise, and to address these issues on a holistic level, the Coalition offers a variety of programs that speak to the physical and emotional impact of this disease. We are now given an opportunity to thoroughly evaluate and refine these offerings.

The programs supported by this grant include:

- **Our Common Ground Advanced Breast Cancer Support Group** is professionally moderated and open to those facing a diagnosis of stage IV or metastatic breast and/or GYN cancer.

- **Healing Arts Initiative** classes are open to those with any stage of breast cancer, and can be modified as needed to suit the needs of all participants regardless of the challenges they face. These classes include such offerings as Tai Chi, Qi Gong, Yoga, and Fluid Motion.

- **Gentle Yoga** classes are also offered to the entire community of breast cancer survivors, and afford great benefit to those facing metastatic disease.

- **The Annual Cindy L. Dertinger Advanced Breast Cancer Seminar: Tools for the Journey.** This half-day session features presentations by professionals and leaders in the treatment of metastatic disease, as well as survivors. It is open to the entire breast cancer community: patients, their families and friends, care providers, and all interested individuals.

We at the Coalition open our arms and hearts to all who are affected by breast cancer. Thanks to the NYS DOH support, our programs will continue to give those facing a diagnosis of metastatic breast cancer the chance to learn new coping strategies along with techniques for improving their overall health. Becoming part of a caring community of survivors and meeting others facing similar challenges sends a very powerful message: “You are not alone.”

Though this group is not living with metastatic breast cancer, these survivors are participating in a recent Healing Arts Initiative session of Fluid Motion. This group is open to those diagnosed with any stage of breast or GYN cancer.
Our Programs at the Breast Cancer Coalition of Rochester... *all FREE of charge!*

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

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

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

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

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

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

**The Lymphedema Awareness Network of Rochester**
This networking group meets every second Wednesday of the month from October 2013 through March 2014. See page 7 for more information.
For more information or to register for our programs, please call the BCCR at (585) 473-8177

**Peer Advocates Lending Support: PALS SM**

The concept of this program is simple: individual breast cancer survivors reach out to those who are new to the disease, providing a foundation of caring through one-to-one contact, helping them connect to needed resources, and instilling confidence in the face of a difficult situation. Please call to learn how to be enrolled in the program after your own diagnosis, or if you would like to become involved as a mentor.

*See page 29 for PALS Program updates.*

**Brown Bag Fridays**

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

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

This well-loved group gives people with breast cancer an opportunity to explore and express their feelings through writing. Led by a professional instructor, these workshops run in five week cycles on Tuesday evenings. Seating is limited, and advance registration is required.

**Gentle Yoga**

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

**The Healing Arts Initiative**

Offering instruction in practices such as Fluid Motion, Gentle Yoga, Qi Gong, and Tai Chi, this initiative is an opportunity to learn a new modality or become reacquainted with one that may have fallen by the wayside. Classes are held in four-week sessions on Saturday mornings throughout the year.

**Young Survivor Soiree**

A young survivor may identify with those who have been dealt a breast cancer blow in the midst of a career climb, or while raising children, or perhaps with those whose family plans have been derailed by breast cancer treatment. Four times a year, we hold our Young Survivor Soirees as an informal way to meet and network with others who have faced a similar journey. The next soiree will be on November 15th. Please call if you would like to be added to the invitation list.
Knowledge is power. Education is essential for making informed decisions about breast cancer treatment options, as well as learning ways to enhance our well-being. As we wrap up another year of educational evening seminars, it is a perfect time to reflect on the interesting and informative presentations that were held at the Coalition in 2013. How fortunate we are to live in a community of highly-skilled, experienced health care providers and other professionals who are willing to share their knowledge with us.

We heard from Marilyn Ling, M.D., who discussed Integrative Medicine and shared her expertise in prone breast radiation. A local breast imaging specialist, Avice O’Connell, M.D., M.A., explained the relevance of breast density in screening for breast cancer. Katherine Streeter, R.D., gave an overview of proper nutrition for breast cancer survivors. We expanded our knowledge about complementary techniques such as massage therapy and acupuncture when we hosted Karin Cole, L.M.T, and Shannon Chanler, L.Ac.. As we geared up for the growing season, Kate Mendenhall and Chris Hartman shared how eating fresh, local, organic food can enhance our health. Marcia Krebs, M.D. discussed long term effects of chemotherapy. Karen Mustian, Ph.D., M.P.H. gave an overview of the benefits of exercise during and after treatment for breast cancer. In the past year we have also learned about the role of a Pathologist in breast cancer diagnosis and treatment from Dawn Reidy, M.D., and heard an update about the surgical management of breast cancer from Ruth Hetland, M.D.

What a year of dynamic, informative presentations it has been!

Plans are under way to secure speakers for the 2014 seminar series and the calendar is quickly filling with a variety of fascinating topics. We look forward to a broad range of interesting presentations including “Long Term Effects of Radiation” and “Vitamin D and Nutritional Supplements”. From learning about how to reduce the risk of breast cancer recurrence to how chemotherapy affects oral health, there will be something for everyone.

Please join us on the fourth Wednesday of every month (except November and December) at 7:00pm.

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

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

Thanks!

These seminars are free and open to the public. I encourage you to tap into the wealth of knowledge we will be offering you.

Raffle Winners

Two of the multitude of visitors to our booth at the Park Ave Fest got a pleasant surprise the following week.

The winner of the Wegmans $250 gift card was Park Ave neighborhood resident and cancer survivor Deborah Zaretsky. Deb planned to put the card to use at the brand new Wegmans on East Avenue.

Congratulations also to Linda Fagan of Greece. Linda was the second prize winner of the six premium Lancers Soccer Tickets drawn in our raffle. Linda will be sharing her tickets with some of her ten grandchildren.

Thanks to our friends at Wegmans as well as the wonderful Rochester Lancers for their donations and the help they give the Coalition. And thank you, Deborah and Linda, for visiting our booth and supporting the Breast Cancer Coalition of Rochester.
Outreach clearly goes both ways, as these last few months have proven once again. As we at the Coalition have focused on bringing our message and services to less-served areas and populations, so have we been the recipients of giving from an amazing array of sources.

The gifts we receive, both monetary and material, come from all ages, many professions, a variety of efforts and a multitude of kind hearts. There are large corporate events, and small neighborhood parties. Groups run, shoot hoops, cook steak, sell ribbons, wear jeans, skate, tell jokes, make music, create art, style hair, dance, golf, kick soccer balls, race horses, tan, get massages; the list goes on and on. The ideas and motivations to raise money for families dealing with breast cancer are unlimited and gratifying.

The ways and places we go out into the community are just as diverse. Of course we greet folks at the big festivals and health fairs, employee lunch & learns, and civic groups. But we also go into schools, community centers, neighborhood streets, vacant lots, free health testing events, and retirement communities. We sit in grand ballrooms and on grassy playgrounds, under pavilions, in the blazing sun, in challenging wind, and sometimes, the rain. We schlep tents and tables, sell t-shirts. We listen to stories, suggestions, frustrations, fears and triumphs.

And we LEARN.

We want to be where people need us, and offer what people need. We continually update and revise programs and pilot new ones, based on what we hear.

Thank you to the amazing army of volunteers who make it possible for us to go all the places we do and reach people who may need us. Thanks to the people who hear us, and decide to help out in some way. Thanks to the people who stop by our booths and pick up information to share with a friend, relative or coworker. Thanks to businesses and organizations for letting us come and share our message.

Whether you need us or want to help out others who do, you are vital, and appreciated.

Volunteer SPOTLIGHT

When her best friend’s mother passed away from breast cancer in 2005, Ayanna Jackson deeply felt the sting of this disease. As a former hospice nurse at Isaiah House, her memories of those going through breast cancer remain powerful. So, when she received a mailing on the Cindy Derringer Advanced Breast Cancer Seminar a few years ago, her interest was piqued. Ayanna signed up to attend the event. What she found there were stories from those facing this disease that inspired her, energized her, and spurred her on to action.

Ayanna has been a friendly face behind our tables at several local events, including the Lilac Festival, the Clothesline Art Show, and the Clarissa Street Reunion. She is impressed and motivated by the diverse people she has met at these events. Some approached the table with stories of their breast cancer journeys - from the newly diagnosed to those who have moved beyond their treatment, and some who live with the disease every day. Others have loved ones and friends who have been diagnosed. To all, Ayanna has offered hope in the form of a listening ear, as well as advice on ways to connect with the Coalition.

“I enjoy getting the message out,” she says. “Women need to know they’re not alone.” In the face of what can be a very frightening, isolating diagnosis, that is indeed a powerful message.

Ayanna seeks and finds every opportunity to spread the word about the Coalition’s programs and services to those who may need them. Her work as a nurse offers her many openings for this type of conversation, and connecting with others through social media affords another outlet.

This vibrant, cheerful woman gives her all to whatever she does. “I go for the gusto,” Ayanna proudly asserts, and we are thrilled to have her as a goodwill ambassador for the Coalition. Thank you from the bottom of our hearts, Ayanna. You go, girl!
New Survey Released by Empire State Consumer Project: 
*The Use of Pesticides in Public Areas*

-By Pat Battaglia

Pesticides have been banned from use in and around schools in New York State since 2010. But many businesses, governments, health institutions, and other public facilities continue to use chemical approaches to pest control.

A recent report from the Empire State Consumer Project (ESCP) details the results of a survey of pesticide usage in a cross section of Rochester area public facilities, such as hospitals, shopping centers, and public roadways. Its findings show that some have “gone green”, but many still employ pesticides for cosmetic purposes in their landscaping. The specific chemicals that have been applied are listed (if that information has been provided).

The report also highlights potential dangers of exposures to these chemicals. Children, pregnant women, and animals have been found to be especially vulnerable to chemical toxicities, but exposures to certain chemicals carry risks for all. The known effects of the specific substances found to be in use locally include reproductive harm, nervous system damage, endocrine disruption, and birth defects, among others.

Judy Braiman, leader of the ESCP, says, “Consumers, employees, and neighboring residents have no say about the pesticides they are exposed to while shopping, working, visiting, or living near these locations. Recent applications, even when posted with signs, cannot be avoided altogether. Pesticide drift caused by wind and runoff from rain extend the reach of the toxics well beyond their intended targets.”

Maintaining the safety and effectiveness of organic methods for grounds-keeping purposes, the ESCP urges that all public places can and should be maintained using non-toxic approaches.

The report concludes that “Schools have been forced to change their perspective on what constitutes beautiful grounds in favor of healthier, pesticide-free grounds for students, staff, and the public. We believe that businesses and government must follow suit as a matter of public health policy.”

The current rate of breast cancer incidence in Monroe County is over 140 per 100,000 women, compared with an average of 127.7 per 100,000 statewide.(1) Ascribing a breast cancer diagnosis to any one factor such as environmental exposures is a difficult proposition at best. Cancers may appear from five to forty years after exposure to a causative agent.(2) However, the known health risks of certain pesticides make it prudent to employ the precautionary principle and work to limit exposures to questionable substances for the health of all, especially the more susceptible and defenseless among us. 

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To read the report in its entirety, follow this link: 

Bright orange pumpkins on doorsteps are one of the hallmarks of autumn. As an ingredient in Thanksgiving pies, they can’t be beat. But there is more to this ubiquitous fall ornament - a lot more.

As a member of the squash family, pumpkins are a delicious, versatile, low-calorie vegetable loaded with nutrients. One cup of cooked mashed pumpkin contains 200% of the RDA of vitamin A. They are also high in vitamin C, beta-carotene, and fiber. Pumpkin seeds are a good source of protein, iron, and B-vitamins. And the athletes among us may be interested to know that one cup of pumpkin puree provides more body-replenishing potassium than a banana.1

Small "pie pumpkins" have a sweeter flavor and smoother texture than larger "jack-o-lantern" types, and are best for cooking. They can be baked, boiled, steamed, or microwaved to produce a soft puree that works in any recipe calling for canned pumpkin.2 While the canned variety is also highly nutritious, for maximum flavor and nutrients, fresh is best. Better still, support a local farmer and buy your pumpkins from a farmer’s market or roadside stand, or visit a farm where you can pick your own.

Pumpkin is showing up with increasing frequency in a wide variety of dishes, from appetizers to soups, pasta dishes to curries, in smoothies, and even enchiladas. Its soft texture and mild flavor make it a great starting point for many recipes that can tempt the most reluctant vegetable-eaters among us.

Don’t tell them it’s good for them, and they may not think you’re out of your gourd! >>

1. http://www.huffingtonpost.com/2012/10/05/pumpkin-health-benefits_n_1936919.html
2. For detailed instructions on cooking fresh pumpkins, go to: http://www.pickyourown.org/pumpinkcooking.php

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### Pumpkin Ravioli

- Combine 1 cup pumpkin, 1/3 cup Parmesan, 1/4 teaspoon salt, and 1/8 teaspoon black pepper.
- Spoon about 2 teaspoons pumpkin mixture into center of each wonton wrapper.
- Moisten edges of dough with water; bring 2 opposite sides together to form a triangle, pinching edges to seal.
- Place ravioli into a large saucepan of boiling water with 1 teaspoon salt; cook 7 minutes, and drain in a colander.
- Place 1/2 cup broth and 1 1/2 tablespoons butter in pan; bring to a boil. Add ravioli, tossing to coat.
- Sprinkle with parsley.
- Serves 6 (serving size 4 raviolis).

Source: [http://www.health.com/health/recipe/0,,100000001046792,00.html](http://www.health.com/health/recipe/0,,100000001046792,00.html)

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### Pumpkin Spice Hummus

A slightly sweet, delicious take on traditional hummus. Enjoy with sliced fruit such as apple or pear, with chopped fresh vegetables, or pita chips

**Ingredients**

- 1.5 cups chickpeas (1, 15oz can)
- 1 cup pumpkin puree
- 1/4 cup tahini, cashew butter, or almond butter
- 2 T. sunflower oil
- 2-3 T. maple syrup
- 1 tsp. vanilla extract
- 1.5 tsp. cinnamon
- 1/4-1/3 tsp. ginger
- 1/8 tsp. nutmeg
- 1/16 tsp. cloves
- 1/2 tsp. salt

- Combine all ingredients in your food processor.
- Taste and adjust spices if needed.
- Serves 12 (1/4 cup each).

The eleventh annual Teed Off at Breast Cancer Golf Tournament was a rousing success. The event sold out, and the addition of three foursomes resulted in an early morning round for four teams, with the rest of the golfers hitting the course at noon. A light, late afternoon rain did not dampen the spirits of the participants, who finished their games and headed inside Brook-Lea Country Club to enjoy dinner and raffle prizes.

Co-Chairs Sean Patton and Lee Cordero, with their dedicated committee members, recruited a record-breaking fifty-five sponsors, including three Eagle sponsors, making this the most successful tournament yet. Applause and thanks go out to Sean, Lee, and committee members Sylvia Cappellino, Dick Cougherty, Kay Kolb, Charlot and Remo Rossi, Susie Smith and staff members Cindy Dykes, Connie Zeller and Holly Anderson. Of course, we could not host a successful event like this without the tremendous effort of our volunteers, who worked hard and helped make this a memorable event.
TOURNAMENT RESULTS

1st Place Men's Flight
Wynn Bowman
Adam Chen
Rick Dougherty
Lucas Whoppel

1st Place Women's Flight
Cheryl Deyle
JaneEllen Bailey
Kay Kolb
Rosalie Pusateri

1st Place Mixed Flight
Donna Patton
Ben Carlson
Sam Burgess
Phyllis Haberer

Closest to Pin Women
Lori Ramsperger

Closest to Pin Men
Bill Laforte

Long Drive Women
Sherri Thaney

Long Drive Men
Ben Carlson

Donna Metelsky and Connie Zeller

Event photos taken by Ria Tafani

Cheryl Deyle and Sean Patton stretching

Drawing close for comfort and high spirits!
Golf Tournament continued

Our Generous Sponsors

Eagle Sponsors - $2,500
- John Hancock Funds, LLC • The Richard T. Bell Foundation
- Thornburg Investment Management • Towpath Bike, Inc.

Cart Sponsor - $1,000
- William H. King, Jr., Attorney & Counselor at Law

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- Steadfast Capital Markets Group • Visiting Nurse Service of Rochester & Monroe County, Inc.

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- Barb & Donnie Pifer • Prudential Retirement • Ontario Offshore Performance Specialists
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- Transamerica • Upstate Niagara Cooperative, Inc.
- Richard Warner • Wells Fargo Home Mortgage

Recognition Sponsors - $125
- Walter J. Deck, DMD, PC • Hill Creek Consulting • Barb & Donnie Pifer – in memory of Mae O’Neill
- Prudential Retirement • Upstate Niagara Cooperative, Inc.
lymphedema occurs when lymph nodes are removed or damaged due to an infection, accident, surgery or other medical treatment such as radiation. Cancer survivors --- particularly those who have had breast cancer --- make up the majority of lymphedema patients in this country.

Left untreated, people with lymphedema are at risk of developing disfigured and immobile limbs, contracting potentially fatal infections, and in very rare cases, developing a deadly form of lymph cancer.

There is no cure yet for lymphedema, but for many people it can be successfully managed, especially if it is diagnosed and treated in its early stages.

My lymphedema was officially diagnosed five months after my surgery. I immediately began seeing a physical therapist certified in lymphedema therapy.

Treating lymphedema involves a combination of things, all of which are mechanical rather than pharmaceutical. Special massage needs to be done daily to stimulate and redirect lymph fluid, and most patients learn to do this themselves. Compression garments must be worn to keep swelling down, and some patients also have to wrap their limbs in bandages at night. Skin care is important in order to prevent irritations, burns or cuts that could lead to serious infections.

My cancer experience was short-lived, but lymphedema is now part of my everyday life. It took a while, but I am definitely feeling better.

Lymphedema, like cancer, can feel isolating and overwhelming. That is why we are launching a group where people with lymphedema can share practical information, find support and learn more about how to stay healthy and live well.

The Breast Cancer Coalition of Rochester has generously offered to host this group, which will meet the second Wednesday of each month. The first session in October welcomed 21 participants. On even months, we will invite a medical professional to talk about a lymphedema-related topic. On odd months, we will offer a traditional peer networking group where attendees can talk about their issues and share information and support. We will introduce this as a six-month pilot program to gauge interest and then decide if we should proceed with a year-round, ongoing group.

The Research Committee has finished updating the Request for Proposals (RFP) and Guide for Proposal Review (GFPR), documents key to the Coalition’s Breast Cancer Research Initiative. The 2013-2014 RFP was posted on the Coalition’s website on September 1, 2013. Area scientists and medical professionals, Research Advisory Board members, and potential applicants on record received email notification that the RFP was posted and available for downloading. Research proposals are due at the Coalition by Tuesday, December 31, 2013 at 5:00 pm.

The Coalition has received midterm reports from Ryan Dawes and Dr. Ashwani Sood, our 2012-2013 grant recipients. The preliminary results reported for both studies are promising. The Research Committee visited their laboratories in September and October. We are excited to follow the progress of these researchers whose efforts should move us closer to fulfilling the Coalition’s goal of preventing and eliminating breast cancer and its metastasis.

The Breast Cancer Coalition cordially invites you to our Holiday Open House

Wednesday, December 4, 2013
4:00pm to 6:00pm
RSVP: 585.473.8177 or jean@bccr.org
Sexual Health of Young Breast Cancer Survivors

Reprinted with permission from CRAAB!, Empowering People Affected by Breast Cancer, Vol. 15, No. 3, Summer/Fall 2013

By Jessica Werder, MPH

BACKGROUND AND RECENT EVIDENCE:

It is well known that a breast cancer diagnosis, and subsequent treatment, can have a lasting impact on a woman's sexual life. For young women in particular, the experience of breast cancer seems to have significant negative consequences for their sexuality. In 2012, The European Society of Breast Cancer Specialists published a position paper on the management of breast cancer in young women. Among the topics addressed in the paper was sexual dysfunction, with a recognition that physical, social and psychological complications should be addressed for these women.

In February, a group of researchers from the Netherlands published data from a survey conducted with young women, 45 years of age or younger, who had been diagnosed with breast cancer in the last 6 years. They found that, when compared to women without a breast cancer diagnosis, women undergoing treatment for breast cancer experienced significantly more sexual stress, were less satisfied with their sex lives, and were more likely to feel guilty about their sexual behavior.

In March, a "best practices" review article was published entitled Rehabilitation Following Cancer Treatment. The intent of the research was to review existing evidence on rehabilitative interventions that addressed physical, cognitive and emotional problems during cancer survivorship. According to the authors, "The review took as its starting point a systematic review of patient needs and supportive care interventions following cancer treatment." Yet, while the article included a section on sexual functioning, the studies reviewed largely focused on male sexual functioning following prostate cancer treatment or women's sexual functioning following gynecological cancers; no mention was made of the emotional or psychological effects of breast cancer on a woman's sexual functioning.

INTERPRETATION AND IMPLICATIONS:

Clearly, there is a growing recognition within the medical and scientific communities that breast cancer diagnosis and treatment can have negative effects on a woman's sex life. For young women in particular, such a diagnosis can lead to severe emotional outcomes. And yet, it appears that little effort has been given to studying approaches that may prove therapeutic for women in these circumstances. More research needs to be done, and more attention needs to be drawn, to this consequence of breast cancer among survivors.

continued on page 28

Courage, Hard Work & Tea continued

say that Verizon doesn’t make a plan that would have enough minutes for her. But again, she was connecting with people and listening to their stories, so it didn’t feel like work to her to catch up with her friends – I mean, co-workers and constituents. And for those lucky enough to be there, her post-event (party, fundraiser, whatever) debriefs were usually the best part of the night.

We should all try to live with the passion she had. Let your passion fuel your drive to work hard and do exceptional work. Hard work pays off. You can make a difference, you can have an impact. Many already are. For those who want to be involved, the Coalition is a great place to channel this motivation; for the recently diagnosed, for the friends and families of those touched by cancer, or for those who just want to help. All you have to do is want to make a positive impact and have the courage to volunteer.

Rob (aka "Bix" DeBaise, Pink Ribbon Race Director), and now Peg (DeBaise, who leads the volunteers for that event), are great examples of this. The Coalition’s Mother’s Day Race started out in the rain, with a few brave walkers and runners at St. John Fisher. It has now grown too big for this location, and has become one of the largest road races in Monroe County.

You can help. You can get involved. The Coalition is exactly the kind of place where you can make a difference. You can help fight this terrible disease by helping raise money that goes directly to research, education, and community outreach efforts. You can help people locally and also help the global fight against this disease.

But unfortunately, this fight isn’t over. While strides are being made and survival rates are increasing, far too many women (and a few men as well) in Rochester and around the world still face the prospect of this disease. Advances in targeted therapies are helping, but breast cancer still has no cure. There is still work to be done. And thanks to organizations like the Coalition, we are all working towards a better day when daughters, sisters, wives, nieces, grandmothers, and aunts no longer worry about the “c” word.

Thank you all so much for your time, and for coming out to support this event. And many more thanks to the organizers and volunteers who helped make this event possible.
Friends Remembered...

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

Rena Cignarale
Coleen Jones
April O'Malley
Ann Marie Ritter Raynor
Anne Marie Wrights

Would you like to write about someone you have lost to breast cancer? We welcome submissions from friends and family members and are particularly interested in hearing stories about how they have touched and changed your lives. Please send your submission (300-500 words) with a digital photograph to Susan Meynadasy, BCCR Voices of the Ribbon Newsletter Editor, at susan@bccr.org.

We would be happy to honor your loved ones.

Tributes Welcomed

If you’ve never had the pleasure of having my mom cook for you, you’ve missed out. On many occasions, she called creating food her “art.” She would research recipes, discover new foods, and make plenty so she could share her masterpiece with family and friends. It was always a treat to take home leftovers, and knowing she could feed you tomorrow made her extra happy. Mom always made kind gestures, but feeding people was her favorite way to show her love.

Food was a good barometer for our family to use over the past year. We could tell how well Mom was feeling based on what she was eating or planning to cook tomorrow. Last summer, she was not doing well, but was fighting to make a family vacation to the Adirondacks “normal.” She had shopped for unique and high-quality ingredients, and tried to stand at the counter and prepare our meal. We all offered to help and it didn’t take long before she assumed a supervisory position on the couch. From that seat, she told us everything we were doing wrong and eventually got annoyed enough to take over. No one was offended. The kitchen was her studio and the medium she chose was food.

I promise Mom, I’ll always let the pan warm up before I put the oil in so it doesn’t burn, just like you said.

A social worker by trade, Mom lived her work, always listening, connecting, suggesting, and helping. If she didn’t have an idea or answer, she’d do plenty of research. She was able to understand people and discover their talents, which made her a wonderful career counselor for me and many others.

Recently, my daughter Samantha and I did an informal interview with Mom during which we asked her to describe herself using only two words. She paused and gave a thoughtful answer: Enthusiastic and Positive. I was surprised at how accurate her answer was. My Dad had a similar reaction.

My parents have always had an extraordinary marriage, a nice “yin-yang” relationship. Mom never wanted to bother others and rarely asked for anything. But Dad was always “in tune”, and usually knew what to do.

Once I became a mother, I had a whole new appreciation for Mom. I now know that every day, when I take care of my kids, I honor her. Every day, I am reminded of all she did for my brother and me over the past 30 years. But Mom would not want us to be sad at her passing. She would want us to pick up right where she left off: helping, being kind and “loving” by means of our own art.

While writing this, I was enjoying a cup of tea. On the tag, it said: “Helping others find happiness brings us the most happiness.” That could be my mother’s life mantra.

Thanks for helping me out, Mom. ☺
The Power of Passionate Women

Get a group of Italian women together on a monthly basis and you have a powerhouse group characterized by passion, dedication and altruism, fueled by good food and laughter. Armed with knowledge and community spirit the Rochester Italian Women’s Civic Club puts its considerable energies into making Rochester a great place to live. Your donation of $297 to the Breast Cancer Coalition of Rochester will be put to good use, ladies. Keep up all of your great works.

We Get By With a Little Help

Once again, it was “all hands on deck” for the Duke Company, as they put on another incredibly successful golf tournament on a fine September day. As a dedicated friend of the Coalition, the Duke Company frequently makes us the beneficiaries of the appreciation events they offer for their customers. In essence, through Duke’s generosity, we become the recipients of donations from scores of area contractors and vendors. These people know how to have fun!! And they know how to give. This year, the tournament raised $10,915. We get by with A LOT of help from our friends at Duke.

A few of the hardworking volunteers that made this day a grand success!

Drive, Donate & Follow Thorough

Heavy cloud cover and wet bursts marked a good part of the day on June 25 at Midvale Country Club. But right on schedule, the dramatic clouds cleared and brilliant sunshine reigned. This exciting tournament raised $4,745 for the Coalition under the expert guidance of Betty Podlesh and our own Marcy Lazio.

Rain? No matter! When the powerhouse ladies at the Midvale plan a tournament, a little rain will not stop them.

The Great Bulldog Benefit

Youth Football is a long standing and beloved tradition in Livonia. And from an early age, the emphasis is not only on personal growth, but community growth and giving as well. The Breast Cancer Coalition is once again honored and humbled to be chosen to receive the proceeds of the annual Livonia Junior Bulldogs Breast Cancer Benefit Games. This years’ hard work and play netted $1,526.88. Thanks once again to this group of dedicated young people.

Trucks, Trains, and Tiaras

There can’t be a child, whether dressed as a super-hero or a princess, who does not relish the idea of climbing on giant construction equipment. When there is also face painting, a castle bounce house, train rides and a REAL princess, the day is just about perfect! AP Enterprises partnered with the Toddler’s Workshop and Railroad Junction child care centers to offer two hours of pure (free) fun to little people Saturday September 29. Grateful parents and grandparents in turn donated a total of over $738 to The Coalition.

Kessa Weetman is diggin’ the back hoe!

Maria Migliore—“a Breath of Sunshine”

The death of a family member, friend, and colleague leaves a void that can only be filled by sharing memories and laughter, and celebrating the joy of a life well lived and too short.

The family and friends of Maria Migliore who lost her fight with breast cancer in December 2011 gathered last Fall to join in a celebration of her life which culminated in the release of 200 pink and yellow balloons. Maria was a lover of flowers and especially sunflowers, which her sister in law Nancy mused reflected Maria’s knack for “bringing a breath of sunshine” to every situation. In her honor, the Coalition received a wonderful gift of $250.
The Fabulous Flash

Rochester’s own women’s soccer team provided a thrilling evening at Sahlen Stadium August 17 under the lights, winning their game and a spot in the playoffs. The evening was part of their “Project Pink” and was thoroughly enjoyed by several Coalition families. Special edition pink jerseys were raffled right after the match, and winners were able to pose with their favorite player as the jersey changed hands. Additional raffle items and autograph signings raised an amazing total of $11,772 for the Coalition.

Baja-Ha!

This is a fun name for a spirited group of women who gather each August for a day of camaraderie, good food, and lots of laughs on the golf course. At the end of the day, a local charity is selected by the winning team to receive a generous donation of $1,000. A big thanks goes to the organizers as well as the winning team members: Shannon Losey, Charity Clancey, Jess Quick and Phyllis Haberer for sending this wonderful gift our way.

Artofest- A Birthday Bash for Breast Cancer

A 50/50 raffle; T shirts, great company, a friendly pub, a fancy adult beverage dubbed “Pink Revenge”. This was a recipe for good times, great memories, and a chance to give to a cause near and dear to the hearts of Rosalyn Smith, her boyfriend Arto and their friends. This merry group collected $1,342 in honor and memory of beloved ladies lost to breast cancer.

Celebrating Survivors

As one of the stately ladies pointed out “You don’t get to your 80’s and beyond without going through some tough times, honey”. Indeed! Many of the residents of the beautiful Fleming Point Senior Community have seen their share of challenges. On October 4, they gathered to honor, remember and celebrate those who had faced breast cancer. Among the sixteen survivors that day was one charming lady who had left her cancer behind in 1973! They shared their stories with the aplomb that growing older seems to grant. And they offered a gift of $53 in thanks for the work of the Coalition.

Greathearted Youth

The young people of the Marianne Cope Roman Catholic parish in Henrietta make it their business to seek others who need a helping hand. This Spring, because of connections with family and friends dealing with breast cancer, they directed their charitable efforts to the Coalition. Kudos to this altruistic group for a gift of $807.31. Nice work!

Bejewelled Generosity

In many women, a diagnosis of breast cancer awakens a deep desire to “pay it forward” to the women who will walk the same path. Dr. Cheryl Kleist shared her talent for jewelry design as well as her commitment to early diagnosis and support by selling her creations in several RIT locations and at St. John’s Senior Living Center. In addition to sharing $240 with the Coalition, she convinced a reluctant and fearful customer to schedule her long overdue mammogram. Thanks for making a difference, Chery!!

Aaaaaand They’re Off!

Several of the Coalition’s Board of Directors and friends and family enjoyed a gorgeous summer evening of live harness racing at Batavia Downs Casino and Race Track on July 24. It was the annual Batavia Downs fundraiser for the Coalition, and a chance to check out the newly remodeled dining room and casino area. The generosity and enthusiasm of the staff, the jockeys, and many excited race-goers resulted in a much appreciated gift of $6,491.

Sharing the Love

On a day of great celebration, bride Taylor Smith and her groom Blair Veenema decided to share a bit of their joy. In lieu of wedding favors, the young couple made a donation of $250 to the Breast Cancer Coalition of Rochester. Best wishes and thanks to this couple as they begin their life together on such a kind note.
Antoinette Capellupo
Anayberca Camilo
Stacy Calvin
Nicholas Mannella
Marianne Abraham
Michael Abraham
Christa Abugasea
Stephanie Adler
Rose Mary Agins
Mafalda Agostinelli
Ron Aikin
Lori Allison
Mary Allyn
Craig Anderson
Garth Anderson
Louis Andolino
Lisa Arbore
Barbara Arnold
James Ashman
Jennifer Atseff
Jana Aubertine
Glenda Ayers
Elizabeth Baker
Kimberly Barclay
Morgan Barron-Bozman
Joan Batzold
Scot Beaumont
Tammy Becker
Carmen Bello
Stacey Bershod
Richard Bianchi
Jane Biggs
Christine Bird
Tracey Birge
Tracy Bischoff
Kelsee Bodine
Shelby Bowman
Debora Braman
Tanya Brandenburg
Dawn Brenn
Paulette Briskie
Shirley Broomfield
Katrina Brown
Tynisha Brown
Dawn Bruno
Rossana Burgess
Nancy Jean Burke
William Burnett
Lorraine Busch
Kerstijan Bushey
Jerome Butterbrodt
Donna Caffrey
Linda Cala
Christina Calloway
Bryan Calmes
Stacy Calvin
Anayberca Camilo
Diane Campbell
Antoinette Capellupo
Cheryl Cappon
Annette Cappetto
Christine Cardinell
Shannon Carey-Wollschleger
Mary Cassidy
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Donald Clark
Patricia Clark
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Cora Conklin
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Johanna Cummings
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Jeanne Cunningham
Robin CPPazzpoli
Nick Danizio
Adelina Davin
Wordene Day
Timothy Dean
Gina DeBellis
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Jessica Hoyt
Wende Huell-Schultz
David Husk
Scott Ingalls
Carolyn Insalaco
Megan Insalaco
Steven Inzana
Marcelino Jaime
Michelle Janelins-Benton
Audrey Janicki
Duane Jennings
Kathi Johnson
Cynthia Jones
Deanna Jones
Kelly Jones
Linda Joseph
Jared Joy
Lea Joy
Helen Kastan
Michael Kauffman
Gregory Kayes
Thomas Kessler
Edison Kier
Steven Kilner
Robbin Kinsella
Thomas Kinslow
Joan Kircher
Tina Knapp
Diane Kolodziejski
Cathy Korn
Dawn Kowaljak
Sarah Switzer
Debra Kusse
Judith Laing
Sheri Landers
Valerie Lang
Josh Lawrence
Deborah Lazio
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Jeri Liles
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Carol Prunty
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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 spring newsletter.)
We apologize for any errors and/or omissions on our donor pages.

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**United Way Campaign continued**

**Surgical Pillows for PALS Paks** - By Pat Battaglia

When we added an item to our wish list seeking people to make surgical pillows for inclusion in PALS paks, we never imagined the overwhelming response we would receive. Amy Weetman, a member of our young survivor community, got the ball rolling by designing and making a number of pillows for us. These soft, heart-shaped pillows can be tucked under an arm or slipped behind a shoulder harness while driving to protect areas that are tender from surgery. Amy shared a picture of her colorful pillows with us, along with a copy of her pattern for others who might be inclined to stitch and stuff a few pillows. And stitch and stuff they did, as Julie Overbeck and Judi Stewart took to their sewing machines and produced more pillows. We have amassed a good-sized collection of pillows, and are grateful to Amy, Julie, and Judi for their generosity and hard work.

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**THE COALITION’S CURRENT WISH LIST**

- A cure for breast cancer
- Books about breast cancer for women, men, children, families (2010 or later)
- Books about endometrial, ovarian, cervical, fallopian, or other GYN cancers (2010 or later)
- Books about prostate or testicular cancers (2010 or later)
- Blank CDs and DVDs (writable)
- Computer paper, white
- Fleece throws/blankets for our PALS paks
- Foam core (new)
- Gift cards: Wegmans, Tops, DiBella’s, Staples, Target, Barnes & Noble, Michaels, pizza, etc.
- Journals
- Note cards
- Sleeping masks (lavender or unscented only)
- Thank you cards
- Paper products: napkins, cups for hot and cold beverages, small and medium plates (no Styrofoam products)
- Large glass display case for merchandise
- A Pantone Matching Guide
- Tablecloths 70x90 and 70x108 (white, sage green, pink)
- New, unused fabric
- Poly-fil stuffing for pillows
that level of control over her experience. Chemotherapy was difficult, but Rachel was able to maintain her work schedule with only a handful of days taken off to deal with the side effects of her treatment. She worked in the billing department of a neurology and rehabilitation outpatient clinic at a local hospital, and her employer was compassionate and supportive as she made her way through the months of treatment. (Rachel is now the Office Coordinator of that same facility.)

At her side throughout this journey as he has been in their life together, Rachel's husband, Michael took charge of the family's day-to-day tasks, preparing meals, cleaning house, and handling much of the child care, which allowed Rachel to focus on healing and spending quality time with her children. He was “absolutely wonderful,” Rachel says. In addition, his connections as a volunteer firefighter brought help in the form of meals prepared by the families of other department members.

As weeks turned into months, winter approached and settled in, the holidays came and went, and a new year dawned. Rachel finished chemo and began six weeks of radiation therapy, which she found much easier to deal with than chemo had been. The time passed quickly.

As she moved beyond her treatment and into healing mode, Rachel began to find ways to help others. She signed on to become a PALS Mentor. That was wonderful and very necessary, but she felt the need to do more. “I didn’t know what I wanted to do or how to go about doing it,” she says. “Then I got the letter for the Advocacy Committee’s Meet & Greet, to come and see if it was something I was interested in.” Rachel attended that reception, and joined the Advocacy Committee. “I really enjoy it. I think it’s wonderful and I’m learning a lot of new things.”

This year marks the fifth anniversary of Rachel’s diagnosis — a milestone by many measures. Her world view has shifted since that fateful day. “As devastating as (breast cancer) is — and nobody ever wants to have it — I think it makes you look at things differently,” Rachel muses. “I don’t worry that there are dishes in the sink any more. They’ll always be there. But enjoying the day and enjoying the time you have — that might not.”

Rachel’s advice for those who face a breast cancer diagnosis is “Take one day at a time. Reach out to others who are going through the same thing.” A Personal Journey continued

In “Life, Interrupted,” her online column for The New York Times, Suleika Jaouad often writes about her experiences as a young women with cancer. In February, she addressed the topic of sex and cancer, writing “to my surprise, sex is not at the center of the conversation in the oncology unit — far from it. No one has ever broached the topic of sex and cancer during my diagnosis and treatment. Not doctors, not nurses.” Referring to herself and friends with cancer, she writes “we are at a loss when it comes to answering crucial medical questions about sexual health and cancer. Who can we talk to? Are these common side effects? And what treatments or remedies exist, if any, for the sexual side effects associated with cancer?”(4)

As noted above, there does appear to be a growing recognition that the issue of sexuality is closely linked with breast cancer in young women. And yet, patients still clearly feel lost when it comes to this topic. Continued conversation and activism help to draw attention to the fact that more resources are needed for patients and survivors. Rebuilding identity after breast cancer is the goal of Parisian activist Cathie Malhouitre’s Web site, http://austeindesadifference.com (“within our differences”), to promote these sensitive and crucial discussions. ◼


Sexual Health continued

Reprinted with permission from CRAAB!, Empowering People Affected by Breast Cancer, Vol. 15, No. 3, Summer/Fall 2013
http://craab.org/wp-content/uploads/2013/07/CRAAB_NL_SummerFall201 WEB.pdf
The Peer Advocates Lending Support (PALS) Program, which pairs newly diagnosed women with trained peer mentors, is a natural outgrowth of another program, the SisterSak. Conceived and run independently by Megan Dombrowski, a young survivor, the SisterSak program matched those who were diagnosed at a young age with others similarly diagnosed. A key feature of the program was the “SisterSak”, which was delivered to the newly diagnosed young woman by her “sister” in breast cancer, and contained many of the lovely things that are still used in PALS paks today.

Many “older” survivors gazed longingly on this program when it came under the wing of the Coalition in 2006. Some joked about what to call a goodie bag geared toward them. “The Old Bag”, quipped one.

Many smiled at this, but Holly Anderson, the Coalition’s Executive Director, was serious about developing a program that would be inclusive of all who received a breast cancer diagnosis. To realize this vision, Holly spent countless hours that turned into days and weeks meticulously crafting a grant proposal that was submitted to the New York State Department of Health (DOH) Cancer Services Program. Without the support of the DOH, the Coalition would be unable to devote the time and financial resources necessary for the new program. The DOH responded favorably, providing five years of funding, and in 2008, the PALS Program was born. Tracy Brown was at the helm as our Program Coordinator, and with her fine organizational skills, she laid much of the groundwork for PALS. Tracey Dello Stritto took the baton from Tracy Brown and ran with it, using her eloquence and thoughtfulness to ensure that all who could benefit from having a PALS Mentor would be able to. I came onto the scene as the Coordinator of the program in 2009 to enable Tracey and Holly to fully engage with the newly diagnosed while I facilitated their PALS connections.

Since September of 2012, Jean Sobraske has been running the show as our Program Coordinator, and her compassion, energy, and hard work have made their mark throughout the Coalition, including the PALS Program. Jean’s is often the first voice that a newly diagnosed person will hear when calling the Coalition after receiving a diagnosis. Together, she and Holly gently steer them toward needed programs, including BC101 and PALS.

If you or anyone you know has been recently diagnosed with breast cancer, they can receive a world of information and support by turning to the Coalition. This includes one-to-one conversations with someone who’s “been there”, and a PALS pak full of comfort items.

Call 473-8177 if you are ever in need of any of our programs. We’re here for you.
Upcoming Events & Programs at the Coalition

Wednesday, December 4, 2013
Holiday Open House
4:00 - 6:00pm
RSVP: 585.473.8177 or jean@bccr.org

Wednesday, January 22, 2014
Lesley James, M.D.
Breast Cancer: Utilizing a Holistic Approach to Care
7:00 - 9:00pm

Wednesday, February 26, 2014
Alissa Huston, M.D. and Luke Peppone, Ph.D.
Vitamin D, Dietary Supplements and Breast Cancer
7:00 - 9:00pm

Find us on Facebook

All events unless otherwise noted are at:
THE BREAST CANCER COALITION OF ROCHESTER
840 University Avenue
(Between Culver and Goodman)
Questions? Contact the Coalition at (585) 473-8177

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Take Action!

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

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

Name ________________________________
Address ________________________________
City ___________________ State ______ Zip ______
Phone ________________________________
E-mail ________________________________

☐ I am a breast cancer survivor

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

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

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

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

OTHER:
☐ I am bi-lingual in ________________________________
☐ I am a deaf interpreter
☐ I am able to deliver newsletters (Quarterly)
I am available: ☐ Days ☐ Evenings ☐ Weekends

Gifts of $100 + receive a complimentary Comfort Heart.

☐ $5000 Founder’s Circle
☐ $1000 Visionary Circle
☐ $500 Advocate’s Circle
☐ $100 Pink Ribbon Circle
☐ $50 Friend’s Circle
☐ $25 Contributor’s Circle
☐ $ Other
☐ I am not able to make a donation at this time but would like to be on your mailing list.

I would like to make a gift of $ ____________
In ☐ Honor of ________________________________
☐ Memory of ________________________________

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

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Signature ________________________________
Name on Card ________________________________

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

Volunteer Information Form

Name ________________________________
Address ________________________________
Phone ________________________________ Work/Cell ________________________________
E-mail ________________________________

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

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☐ I am bi-lingual in ________________________________
☐ I am a deaf interpreter
☐ I am able to deliver newsletters (Quarterly)
I am available: ☐ Days ☐ Evenings ☐ Weekends

Other ways I would like to volunteer: ________________________________
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Breast Cancer Coalition of Rochester
840 University Avenue Rochester, NY 14607
585.473.8177 • 585.473.7689 fax
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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.

Subaru “Share the Love” Campaign

Van Bortel Subaru on Route 96 in Victor, NY has chosen the Breast Cancer Coalition of Rochester!

From November 21, 2013 to January 2, 2014, Subaru will donate $250 for every new Subaru vehicle sold or leased to the customer’s choice of six charities, including one local charity - the COALITION!

Thank you, Van Bortel, for supporting those in the greater Rochester area who have been affected by a breast cancer diagnosis. You are making a difference for many!