An ARTrageously Lovely Evening

The ballroom at the Crowne Plaza Hotel looked magical surrounded by tables carefully arranged with the more than 250 pieces of artwork donated to BCCR’s 2007 ARTrageous Affair. Pink balloons punctuated the air as they were quickly purchased by attendees and taken to their seats.

The largest item in the room, though, was the fiberglass horse entitled In Honor of Warrior Women painted by Holly Garver, BCCR resident artist and our newsletter editor. The horse was placed near the doors to the ballroom, waiting for his grand entrance at a special part of the live auction.

There was a wide array of quality artwork, carefully vetted by Kim Kircher and many volunteers and everything from pottery to fine art, jewelry to even a chandelier, graced the room.

The Silent Auction lasted until 8:30 when emcee Maureen McGuire, from WROC TV News 8, began the evening’s events.

Dr. Christopher Caldwell was this year’s honoree for the “ Advocate’s Spirit Award”. This recognition is given annually in honor of Harriet Susskind-Rosenblum, one of BCCR’s beloved founders, who died of her breast cancer in 2002. Harriet was a gifted poet and teacher and especially devoted to her family. Her daughters Andrea and Melinda presented the award.

Dr. Caldwell accepted the award with humility and grace. He is well known for his kind and personalized care of his patients.

Mike Deming took the stage after the award presentation to begin the Live Auction portion of the evening. “The Antique Guy”, as he is known from his stint on R News in Rochester, is the annual auctioneer for the BCCR galas. Mike enter-
Could there be anything more frightening than a diagnosis of cancer?

I was recently struck by a conversation I had with a woman who was newly diagnosed with breast cancer. She said, “Getting this diagnosis feels like I am being pushed up a mountain I don’t want to climb. I never asked to climb this mountain. I want off this mountain.”

Her comments resonated with me. People often refer to the great hardships and challenges in life using the mountain as a metaphor. I have used it myself because it’s an image that helps me remember to appreciate each step of a difficult journey. Having climbed a few mountains, I know that it matters which route you take… and it matters what tools you pack. It matters who you chose to climb with.

A diagnosis of breast cancer comes with many instructions. A map, if you will, that includes many different routes. Making decisions about the seemingly endless treatment choices can seem overwhelming. Which route is shortest? Which is easiest? Which will guarantee the outcome you desire? Which is best? Why won’t someone just tell you?

Whenever we launch out into the unknown, we can expect to experience a bit of uncertainty and anxiety. Even some measure of fear is normal. Fear of the unfamiliar. Fear of what is ahead. Fear of falling… of making the wrong decisions… of choosing the wrong path. Fear of the worst-case scenarios our imaginations can dream up. Just remember, though no one else can make our decisions for us, we don’t need to embark on this climb alone.

Here is a list of potential members for your very own climbing team: Your Family. Your Friends. Your Surgeon. Your Oncologist. Your Nurses. Your Social Worker. Your Nutritionist. Your Breast Cancer Sisters… us. Other reluctant mountain climbers who have also found ourselves on the edge of this same cliff. As one fellow traveler, one of our wise brown-baggers, put it, “all those cliffs just mean you’re closer to the top.”

Come join us here at the Coalition. Meet others who are on this journey. Hook up with a buddy. Recruit a couple of Sherpas. Lighten your load. Though it can be a tough climb, there really is beauty on the path.
2004

As BCCR continued to grow, program offerings began to expand in number as well as attendance. We hired a Program Coordinator to help our Executive Director manage the growing number of programs and participants. The Resource Room, funded by Jane Gordon’s magnificent “Bosom Buddies Cookbook,” moved out of the Great Meeting Room and into its own room, as we acquired more space in our 840 University Avenue home. Here, internet service was added, as well as an expansive offering of every book and periodical about breast cancer and other women’s cancers we could find.

Thanks to the generous support of M&T Bank, we were able to offer Advanced Breast Cancer: Tools for the Journey to breast cancer survivors who were receiving little attention in the mainstream media - those living with advanced, or metastatic, breast cancer. The seminar was presented in memory of M&T employee and BCCR participant, Cindy L. Dertinger, who died of breast cancer in March of 2003. This program, offered annually, was a milestone for the community as this was the first offering geared to women and men with advanced breast cancer, as well as family, friends and care providers. The seminar, followed by a reception, made networking a bit easier for those on a more strenuous journey. Other programs created for those living with advanced disease were BC.201, a one-to-one program offered to those with a diagnosis of advanced breast cancer, as well as a bi-monthly support group facilitated by Nancy Cooper, a licensed clinical psychologist and breast cancer survivor with professional expertise in working with people who are coping with life changing illnesses.

Though there were many wonderful fundraisers produced by a generous community, our own fundraising initiatives, the Pink Ribbon Run & Family Fitness Walk, Teed-off at Breast Cancer Golf Tournament, and Autumn Gala “ARTrageous Affair” continued to grow allowing us to increase programs even more, as well as award a $35,000 research grant.

Our legislative activities continued locally, as well as in Albany and Washington, DC.

2005

Our advocacy efforts were in full swing as we increased our efforts towards passage of the Neighbor Notification Bill through the Monroe County Legislature. We were ecstatic when County Executive Maggie Brooks announced support for this bill. The bill was passed in June of that year, demonstrating that both sides of the political aisle could work together towards the common good.

We were all very proud of our own Phyllis Connelly who was awarded a 2005 Women of Distinction Award in Albany. Nominated by Senator Nozzolio for her outstanding work in keeping legislators informed and accountable, Phyllis’ work has impacted BCCR and women throughout the state.

This year saw the launching of The Sister Sak Project, Gentle Yoga, Advanced Breast Cancer Tea, and the Young Survivor Soiree. All of these programs became regular offerings, proving to be popular beyond our expectations. Voices & Vision, our writing workshop, was taking shape as Cathy Salibian and Holly Anderson worked out funding possibilities.

Lives Touched, Lives Changed, a beautiful photographic calendar of children whose lives were touched by breast cancer, was the latest successful fundraiser on behalf of BCCR. The photographer, Jacqueline Freitas, was moved to do this project as a result of her own mother’s diagnosis.

We awarded our third research grant of $40,000.

2006

This year saw the launching of our Men’s Night, a support group for men whose wives, daughters, mothers, or friends had been diagnosed with breast cancer. Voices & Vision, finally funded, had sprouted wings and was...
tained the crowd as he auctioned off the Live Auction pieces, which included a beautifully painted cabinet by Kathy Kosel, hockey tickets donated by Amerks and Sabres for their games, a necklace designed with authentic fossils by Dr. Wende Logan Young and more.

Howie Jacobson then took the stage to complete the auction portion of the evening by auctioning donations for the Warrior horse. The enthusiasm was incredible! More than $15,000 was raised by this auction item that will benefit BCCR and keep the horse at BCCR's home. Call BCCR to find out how you can be a part of the Warrior Horse initiative.

Cindy Miller rounded out the evening to perfection by entertaining the ballroom with her beautiful voice and many talents as an actor and vocal impressionist.

BCCR wishes to thank our sponsors, beginning with our premier sponsor Excellus, our Gold sponsors, Silver sponsors, and Bronze sponsors (see the center pages for a listing of names). Also, the work of all the ARTrageous Affair committees that made this event possible is deeply appreciated.

Thank you to the many people who attended the 6th Annual ARTrageous Affair.

BCCR History - Conclusion

flying high. It continues to be one of our most popular offerings.

Our Advocacy Committee was very strong this year and sent many more people to the Advocacy Training Conference in Washington DC. Our priorities remain the same; an ongoing battle to ensure quality health care for all. We fight every year to get the DOD (Department of Defense) peer-reviewed Breast Cancer Research Program through Congress. See page 10 for more information.

All annual fundraisers rose to new heights, allowing a yearly increase in revenue for BCCR programs. We remain eternally grateful to three Chairs of our major fundraisers, Debra Bonsignore (Run/Walk), Sean Patton and Lee Cordero (Teed-off at Breast Cancer) for their dedication, commitment and perseverance. They have graciously continued in their roles every single year!

During this year, we awarded a $50,000 research grant to another deserving breast cancer scientist.

Whew! As you have read through these installments in the last four issues, BCCR has traveled far in the past ten years. We will continue our efforts to provide a warm, safe, welcoming, and FREE community to women, men and families coping with a breast cancer diagnosis. When the ever-elusive cure is discovered, only THEN will we close our doors and go home.

Correction: In our last issue, in our BCCR History article, we misstated the year that Harriet Susskind Rosenblum passed away. The correct year was 2002, not 2003. Our thanks to Mark Rosenblum for pointing this out.

Five Steps to Good Breast Cancer Care

1. Take Some Time

Most women don’t need to rush into treatment. By taking some time to learn about your breast cancer, you can make better choices. Ask your doctor if your decisions can wait a few weeks.

2. Learn About Your Cancer

Your treatment depends on your diagnosis (what kind of cancer you have). Ask your doctor or nurse: “What is my diagnosis?” “Are there any other names for it?” “What are all my treatment options?”

Try to get a second opinion on both your diagnosis and treatment options.

3. Ask Questions

Ask lots of questions. After all, it’s your breast cancer, your body, your life. It is often helpful to bring a friend or family member if you can. Before choosing a treatment, ask your doctor or nurse: “What is this treatment supposed to do?” “What is my risk of getting breast cancer again if I do have this treatment? What if I don’t?” “How likely am I to be alive in 5 or 10 years if I do have this treatment? What if I don’t?” “What are the risks of bad side effects? Will any side effects last the rest of my life?”

Continued on page 11
Carrie Dailor

I found out last October that I had breast cancer at the age of 35. One night while I was changing my clothes I found a lump the size of a gumball. For the next two days I questioned myself and went back and forth thinking it was nothing and then thinking, “I need to get this checked out.” The next day I made an appointment with my gynecologist. In the office he was able to do a fine-needle aspiration. If it drained fluid, it most likely was a benign cyst. Unfortunately, very little fluid came out.

He sent it to the lab and in the meantime he sent me that same day to get a breast ultrasound. Based on those images, I had a core-needle biopsy done the next day. By then, my results were in from the fine needle aspiration — it was cancer. I had just celebrated my 2-year wedding anniversary in September and was in my thirties; cancer was not part of the plan.

Within that week I decided to search for local help here in Rochester. I came across the bccr.org website and emailed the contact email address. Within an hour I received an email back from Holly Anderson. Her words were so empathetic and comforting. I set up a meeting with her later that week. Holly met with me for over an hour listening to me and offering such great direction, guidance and hope.

The months of treatments were long and difficult, but I was able to get through it all with the love and support of my husband, family and friends. My husband went to every appointment with me, made me laugh during the most difficult times and he always made sure we took a walk outside no matter how cold it was or how sick I felt. Through email, I was able to send weekly updates to my family, friends and co-workers. Being able to write about and share my experiences made me feel more connected with everyone that was there for me. What really kept my spirits up were the replies back with words of encouragement, thoughts and well wishes.

No one can explain how or why I got breast cancer. But during this time I met so many other young women facing the same disease. Before my diagnosis, I never met anyone with breast cancer at or near my age. I thought breast cancer was a death sentence. But, it clearly is not. The message is clear. The sooner it is found, the better your prognosis. It is so important to do monthly self-breast exams. Trust your body, listen to your gut and go to the doctor. If your doctor ignores the situation, go to another doctor. Get the answers you deserve.

It has been the toughest year of my life. I still haven’t been able to put it all in perspective. It all seems very surreal to me and I feel like time has been lost in space. But, I am grateful for finding out how strong our human spirit is and I feel so fortunate to have so many people that care for me in my life.

Lori Griffin

I knew I had breast cancer on Friday, February 3, 2006, after I had a mammogram, ultrasound and biopsy and the radiologist stated that she was very concerned. This was confirmed the following Monday. I was 31 years old at the time and I had a four-month-old son. I noticed the lump after breast feeding and thought it was just a plugged milk duct or some weird breast feeding thing. After letting it go for a couple of weeks to see if it would go away, I contacted my OB GYN and went in to see her. Thank God she sent me to the breast clinic and it was diagnosed early. My life from that moment was turned upside down. There have been countless doctor’s appointments and discussions about various treatments and even though I am a registered nurse, all of this oncology stuff was new to me.

During this experience I have been given so much support from family and friends. Because of their support, getting through this period in my life was as easy as it could be. I am so grateful for their love. I have also met many other breast cancer survivors through the Breast Cancer Coalition of Rochester. Recently I have
bonded with four young survivors and together we share similar issues, concerns, and information that is more pertinent to a younger generation dealing with this disease.

Today, after five months of chemotherapy, six weeks of radiation, two big surgeries and one year of a drug called Herceptin, I say that I am cancer free. I know that you can really never say that but I believe it and need to say it. Today I am back at work and enjoying the giggles and silliness that comes from my two-year old son.

It has been a long journey but I am grateful for the many great lessons that I have learned about love, family and friends.

Amy Weetman

During my visits to the BCCR and the online community at www.youngsurvival.org, I have met many young women who have been diagnosed with breast cancer. The Young Survival Coalition estimates that there are 250,000 women under forty living with breast cancer in the U.S. I was diagnosed at the age of 34, the mother of two young children and breastfeeding.

My journey began early one morning last October as I awoke with my finger resting on a pea-sized lump. I felt certain that I would have it checked out immediately, but not certain that it was cancer. Throughout the diagnostic phase, medical professionals felt that it was nothing, but a good idea to do the next test. After a core needle biopsy gave the diagnosis of ductal carcinoma in situ (DCIS), I had the then marble-sized lump removed in February with a nice clean margin. It was after this surgery that I learned there was a small invasive ductal carcinoma hidden inside a larger mass of DCIS.

Due to my age, more aggressive treatments were suggested by the many opinions I sought. After considering these opinions, reading many books and online resources and listening to my intuition, I started a twelve-week treatment of Taxol and Herceptin. While I continued Herceptin, I began second guessing the recommendation of radiation therapy. Once again it was a gut feeling that it was not right for me. Instead, on my 35th birthday this September, I chose a unilateral mastectomy with immediate reconstruction.

Throughout my journey I felt very much supported by my husband, family, and friends. It was hard sometimes to acknowledge that I needed to have someone else watch my children while I went out for chemo or another long doctor visit. When I was hospitalized for the mastectomy and reconstruction, I made lists and schedules of what everyone might need.

Being 34 and entering the cancer centers on a regular basis is a strange feeling. I often feel out of place. When speaking with medical receptionists I often hear, “You’re so young.” Filling out forms is actually quite simplistic, there are no other major health ailments to list, no other drugs taken. I felt I recovered from surgery quite easily as I am otherwise a healthy young woman. It is true that the majority of breast cancer patients are not in their thirties, but I am certainly not the only one. Unfortunately, there are many of us facing similar challenges having breast cancer at a young age.

Save the date to attend the annual Cindy L. Dertinger Seminar

**Tools for the Journey**

**Friday, April 4, 2008**

Memorial Art Gallery
500 University Avenue

Call the BCCR for more information 585-473-8177
Everyone is stunned when first diagnosed with breast cancer. I was probably more stunned than most. Being a 40 year-old male, breast cancer was somewhere behind being hit by an asteroid on my list of worries.

Early in August of 1996, I noticed a small lump under my left nipple. I wasn’t too concerned - I assumed it was a cyst or abscess that would go away in a week or two. Some three weeks later, I was driving home from work and felt some wetness on my chest. A quick peek inside my shirt revealed that blood was dripping from my nipple. My first reaction was not of worry, but of surprise that I had a working orifice there.

My second reaction was the gut feeling that the bleeding was related to the lump and that this was not good news. I made an appointment later that week with my family practitioner who said that, although rare, breast cancer does occur in men and that my symptoms merited further investigation. I saw a surgeon later that day and he did a needle biopsy that came back as being suspicious. That led to an excisional biopsy. The pathology report stated that it was malignant - an infiltrating ductal carcinoma - the most common form of breast cancer in both women and men.

In essence, breast cancer is the same disease in men and women. Diagnosis, staging, and treatment are all the same (with the exception that a modified radical mastectomy is the usual surgical intervention, since men have so little breast tissue). And, of course, the psychological issues are different. Losing a breast does not have the same significance for a man as for a woman. On the flip side, men are more likely to go around shirtless. (Over the past ten years I’ve gotten used to being the only single-nippled man at the beach.)

I had my modified radical mastectomy in late August. Sixteen lymph nodes were examined and one was positive for malignancy. The oncologist recommended six months of chemotherapy.

A person’s first round of chemotherapy is an anxiety-producing event of the highest order because you have no internal frame of reference as to what to expect. In my case, actually getting the chemo was rather anticlimactic. It took 30 minutes. They put on a band-aid and sent me home. Then it was the time to wait and see what would happen once the drugs kicked in. It’s an odd window of several hours in which you sit and prepare for bad things to happen. I cleaned my toilet - just in case. Fortunately, my side effects were relatively mild with fatigue being the primary problem. The new anti-nausea medications are wonderful. I never threw up once during all of chemo. Oddly, my dog puked that first night as I waited to be sick. Man’s most empathetic friend.

My lowest point was when I examined the survival statistics. I remember reading a table that provided five and ten-year survival rates for people with different stages of breast cancer. The five-year survival rate for persons with my stage of breast cancer was about 80 percent. Sobering, but reasonably good news. Then I saw the ten-year survival rate. It was closer to 60 percent. My first reaction was that must have been a misprint. It wasn’t. We’ve all heard that if you survive five years without a recurrence of cancer, you’re home free. But while the five-year benchmark is significant in some cancers, it’s no cause for relief in breast cancer because the cancer can occur in 10, 15, or 20 years down the line. For the first time, I realized that the five-year survival rates - often lauded in the popular media - weren’t synonymous with cure rates. Living five years doesn’t mean that I’ll live ten years. Shortly after being diagnosed, I opened a fortune cookie and read a message that said, “You have yet to live the best years of your life.” I’m still not sure if I should find that comforting or worrisome.

Whenever I tell someone that I have had breast cancer, there’s an inevitable pause. The news is so completely out of the blue that everyone’s initial reaction is stunned, open-mouthed, silence. I used to think that a person’s jaw dropping open was a figure of speech. I now know otherwise. Continued on next page
I became the first man to be a full-fledged member of the Ithaca Breast Cancer Alliance. Based on statistics, I’m probably not the only man in this area of New York with breast cancer, but men with breast cancer are not likely to wear pink ribbons or join support groups. It’s partly generational - most men with breast cancer are older and just aren’t prone to talk about such personal matters. It’s hard enough for men to discuss prostate cancer, let alone a female disease like breast cancer.

The Internet has been extremely helpful. Shortly after I was diagnosed, I logged on and searched for the keyword breasts. There were three categories of response: pornography, information about breast cancer, and an astounding number of chicken recipes. Eventually, I joined a Breast Cancer Listserv. For the first time, the notion of a virtual community was not an abstraction. I really do feel a sense of community by sharing with people who have been through the same journey. It’s a wonderful resource because it’s available 24 hours a day, which was especially useful when the chemo wreaked havoc with my sleep patterns.

A few weeks after my mastectomy, I went to a department store looking for a new navy blazer. But I was stumped when choosing between single-breast and double-breasted models. Whichever I chose would be making some sort of statement - perhaps the single-breasted would say that I’m proud of my single-breasted self or the double-breasted would say that I’m still the same, complete person. But chemobrain made my thinking fuzzy, so I bought a sweater to avoid making a statement that I might regret later.

There are certain indignities that happen to a man with breast cancer. I once went to the hospital for some lab work and the lab tech, noting the referral slip, asked, “Is this the correct diagnosis?” I suspect that she doesn’t ask that question to women with breast cancer. And I felt a little odd going to a women’s imaging center for a mammogram.

The radiology tech did note that I had the hairiest chest she’s ever seen in a mammogram room. I think that deserves some kind of award.

**Update: December 2006**

It’s hard to believe, but 20 percent of my life has now been lived after my cancer diagnosis. What I didn’t expect from cancer is a change of career, but that’s exactly what happened. I’m no longer just a member of the Ithaca Breast Cancer Alliance. Since 2000, I’ve served as the associate director. As far as I know, I’m the only male survivor of breast cancer to work for a breast cancer organization in the United States. While I have a special interest in male breast cancer, the vast majority of my work is with breast cancer more generically.

As often as possible, I attend national breast cancer meetings to be - quite literally - a face at the table. People routinely say, “I knew that men got breast cancer, but you’re the first man with breast cancer that I’ve actually met.” I love hearing that because male breast cancer tends to be an abstraction of people until they have a face to go with it.

In addition to my work at the Ithaca Breast Cancer Alliance, I assist men and women with all types of cancer at Cayuga Medical Center. Being a man with breast cancer puts me in a fairly unique position to connect with men with cancer (because I’m a guy), and with women with cancer (because I have what’s generally thought of as a women’s cancer).

I certainly didn’t grow up thinking that, “Someday I hope to work for a breast cancer support organization.” But I do. And I love it.

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**Are you on our mailing list?**

Is your e-mail address and/or phone number a part of your 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 Tracy Brown at Tracy@bccr.org.

Thanks!
Close the Door When You Leave

I never asked you to visit...at least I don’t believe I did
Maybe...I don’t know
it’s so confusing
At any rate, you’re a rude guest
You take away my energy, rob my sleep, and with a stick
You swirl and distort my dreams
All right; You are here - for now
But understand
There are two places that are forever off limits
You may not tread on my spirit
You may not occupy my soul
I have heard of your visits to others
I know the damage you leave in your path
The wanton disregard for innocence, value, and what some would call fairness
Also, I hear that laughter confuses you; that good foods make you feel bad, and
That nothing causes you more distress than an autumn sunset, the
forever blue of a summer sky,
Or the unconditional radiance of a child’s smile
Listen and understand
You might pilfer my closets, empty all the drawers, and trash my house
But there are two places forever off limits
You may not tread on my spirit
You may not occupy my soul
Do not mistake my nausea, weakness, and pain as signs of your victory
They are simply small dents in the armor I wear to fight you
Instead, look deeply into my eyes
They will once again remind you that there are two places forever off limits
You must not...
May not...
Will not tread on my spirit
You must not...
May not...
Will not occupy my soul

by Michael Hayes Samuelson, cancer survivor
Grassroots Advocates at the National Breast Cancer Coalition’s Annual Lobby Day in Washington, D.C.

The Difference a Countrywide Team Effort Can Make
by Phyllis Connelly

Treatment for my breast cancer was completed by the fall of 1999 and I was a fledgling member of BCCR. At the time I had minimal exposure to the political world (meaning I voted every November and most Primary Days).

One day in March of 2000, driven by curiosity, I went along with BCCR to Albany to participate in the New York State Breast Cancer Network (NYSBCN) Advocacy Day. My curiosity did not kill this cat, but it opened my eyes - wide. I found it intriguing enough to be drawn in May of that year, along with other BCCR members, to the National Breast Cancer Coalition’s (NBCC) four-day Advocacy Training Conference.

I defy anyone to walk into the conference’s hotel ballroom filled with over 600 women from every state of the Union (as well as other countries) and not have the hair on their arms stand up from the positive electricity in the air, to say nothing of the sensations created by walking the halls on Capitol Hill on the 4th Day to meet with our New York Legislators. This means constituents speaking out to their elected officials face-to-face and explaining how they feel about the NBCC’s priorities and why these issues are so important in our battle to eradicate breast cancer.

That conference did it! I was hooked. Many have told me, “Politics is about as exciting as watching paint dry.” Don’t you believe it! Irritatingly snail-like perhaps, but not dull. Plus, like it or not, I learned Breast Cancer is a political issue.

Priority #1 is a work in progress - Guaranteed Access to Quality Health Care for All.

NBCC has established eight principles (see www.stopbreastcancer.org - click on Advocacy in Action), that are being used as a guide to develop a comprehensive health care reform plan. This system must also reflect the following values: access, information, choice, respect, accountability, and improvement.

Priority #2 – The Department of Defense (DOD) Breast Cancer Research Program.

Every year, advocates from around the country work diligently and tirelessly, urging our Representatives and Senators to sign onto a letter supporting an appropriation for Breast Cancer Research for that fiscal year.

This program was created in 1992 as a result of NBCC’s $300 Million More campaign, which was designed to increase federal funding for breast cancer research at a time when very little money was going into breast cancer research.

Why under the DOD’s budget? This is an interesting story. NBCC worked with the Congressional leadership of Senators Tom Harkin and Alfonse D’Amato to gain support for a $210 million appropriation. But whose budget could accommodate that amount? No one came to mind except the DOD. At that period of time, the DOD had excess funds – and who better to fight a war? So the Army became the administrator. Each subsequent year, Congress has appropriated funding from the DOD budget as advocates work hard to ensure maintenance of the program’s integrity and that the funding remains separate from other programs.

Due to the war in Iraq, the funding the last two years was decreased to $127.5 million.

That second year, one of our Western New York (WNY) Representatives, Congressman James Walsh, was made Chair of a new Appropriations Sub-Committee that would be responsible for allocating this money. A couple of BCCR advocates met with him in his district office and learned that, although very sympathetic to the cause, he saw no way he could allocate this money from his budget. Millions of dollars for Breast Cancer research were in jeopardy for that fiscal year. In January 2007 we were back asking for $150 million for fiscal year 2008. The plot then thickened...

It was September 2007 in the Congressional calendar, and we were at a fork in the road. The Senate had okayed $150 million. The House had okayed $127.5 million. The final amount was soon to be determined by a Conference meeting.

To our absolute delight, all of our WNY Representatives, Republicans and Democrats alike, had signed...
a letter sent to the conferees asking that they accede to the Senate language. The signing closed and the letter received more signatures than ever before - close to 200. This was great progress!

**Excitement is in the air.** On November 9th we received great news. The Joint Appropriations Conferees approved $138 million in fiscal year 2008 funding for the Breast Cancer Research Program. This is $10.5 million more than last year. It is now awaiting presidential signature.

**Priority #3 Enactment of the Breast Cancer and Environmental Research Act**

This bill would create grants for the establishment of a research collaborative consortium, consisting of teams from many institutions and disciplines to study the potential link between the environment and breast cancer. Grants would be awarded once again, on a competitive, peer reviewed process that involves consumer advocates.

This bill was first introduced in the 106th Congress. By the end of 2000, it had 16 Senate co-sponsors and 98 House co-sponsors.

This year, the first session of the 110th Congress, it has close to 70 Senate co-sponsors and over 250 in the House.

**Priority #4 Preservation of the Medicaid Breast and Cervical Cancer Treatment Program**

This Act provides full Medicaid coverage to low-income, uninsured and under-insured women diagnosed with breast and/or cervical cancer through a federal program.

In 2000, after years of grassroots influence and the first year I was involved with the NBCC and its Legislative workings, President Clinton signed this bill into law. States have to match federal funds so all states had to opt in. Federal funds, as well as our New York State funds, appear intact for this program at this point... but we are ever vigilant.

If this article has convinced you of the effectiveness of a team consisting of many individuals who keep planting those seeds and has sufficiently piqued your interest in playing a role in this endeavor, you can help by joining our Action Alert Team. Your action is simple and quick. One short phone call to your Congressman’s office once or twice a year: What could be easier yet make such an important difference?

Please call BCCR at 473-8177 and ask how you can become part of this team or about joining our Advocacy Committee.

Or, perhaps you would like to know more about going to the April Advocacy Training Conference in DC this April. Please go to NBCC’s website: www.stopbreastcancer.org or call BCCR.

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**Five Steps to Good Breast Cancer Care, continued**

Find out how many new breast cancer patients your doctor treats each year. Studies show that the best patient outcomes result from doctors who treat at least 30 to 50 new breast cancer patients per year.

4. **Investigate Medical Evidence**

There isn’t a “one size fits all” treatment for breast cancer. Ask your doctor or nurse for evidence-based guidelines explaining which treatments are most likely to work. For more information you can trust, visit the National Breast Cancer Coalition website, www.stopbreastcancer.org to use our complete Guide to Quality Breast Cancer Care. You can also explore the National Cancer Institute site at www.cancer.gov. The guides are available at BCCR. Please call 585-473-8177.

5. **Get Support**

You may be able to get help dealing with your feelings, getting to and from the doctor, paying the bills, taking care of your family and/or solving problems with your treatment or insurance. Ask your doctors, nurses or social workers for local resources.

This article is courtesy of the National Breast Cancer Coalition Fund.

Continued on next page
**Our Fundraising Friends...**

**Big Oak Golf Tournament Donates to BCCR ...**

More than one hundred people enrolled in the Big Oak Golf Tournament on September 22nd, almost all having a connection to someone with breast cancer. Several survivors were present, including a man and the wife of Big Oak’s golf professional, a three-year survivor of breast cancer.

The day’s tournament was punctuated by lunch in mid-day and then a sumptuous clambake dinner after the day’s golf.

More than $8,000 in prizes were won during the tournament and at days’ end, $2,100 was donated to BCCR. Thank you Big Oak golfers!

**Summer Sales Benefit BCCR**

A group of Calkins Road Middle Schoolers put their heads together this summer to raise money at a streetside stand and donate the money to BCCR. Eve Bobrow, Lilli Biltucci, Shannon Peartree, Meredith Glenning, Olivia Marsh, and Julia Blanding named their stand “Treats Trinkets and Garden” for all the crafts, flowers, baked goods and produce they offered and opened for business each Thursday and Sunday of the week.

At summer’s end, they had raised $340, which they donated to the Breast Cancer Coalition in memory of Eve Bobrow’s grandmother, who died from breast cancer.

Our deepest thanks to all the girls for their hard work and generous hearts!
Red Hat Society raises funds for BCCR

On Wednesday, October 10th, members of the Red Hat Society of the greater Finger Lakes area assembled to go on a railway tour between Geneva and Shortsville. The fall foliage was enjoyed by all during the tour, as was the lunch in Shortsville. One of the purposes of the trip, other than enjoying an outing together, was to call attention to Breast Cancer Awareness month. Each participant received a mint wrapped in pink paper reminding them to get their mammograms. In each of the four rail cars filled with Red Hat Society women, BCCR brochures were distributed, all were encouraged to support BCCR and donations were collected. At the end of their railway adventure, the Red Hat Society ladies collected $446 for BCCR!

We extend our deepest thanks to everyone who donated to BCCR and congratulate them on what sounds like a great day out!

Annual Ride for a Cure Donates to BCCR ...

Deanna Amer Haller died from complications of breast cancer on August 12, 2006. The motorcycling community immediately took up arms against the monster breast cancer not only by participating in the Deanna’s Memorial Ride but also by ensuring that future rides would be led by Deanna’s husband, Mike Haller. The first ride in 2006 had Mike participating as a passenger. On August 25, 2007 Mike led the ride.

Every dealership in the area gave something to outfit Mike with the proper motorcycle gear. A long sitting 1992 Kawasaki Vulcan cruiser was dusted off and donated to Mike. Kawasaki Motor Corp-USA contributed $1600 to rehabilitate the bike and Soper’s Powersports in Farmington donated all of the labor to bring the Vulcan back to brand new condition. The Women’s Motorcyclist Foundation donated a scholarship for Mike’s motorcycle rider training through Learn2Ride, Inc. And, finally as in 2006, Country Rode Motowerks, 286 Macedon Center Road, hosted the riders at their dealership with a pizza party and provided some fantastic raffle prizes at the close of the ride too.

Thus far the Deanna Memorial Rides have raised over $5000.00 for the Breast Cancer Coalition of Rochester. Next year’s ride is scheduled for Saturday September 20, 2008. The Women’s Motorcyclist Foundation, organizers of the ride, hope to establish the third Saturday in September as its annual date for this yearly fund raising event. To find out more about the Women’s Motorcyclist Foundation and their efforts to eradicate breast cancer, go to:

www.womensmotorcyclistfoundation.org or e-mail: wmfginsue@aol.com
It was ARTrageous!

Dr. Christopher Caldwell receiving the 2007 Advocate's Spirit Award

Cindy Miller provided excellent entertainment after dinner

The Gala's Emcee Maureen McGuire

Artist Dorothea Hillis

Horse sponsor and special horse auctioneer Howie Jacobson

Artists Dorothea Hillis, Kim Kircher and BCCR Yoga Instructor Susan Meynadasy

Maria Cook and Sandy Monahan shopping the jewelry table

Jim Redmond of Excellus

Sylvia Cappellino, BCCR Founder
Trageous!

Our deepest thanks to our generous sponsors:

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Pat Rechlin, One of One Artworks, Inc.
Pluta Cancer Center
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Highland Hospital
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Rochester Institute of Technology

Silver Sponsors
Dr. Christopher Caldwell and son Ethan
Dr. Alissa Huston
Artists John and Carol Engle

Bronze Sponsors
Some of the Martino Flynn group!

ARtrageous Affair photographs courtesy of Cynthia Fay
Thank you, Cynthia, for your exceptional photos!
Full sponsorship listing on page 24
Our Programs at the Breast Cancer Coalition of Rochester

**Brown Bag Fridays**

At the Breast Cancer Coalition! Any given Friday at noon finds a group of women conversing over whatever they brought to eat and a delectable dessert provided by BCCR. This is a non-traditional support group, which is exactly what many of us have been looking for. Brown Bag is a drop-in program. There is no need to call ahead. However if you would like more information, please call (585) 473-8177.

**Gentle Yoga**

On Monday evenings, you can find women stretched out on BCCR's floor doing Gentle Yoga taught by Susan Meynadasy, a certified yoga instructor. Yoga sessions began in Spring 2005 and have been in high demand ever since. New sessions begin every six weeks. The class starts at 6:30 p.m. and finishes at 7:45 p.m. The class is limited to 15 breast cancer survivors.

Please call (585) 473-1877 to sign up for the next session.

**BC 101**

This program provides information and support to those who are coping with a breast cancer diagnosis. The goals of the program are to assist participants in managing the complex tasks and emotions of a breast cancer diagnosis and to empower women to be their own self-advocates as they proceed through treatment, recovery and survivorship. Our professional facilitators are eager to provide a safe, comfortable atmosphere where information can be absorbed and assimilated, while formulating a strategy for coping with each individual’s breast cancer experience.

Please call (585) 473-8177 for a time that is convenient for you.

**BC 201**

Modeled after Breast Cancer 101, these are one-on-one sessions for those who have been rediagnosed with breast cancer. New issues arising about diagnosis of breast cancer are dealt with on the same one-to-one basis as in BC 101. Maintaining a nurturing and supportive environment while providing a sounding board for treatment modalities and other issues is all part of BC 201.

Please call 585-473-8177 for more information.

**The Sister Sak Project**

The Sister Sak Project, spearheaded by Megan Dombroski, was started by a group of young survivors who wanted to be able to help someone else in their journey with breast cancer. This project provides young women diagnosed with breast cancer a network of support dedicated to their unique concerns. The Sister Sak is a gift bag filled with comfort items, delivered by a young survivor who recently experienced similar challenges.

Please call for a referral and Sak of your own!
Living with Metastatic Breast Cancer Support Group

The Living with Metastatic Breast Cancer Support Group is designed to lend support to those who are coping with a diagnosis of advanced breast cancer. The group is led by a psychologist, Dr. Nancy Cooper, who is a breast cancer survivor as well. The group meets Thursday mornings twice a month at the BCCR office.

Please call (585) 473-8177 for more information about joining!

Breast Cancer Coalition of Rochester Support Group

The Breast Center support group meets at BCCR’s center at 840 University Avenue. Join with others who live with breast cancer each day, share your experiences and lend your support. We meet every third Tuesday at 7pm.

Please call for more information: (585) 473-8177.

Young Survivor Networking Group

After months of planning, the Young Survivors Networking Group is a reality! Co-facilitated by Miriam Iker, a clinical psychologist who specializes in children, adolescents and adult women and Amy Weetman, a young survivor specializing in peer support. Together they address issues including the impact of breast cancer on families and children. The Young Survivors Networking Group meets on the third Thursdays at Noon of every month.

Please call (585) 473-8177 with any questions or for more information.

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

Peer advocacy is at the core of the philosophy behind the Breast Cancer Coalition of Rochester. Women supporting women, partners supporting partners, families supporting families, all are central to this organization that is unique to the western New York region. Breast cancer survivors reach out to those who are new to the disease and also to their significant others, helping them connect to resources in the community, providing a foundation of caring and working hard to instill confidence and comfort in the face of a difficult time.

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

This exciting program gives people with breast cancer an opportunity to explore and express their feelings through writing. Meeting weekly, this warm and supportive group is led by Cathy Salibian, a survivor/writer. Not only has writing proven to be very therapeutic for breast cancer survivors, but this program is getting rave reviews! Register by calling BCCR.

Please call 585-473-8177 for information on upcoming seminars!

Men’s Night

Facilitated by Jay Nittoli, MSW, this group is for men whose wives, daughters, mothers or significant others have been affected by breast cancer. It meets on the 4th Thursday of every month from 7 to 9pm at the BCCR Center, 840 University Avenue, Rochester, NY 14607.

Please call (585) 473-8177 for more information and to register!
What a perfect evening for a candlelit walk to honor those whose lives have been touched by breast cancer! On October 24th, we had a full moon in the sky with sparse clouds, a slight breeze blowing, and more than 50 Breast Cancer Coalition members participating in this annual ceremony. The night continued at 840 University with enchanting music by Lisa Winter, interspersed with moving readings by volunteers, and reflections by Sue Staropoli. It was truly a celebration of lives! We wrapped up with cookies, fry cakes and hot mulled cider. Attendees were able to mingle, catch up, and relax. All in all, it was a beautiful evening for the Lives Touched...Lives Celebrated program. We hope to see all of you and more next year!! 🕉️

Lives Touched...Lives Celebrated

Cinnamon Bay

I felt the cool shade of a palm branch that pierced the scorching sand under my feet.

The sky was a blanket of bright orange and cranberry hues. It seemed too warm to be sunset.

The edge of the beach was wet and jagged from each touch of the ocean. Each wave brought a soft foamy kiss to wear away the sand and uncover its pebbles and shells.

As the trade winds exchange the smell of blossoms and salty breezes. I'm drifting off to sleep now.

Please don’t wake me.

It’s so lovely here.

Sally Majors, 2006

This beautiful poem, written by Sally Majors, who died of her breast cancer at age 35 on June 26, 2007, was a talented and prolific writer. She is survived by her husband Alan, three sons, Damani, Jordan, Bryce and a stepson Alan Jr.
Friends Remembered ...

Catherine Anderson  
Beryl DiLella  
Ted Fitch  
Jackie Giunta  
Kathy Hahn  
Sally Kay Majors  
Grace Reichardt  
Patricia Sofia

Tributes Welcomed

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

Please send your submission with a digital photograph to Holly Garver, BCCR Voices of the Ribbon Newsletter Editor, at hbg@bccc.org.

We look forward to hearing from you! 🌹
"Meet our Board of Directors..."Why am I involved?"

President, Holly Anderson
The BCCR members and volunteers give the words “passion” and “fulfillment” new meaning. Being involved with a group of people so committed to the importance of what they are doing, and to the people with whom and for whom they are doing it, is an absolute pleasure.

Chair, Joyce Wichie
My motivation to be on the Board of the Breast Cancer Coalition of Rochester is the people, the passion and the cause.

Past Chair, Phyllis Connelly
I wanted to be a part of this war on Breast Cancer. BCCR is meeting its challenges head on with incredible successes. I consider it a jewel in the world of community-based organizations.

Vice Chair, Lila Bluestone
I am honored to be a part of this outstanding group of women and men who share so many of my values about the awesome opportunities life provides for us. I profoundly appreciate the support I receive at BCCR.

Secretary, Rhonda St. Amant
I have been searching for a place to volunteer that had meaning to my life. As a breast cancer survivor, the care and support of women with breast cancer means a lot to me.

Treasurer, Paula Martin
My involvement with the Breast Cancer Coalition of Rochester is in honor and memory of my mother, who lost her battle with breast cancer. It is my privilege to serve on the Board of Directors.

Advocacy, Melisande Bianchi
My goals are very basic: I want to be there for whoever needs my support. If I can take away some of the fear and comfort people in their time of need, I feel I am giving back what I received from so many of the wonderful women at BCCR.

Programs, Pat Battaglia
I was diagnosed in 2004 and the midwife who delivered four of my five children referred me to BCCR. I felt an immediate affinity for the women I met at BCCR and to all the organization stands for. It’s an honor to be able to give back to the group which has given me so much.

At Large, Jean LaZeroff
A retired teacher, I turned to BCCR in 2003 after my diagnosis. Now, I want to continue my association with BCCR and somehow give back to the organization and other women who are dealing with a breast cancer diagnosis. In addition to serving on the Board of Directors, I am a member of the Advocacy Committee.

At Large, Anne DaSilva Tella
A two-time survivor for whom BCCR was very welcome, I am returning the favor by serving all who need or will benefit from support, advocacy, research and education on breast cancer. It is an honor for me to do this.

Young Survivors, Eileen McConville
Diagnosed at age 30, I’m very interested in issues that impact young survivors and wanted to help build a network for them. I hope to be able to bring young survivors in the greater Rochester area together the help BCCR with workshops and services that of their particular interest.

Chair Emeritus, Sylvia Cappellino
My motivation for starting BCCR in 1997 was to help women with breast cancer by creating a sisterhood of strong women who would be a viable entity in our community through support, education, advocacy and research.
Interested in attending the next Advocacy Training Conference in Washington DC?

The 2008 Conference will take place at the Renaissance Washington DC Hotel, located at 999 9th Street NW, Washington, DC 20001

April 26 - 29, 2008

Find more information on the conference at:

www.stopbreastcancer.org

Eat Well, Live Well Group Tours Mt. Hope Cemetery

As part of the Eat Well, Live Well initiative, BCCR member Alison Currie organized a group to take a walking tour of Rochester’s famous Mt. Hope Cemetery as one of their walks. This walk, which took place on October 27th, was about two miles long and gave them a chance to exercise in the fresh air while they learned about the many permanent residents of Mt. Hope from their tour guide, T. Emil Homerin, PhD, professor of Religion, Islamic and Arabic Studies at the University of Rochester.

Dr. Homerin explained the many different symbols found on gravestones such as sheaves of wheat, anchor, etc., and the myriad architectural styles of stones and mausoleums. He also gave them a brief history of Mt. Hope Cemetery, the first Victorian municipal cemetery in the US. The lovely fall foliage made the tour all the more enjoyable.

The challenge of the Eat Well, Live Well campaign formulated by Wegman’s supermarkets, is to build up to 10,000 steps a day, as measured on a pedometer, and eat five servings of fruits and vegetables daily for optimal health. BCCR’s team’s name is We’re All One Team. The group is competing with other teams in the community and tracks its statistics online. Team Leader Alison Currie helps everyone stay on course and arranges interesting hikes that are fun, energizing and good for everyone.

The group of walkers - Back, left to right: Marianne Sargent, Linda Campaigne, Joanne McFadden, Alison Currie, and Mary Gross Front: Emil Homerin, PhD and Phyllis Connelly
Sorority Sisters filling a need...

What does a small organization like BCCR do when they need 1500 pink paper ribbons cut out? They call on the community to help and, in this case, we were rescued by a great group of sorority sisters!

These dynamic young women from Nazareth College, University of Rochester and Rochester Institute of Technology have saved the day on several occasions, including helping staff BCCR’s Park Avenue Festival booth.

They represent the Rochester Chapter of Sigma Lambda Upsilon/Señoritas Latinas Unidas Sorority, Inc.

Chance Meeting

Here we are...two breast cancer support groups...new to one another
Mixed purposes...mixed generations...mixed emotions
Graciously, Claire invites our writing group in
Tentatively we enter, smile, and say “hello”.

Then greetings all too familiar:
My name is Deborah; I’m a five year survivor
My name is Janet; I’m still in treatment
My name is Kelli; I am a Stage 4 survivor
My name is Loretta; I’m a nine year survivor
...and my daughter is a 3 year survivor.

Common names...uncommon women
Too common a disease...to share...to overcome
Losses to mourn; survivals to celebrate.

Tonight we remember and celebrate as the beautiful strains of
an accomplished cellist fill the room
Sad strains in remembrance; vibrant, colorful notes of celebration

Yet another serendipitous moment in life that we would not have experienced... but for our breast cancers
A young woman...without cancer...meaningfully shares our
joys and sorrows in her extraordinary music
How wonderful that this has happened on an ordinary summer evening in July.

Sharon O. VanMeenen
Voices and Vision
July 10, 2007

BCCR extends its apologies to Sharon for omitting a line in the fifth stanza of her poem last issue. We are reprinting her poem, in its entirety, and celebrate its beauty. Thank you Sharon!
Donations from July 1, 2007 to September 30, 2007
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.

In Honor Of:

Holly Anderson
Maura Steed

Karen & Stuart Blume’s 30th Anniversary
Paula Ressler & Robert Corwin

Lee Cordero
Dan & Marilyn Uttaro

Alison Currie
Holly Anderson

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Women’s Motorcyclist Foundation, Inc.

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Breast Cancer Coalition of Rochester
January - March 2008 Seminars

Wednesday, January 23, 2008
*Integrative Healing Using Eastern and Western Modalities,* presented by Marilyn Ling, MD

Wednesday, February 27, 2008
*Oh No...Can It Get Any Worse? Dealing with Legal Issues when Facing Breast Cancer,* presented by Patricia Rzepka, Chief of Staff, Susan John, 131st District Assemblyperson, Rebecca Russo, Esq. of Monroe County Legal Assistance and Susan Vetter, S.W. of the Pluta Cancer Center

Wednesday, March 26, 2008
*Breast Cancer Surgery: Understanding Sentinel Node Biopsy,* presented by Christopher Caldwell, MD

All seminars are from 7 to 9 pm at:
BREAST CANCER COALITION OF ROCHESTER
840 University Avenue
(Between Culver and Goodman)

Questions? Contact the BCCR at 473-8177

Also, save the Date for:

**Advanced Breast Cancer: Tools for the Journey**

**Friday, April 4, 2008**
Our larger pin, above, is in color on wood and measures 2 inches square. The smaller pin, shown below, measures 1 1/2 inches square and is also in color on wood.

Both pins are designed and handmade by artist LisaBeth Weber and available only at the Breast Cancer Coalition!

Stop by at 840 University Avenue in Rochester or call us at 585-473-8177 for more information or to order one or more! We do accept Paypal as well as most major credit cards. 🍀

Take Action!

Become a Supporter of the Breast Cancer Coalition of Rochester by making a donation 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, support and research.

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City State Zip
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☐ $1000 Visionary Circle
☐ $500 Advocate’s Circle
☐ $100 Pink Ribbon Circle
☐ $50 Friend’s Circle
☐ $25 Contributor’s Circle
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Remember the BCCR Library:

Browse, Borrow, Read!

Gifts of $100 or more receive a free Comfort Heart.

Breast Cancer Coalition of Rochester
840 University Avenue
Rochester, New York 14607
Tuesday, November 13th was a special day at the Breast Cancer Coalition. Presented by representatives of the Monroe County Legislature, a proclamation honoring the Breast Cancer Coalition’s 10th anniversary this year was received by BCCR. The group in the photo above includes, L. to R., Monroe County Legislator Carrie Andrews, Melisande Bianchi, Rebecca Solomon, Phyllis Connelly and Monroe County Legislator Mary Valerio.