The BCCR Advocacy Committee made their annual trek to Washington DC for the National Breast Cancer Coalition (NBCC) Conference that ran from April 28 to May 1st. The conference, titled *Revolution is Not a One Time Event* was held at the Hyatt Crystal City in Arlington, VA, with many plenary sessions focused on breast cancer advocacy issues for the attendees.

An Advocacy Day with Congressional visits was also part of the conference and allowed the participants to visit individual lawmakers and discuss breast cancer advocacy issues.

Every year, the NBCC sets priorities. For the 2007-2008 year, the legislative priorities are: 1. Guaranteed access to quality health care for all, 2. $150 million in fiscal year 2008 for the Department of Defense Breast Cancer Research Program. 3. Enactment of the Breast Cancer and Environmental Research Act and, 4. Preservation of the Medicaid Breast and Cervical Cancer Treatment Program.

**Priority 1:** Guaranteed access to quality health care for all has been a top priority for NBCC since its inception in 1991. This would ensure that everyone, regardless of their ability to pay, would have access to all the health care choices that are available in the US, thereby making the goal of eradication of breast cancer more attainable. This initiative also includes Accountability and Improvement on the part of the health care system, so that their standards remain high and consistent. The NBCC also feels that full access is inclusive of choice, so that anyone receiving health care has some choice of doctors and their care. NBCC wants to move from incremental changes to health care policy to guaranteed coverage of all individuals in a cost-effective manner.

**Priority 2:** $150 million for the Department of Defense Breast Cancer Research Program. This Program was developed in 1992 and was designed to...
If it is spring and the lovely lilacs are blooming, then rest assured the breast cancer survivor advocates are out in full force! The months of March, April and May are always bursting at the seams with activity related to advocacy, which is why this newsletter is going out a bit later than usual.

March and April saw us hustling from New York State Assembly(wo)men and Senators’ Albany and home offices, checking in with them and sharing concerns about environment and access to care issues (see page 9). Also in March, we hosted the 4th Annual Terri Schmitt Legislative Reception. Though the former Rush Town Supervisor and a former BCCR leader, Terri Schmitt, may be gone... she is far from forgotten (see page 14) By hosting this reception, we bring elected officials together with their constituents so they can talk about the things that matter deeply to them during and following their breast cancer experience. I am embarrassed to admit that I was not sure who my elected officials were, or even which district I lived in, until I was diagnosed with breast cancer eight years ago. I learned from Terri Schmitt and Phyllis Connelly, another BCCR Leader, that breast cancer is very much a political issue... and that one person, indeed, can make a difference!

April and May saw us off to Washington D.C. for four days of intense learning about new and emerging breast cancer therapies, rising healthcare costs, loss of funding for general cancer research, concerns about environmental exposures and timeliness of these exposures, media influence, and how breast cancer advocates can help to change the current paradigm. Our days began at 6:00 a.m. and ended at 10:00 p.m. and our minds were spinning furiously with all we were asked to absorb. Was it meaningful? You bet! Was it exhausting? You bet! Would each of us do it again? You bet! The end of each day would find the BCCR delegation together wherever we could find the room for discussion and examination of all we were learning. We also began to question how we have been influenced to think about these matters. We were challenged to examine each of the issues from an evidence-based perspective. Though a new diagnostic test is touted as the answer, what are the answers really? What are the questions even... and who decides? Though a new therapy may seem
Letters to Elizabeth Edwards ...

Elizabeth Edwards’ recent announcement that her breast cancer had metastasized naturally hit home with everyone at BCCR. In one of our most popular programs, Voices and Vision, the writing participants decided to write letters to Mrs. Edwards. They wanted to share a few with our readers...

Dear Elizabeth Edwards,

When I received my own diagnosis of breast cancer three years ago, it was devastating. I cannot imagine what the diagnosis of metastasis feels like. Yet not only have you experienced this second round of bad news, you have done it in a very public manner. I applaud the grace you have shown under intense media scrutiny, and the life-affirming spirit that is so clearly evident in the decision you and your husband have made to continue with his presidential campaign. You are an inspiration to countless women who face breast cancer diagnoses, as well as their families, caregivers, and advocates.

A diagnosis of cancer, or any other life-threatening disease, is a reminder of our mortality, and facing that is the most intensely personal thing anyone can do. My wish for you is that despite your very public life, you will have the space you need to nurture true inner peace. Take the time to cry when you need to, laugh when you need to, listen to life with your heart and to find the place in your soul that will carry you forward.

In the months and years to come, as you face whatever lies in your path, may you and your family be blessed with many happy moments. They will happen, as surely as springtime follows winter. As we move ever closer to a cure for this disease, look into the eyes of your loved ones, as well as within your own heart, and see the reason we go through all of this. The love you see makes it all worth doing.

Although there are far too many of us who have heard the awful words, “You have breast cancer,” we are all in this together.

My sincere best wishes to you and your family,
Pat Battaglia

Dear Elizabeth,

When I heard I had cancer again, it felt worse than being told the first time! I can just imagine what you’re going through after discovering your cancer has returned. It opens up a hole in your brain that you just can’t explain, and you begin to wonder what’s going on inside, how many times will I hear this, and so on.

All I can say is to continue what you said you’re doing when you were interviewed on several talk shows. You take each day as it comes; you listen to your doctors, and do exactly what’s in your heart. Do not listen to the nay-sayers. Not even your husband can tell you what to decide for your body and what your comfort level will or should be.

It’s wonderful that you are showing the world that life goes on - still campaigning, traveling, and just being with your family. That is your number one goal. After all, none of us knows the hour or the day. You are a great example to the rest of us who are experiencing the same diagnosis that was handed to you.

Be well, pray, and know that so many are praying for you and your family. God has His plan for you, and you are the “star” in that plan. Feel His arms around you and know that He will guide you through the next months with His love.

Fondly, from another “second-hit” survivor,
Betty Miller
Dear Mrs. Edwards,

Congratulations, you’ve got the “good” kind of metastases. That’s how my doctors referred to my situation. I was 35 years old and I was going to continue to live a productive life because the cancer had not caused any organ failure – it was “only” in my bones.

Either way, it’s considered stage 4, and since there are only 4 stages in the procedure of diagnosing where cancer is and how it has spread, you and I have both reached the final stage. Hooray for us?? I’m not sure I feel like celebrating. Cancer has already taken my breasts, my hair, my ability to have children, and God knows a hearty chunk of my self-esteem. However, there remains within me this strong, tiny voice that says, “Go on.” And so I do. I keep working at my job where I am a pediatric occupational therapist, because I know I am good at what I do and I need to see my little ones’ smiling faces every day. I have to work. There’s not a single person in this world who can talk me out of what I feel is important at this stage (no pun intended) in my life. I saw your interview with Katie Couric and despite my being appalled at some of the questions she threw your way, I was cheering inside at the incredulous looks you gave her. Of course you would keep living! Of course you would go on! Of course you were considering your quality of life! For lack of a better descriptor, “Duhhh!”

I am so proud of you for emphasizing that stage 4 doesn’t mean you exit the stage. You stay right on the stage and keep up with your life’s performance. Sometimes you follow the lines you’ve been given, and sometimes you give your audience a hearty dose of improv. Thank you so much for communicating this to the American public. We can do this together!

Sincerely,
Kelli Schwert

Annual Cindy Dertinger Seminar Well Attended

The Memorial Art Gallery’s M&T Ballroom was the setting for our 2007 Advanced Breast Cancer: Tools for the Journey seminar on April 20th. This annual event, funded by M&T Bank, is in memory of Cindy L. Dertinger, an employee who died of breast cancer in 2003. This seminar invites collaboration with other cancer organizations and treatment centers serving the central and western New York region.

The panel consisted of four physicians whose practices are deeply involved with breast cancer as well as three breast cancer survivors. Dr. Marguerite Dynski, SSJ, a surgeon and a breast cancer survivor served as panel moderator. Dr. Alissa Huston, a medical oncologist with the Comprehensive Breast Cancer Program at the James P. Wilmot Cancer Center, presented Using All Your Tools: Navigating Through the Maze of Medical Treatments, a discussion of the many treatments now or soon to be available for breast cancer. Dr. Karin Weichman, a medical oncologist at the Lipson Cancer Center at Rochester General, presented Management of Symptoms and Side Effects of Breast Cancer Therapy, offering information about the myriad side effects of breast cancer treatments. The third physician was Dr. Marilyn Ling, a radiation oncologist with the James P. Wilmot Cancer Center. Dr. Ling’s presentation, Chasing Life: What’s on the Radiation Menu, discussed the radiological approaches to breast cancer treatment along with many different therapies to enhance one’s quality of life, such as meditation, prayer or yoga.

Interspersed with physician presentations were presentations from three cancer survivors, Laurie Pask, Arlyn Grossman and Lisa Kubby. They gave a personal perspective that brought the more clinical discussion to life. The story of their journeys through breast cancer inspired all, as clearly demonstrated by the comments on the seminar evaluations.

The audience of nearly 170 people had an opportunity to question the panel after their presentations and many interesting topics arose from these questions, which were answered by the panel.

A reception was held following the seminar that gave more time for the audience to chat with the panel and each other about the day’s information. Cindy Dertinger always included a party with every event she planned and she would have loved this occasion.

The BCCR extends its thanks to M&T Bank, our community partners, participants and audience members who contributed to this richly informative event.
BCCR History, Part II
A New Millenium by Sylvia Cappellino, Chair Emeritus

2000

Under the leadership of Judith Waldert, BCCR was growing and the need for an office became very apparent. We were using temporary secretarial services along with our members’ aid. A blessing happened in that Sandra Maggio Monahan from American Express offered to complete her sabbatical for three months as an Interim Director and to help us set up an office and long-term goals. Sandy blended her business experience with the needs of the organization, helped us find an office and form new alliances with businesses and individuals to grow BCCR. One of her most innovative contributions was to identify a unique, special fundraising opportunity to sell Comfort Hearts, an idea that originated in Canada. For every heart sold for $10.00 we made $6.00 for our breast cancer research fund. Sandy stayed on and helped us way past her sabbatical and provided us with a real “jump start”.

A meeting with Senator James S. Alesi to express our need for money to open a permanent office and hire an Executive Director was very positive. Later that year a grant for $20,000 was secured and Sandy found our first office at her cousin John Maggio’s accounting office at 200 Park Avenue. On June 8, 2000 our Grand Opening was held: a dream came true and Senator Alesi cut the Pink Ribbon. The Shirley Falvo Resource Room was also dedicated at this time. This was a milestone and now we could begin the search for an Executive Director after Sandy left in July.

2001

Our first Executive Director was Debra Walker, who was very instrumental in setting up our new office and coordinating all the activities within the membership, including selling of the Comfort Hearts and participating in many local health fairs and events. We sent three members to the NBCC Advocacy Training Conference in Washington D.C. Our Advocacy Committee was very active in educating our members and the community about the newly passed state law “Neighbor Notification Bill”. We worked with other environmental groups in the community educating and advocating passage of the law in Monroe County.

In the summer of 2001 a new Board of Directors was selected for 2001-2002. Holly Anderson became the new Chair, Jackie Buck, Vice Chair, Judie Waldert, Treasurer, Debbie Valentine, Secretary, Kathy Clark and Terri Schmitt, Past Chairs, Phyllis Connelly, Advocacy Chair, Greg Eisenbach, Development Chair, Karen Goodkin, Research Chair, Judythe Roth, Outreach Chair, and three Directors-at-large: Sylvia Cappellino, Dino Infantino and Harriet Suskind Rosenblum.

Our Race now became the 5K Carnation Race and was growing in size and revenue. Our Comfort Hearts were being sold in many local stores and venues. A new initiative was in place, again thanks to Sandy Maggio Monahan. “Knitting for a Cure” was launched and was also profiled in a national knitting magazine, reaching out across the nation and in foreign countries. People were knitting scarves and sending them to BCCR for us to sell at 100% profit. We received an $11,000 grant from the Rochester Area Community Foundation for continuing on the next page
ued education in advocacy. Our advocacy work continued both in Albany and Washington, working on legislation that would assist women facing serious health issues. Our educational programs expanded to eleven this year and our Research Committee formed clear objectives. Our website continued to improve with www.bccr.org as our valid website name.

In August we said goodbye to Debra Walker, our first Executive Director who did a great job getting us started and managing our new office. Under the leadership of Holly Anderson, Chair and Executive Director, who began in October 2001, the Breast Cancer Coalition of Rochester turned a new page.

“BCCR History, Part II, continued”

BCCR History, Part II, continued

increase federal funding for breast cancer research. In 1993, the fund was appropriated $210 million, followed by $150 million from 2002 to 2005. Then, in 2006 and 2007, the fund was only appropriated $127.5 million for research. NBCC would like this bipartisan fund to be back at the previous amount of $150 million for the coming fiscal year. This particular research fund is important because it has demonstrated success, has been efficient in the past, is transparent and accountable to the public and has had strong bipartisan support. It is an important tool in finding treatments and a cure for breast cancer.

Priority 3: Enactment of the Breast Cancer and Environmental Research Act. This bill, which historically has had strong bipartisan support, was first introduced in 1999. It has had strong grassroots support as well but is long overdue for passage. This bill would establish a national strategy to study the connection between the environment and breast cancer. It aims to earmark $40 million a year from 2008 to 2012 for this purpose, awarding grants to researchers through a peer-reviewed grant program. The Director of the NIH would award grants to conduct multi-institutional, multi-disciplinary research through a national network of collaborative centers. Each center would be required to collaborate with the other funded centers.

Priority 4: Preservation of the Medicaid Breast and Cervical Cancer Treatment Program. This program was first enacted in 2000, expanding the health care access for thousands of underserved women. It also provides matching funds to states to provide Medicaid coverage to uninsured or underinsured women with a diagnosis of breast or cervical cancer through this federal program. Despite this Program and its success, millions of people in the US (nearly 47 million) are uninsured, underinsured or at risk of losing their health care coverage. In light of the Bush administration’s cuts to Medicaid, the preservation of this program is even more important. Some states have applied for waivers, which would allow them to cut Medicaid benefits and pass along the responsibility for the health care costs of these individuals to local governments. The needs of

BCCR Goes to Washington, continued from cover...

Rebecca Solomon and Phyllis Connelly witness Sen. James Alesi signing the resolution declaring March 20, 2007 as New York State Breast Cancer Network’s Advocacy Day in Albany.

“Next issue: BCCR continues to grow and expand!”
individuals with breast cancer and cervical cancer will be more difficult to meet without the support of this program and the accessibility of quality health care will be at risk.

In addition to attending this conference in Washington DC, BCCR met with their local legislators in Rochester, NY on April 19th for the biennial Local Advocacy Day. Bills with priority for New York State include a package of three bills that would 1. Require state and local agencies to take a precautionary approach when making decisions significantly affecting public health or the environment, 2. Require state agencies to buy safe and sustainable products and services, and

3. Establish a statewide health tracking and bio-monitoring program. The BCCR visit will focus on these and other health issues. There are plans to charter a bus in 2008 to take a larger Rochester delegation to Albany to participate in the Network’s Advocacy Day. Care to get on the bus? We would welcome you aboard!

To learn more about the federal priorities and the NBCC conference in Washington, please visit their website at www.stopbreastcancer.org. For more information on New York State breast cancer advocacy issues and the New York State Breast Cancer Network, please visit their website at www.nysbcn.org.

Executive Director’s Report, continued from page 2

like the answer to everything, we were taught to weigh the facts carefully. How much time to progression of disease or death did a particular therapy buy? At what cost and how do we pay? Was it quality time or were the side effects of the drug or disease marred by what seemed to be inevitable? How does hope fit into all of this? Rest assured, these discussions are continuing. If you are interested in joining the debate, or even listening to the dialog, this can be arranged! E-mail me at holly@bCCR.org and you will find that your breast cancer sisters (and brothers!) will welcome you with open arms.

The media is reporting all sorts of things that need clarifying, which may be why our phones are ringing off the hook with questions about genetic testing, MRI breast imaging and the recent decline in breast cancer incidence.

We share your concerns about the recent push for genetic testing and caution you and your family members that this is the tip of the iceberg. Myriad, the owners of the genetic test kit are ramping up their efforts to sell more kits and are now targeting OB/GYN practices. Their 2006 Annual Report “Momentum”, available on their website www.myriad.com, indicates that they are clearly committed to making 2007 a record-breaking sales year. While there is no argument that testing for BRCA I and BRCA II can be helpful to some breast cancer patients and their family members, ask yourself what this information really gives you. Speak with your doctors and other care providers about what your actual risk really is for having this mutation. If you decide to seek genetic counseling, you should not be urged to have the testing immediately following your counseling session. Learn the facts by visiting websites of the American Cancer Society (www.cancer.org), National Cancer Institute (www.cancer.gov) and National Breast Cancer Coalition (www.stopbreastcancer.org).

The recent guidelines about the use of MRI in breast imaging, as well as the recent reports of lower incidence of breast cancer, will be covered in our next issue of Voices of the Ribbon, so stay tuned. Suffice it to add, we’ll have a lot to say.
When I read *Nordie’s at Noon*, I laughed, I cried, and I told my other young survivor friends they just HAD to read this book. *Nordie’s at Noon* was written by four young women who were all diagnosed with breast cancer before the age of 31. Patti Balwanz was 24, Jana Peters and Jen Johnson were 27, and Kim Carlos was 30. They became friends during different points of their cancer treatment, and met for monthly lunches at Nordstrom’s trendy café “Nordie’s” in New York City. They chronicle their breast cancer experience from finding their lumps, through surgery, treatment, and in some cases, recurrence. They include chapters on topics that are unique to young survivors, such as pregnancy during and after diagnosis, breastfeeding, dating, and career decisions.

I wish this book had been around when I was diagnosed in 1997 at the age of 30. My children were five and three at the time and I had literally just started back to work after taking five years off to be home with them. I felt like no one else had ever been in my situation. I didn’t have a lot of time to make decisions. My doctor minimized my fears at the time. However, once the biopsy came back positive they were ready to operate within days. Looking back, I don’t know how I plowed through it all – the mastectomy, chemotherapy, going back to work, and moving 100 miles away – including moving my son to a new kindergarten! I guess keeping busy helped me keep a positive attitude, but now that it’s been almost 10 years, I look back and think “Holy cow, that was a crazy time!”

Reading the stories of these four women made me realize how lucky I was to have such a loving, supportive family and terrific friends who were there for me through it all. I was both humbled and inspired reading about their advocacy, their friendship, their positive attitudes, and their love for life. I’ve participated in various breast cancer walks since my diagnosis and I have shared my experiences when the opportunity has presented itself. I have joined the Breast Cancer Coalition’s Advocacy Committee and have headed to Arlington, VA and Washington DC for Advocacy Training Conferences; but this book and these women helped me to see that there is so much more I can do to support other young women who are diagnosed with breast cancer.

This book shows the way!
Why Do I Run? by Alison Currie

Why do I run? The simplest answer comes to mind first: for the exercise, health, and fitness benefits. After more thought, I’ve decided that it’s a little more complicated. Running is where I do my thinking, planning, and problem solving. During the week, it’s my quiet time alone to ponder events and people far and near. Running is also a major stress reliever and an outlet for my obsessive side. The first thing I did the morning after I was diagnosed with breast cancer was to run. I ran during chemotherapy until my medi-port failed and I was reduced to merely walking three miles a day. When my central line was removed after the final round of chemotherapy, I came home from the hospital and immediately went for a run. When things are bad, or there’s a letter to write, or some planning to be done, it’s time to hit the road.

There are other reasons too. Running is just a small part of what makes me who I am, along with being a wife, mother, engineer, musician, craftsman, and animal lover. When any one of these elements is missing from my life, I don’t feel whole. Another unexpected benefit of running was the discovery of the Goldrush Runners. Every Saturday morning at 7:00 AM, no matter how awful the weather, we self-proclaimed running addicts (or is that idiots?) meet for our weekly training. After briefly catching up on the events of the week, we set off on a minimum ten-mile run. Anything shorter does not merit getting up early. Often there is a crowd doing 6 at 6 (six extra miles at 6:00 AM) to get in extra distance in preparation for an upcoming marathon. A lot of conversation happens during a ten-to twenty-mile run; consequently we are a tightly knit group who support each other through good and bad times. We have survived cancer, the tragic death of our founder, Cushing’s disease, heart attacks, and many other maladies. The solution to most problems is to talk and run. Oddly enough, it was a very thorough surgeon recommended by two of my fellow runners who found my breast cancer while performing a physical prior to surgery for a completely unrelated problem.

Training for a specific event provides camaraderie and a common goal. I finished my radiation on August 28 and ran a half-marathon on Labor Day weekend one week later. Finishing that race provided me with a huge sense of accomplishment and proof that I was indeed on the road back to my version of normal. I ran a second half-marathon a couple of weeks later. It was a moral victory to realize that I could hold my own among other runners who most likely hadn’t spent the past year in treatment for cancer. On March 23rd, exactly one year after being released from the hospital for a week of intravenous antibiotics, I completed an all-women’s marathon in New York City. This was my first post-cancer “road trip” with my running friends. It was a major accomplishment, a battle won in my post-breast cancer war.

Local Advocacy Day 2007

Every year, the women of BCCR’s Advocacy Committee make visits to our legislators and representatives at their district offices in the Rochester area. This gives them the opportunity to advocate for legislation that benefits those with breast cancer.

The group in the photo for this year’s Advocacy Day, taken during their visit to Senator Jim Alesi’s office is (left to right): Phyllis Connelly, Pat Foucht, Patsy Robertson, Julie Atkinson and Holly Anderson.

Keeping their voices heard with lawmakers is vital to making legislation that supports people with breast cancer a reality.
Learning about Advocacy: a conversation over a cup of coffee between Liz Rich and Phyllis Connelly

Liz Rich (LR): Hey Phyllis, tell me more about why you send me emails marked urgent which contain information about pending breast cancer legislation?

Phyllis Connelly (PC): The urgency is that alerts come at a pivotal point in the process of a bill becoming law. As a volunteer member of BCCR, I have become very interested in the legislative process and have, therefore, become aware of many bills which are pending in our State and National Legislative Houses.

A chain of events takes place. Action or inaction makes or breaks this flow. I have learned to appreciate the importance of citizen participation in this process. I send these urgent emails to you to keep you informed of the status of a bill that often pertains to allocation or authorization of Breast Cancer research monies or public policy initiatives.

LR: Can you give an example of how a response to an urgent email works and what it might accomplish?

PC: Recently the staff of the National Breast Cancer Coalition (NBCC) was following a particular bill through its tedious process. The lead sponsors were preparing to introduce it on the floor of the House of Representatives. Before this would happen, bipartisan co-sponsorship was needed. NBCC sent out an Action Alert to me and its other volunteer Field Coordinators, which included the name and number of the bill, the sponsor, its general content and where the bill stood in the process. I passed this information along through an action alert to you. After considering the information, you decide what action, if any, you wish to take.

LR: How is it decided which bills you keep us informed about?

PC: An agenda is adopted each year by the Board of Directors of the NBCC and the New York State Breast Cancer Network (NYSBCN). BCCR is a member of both organizations and joins them in working toward accomplishing the determined goals. Since these organizations are non-partisan, they work to secure support of representatives on both sides of the aisle. If legislators understand the significance of a bill and its importance to voters back home, they are much more likely to act accordingly.

LR: Do we need to know who our representatives are?
PC: Although the volume of response is definitely important, a constituent’s opinion carries more weight. From that perspective, it is important you know your representatives. If necessary, a quick call to your County Board of Elections can tell you.

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LR: What can I do to become more informed?

PC: Join our Advocacy Alert Team!

Simply call BCCR (473-8177) or email info@bccr.org and ask to be added to the team. (Don’t have access to e-mail? We will be happy to give you an Alert call).

You will receive an Action Alert only 4 or 5 times a year. Granted, the Breast Cancer and Environmental Research Act scenario this past year was an exception. You could then call or email one or two representatives with a very brief – or not so brief - message voicing your opinion.

LR: How much information will we be getting pertaining to the issues? How will we know whom to contact and how to reach them if we wish to do so?

PC: As much as you want. The Action Alert from the NBCC, which is included in the message you receive from me as a volunteer Field Coordinator, gives quite a bit of information. Or, just reply to the e-mail and ask any further questions you may have. Detailed information will be in the Action Alert message.

LR: How can we learn more about these issues in general?

PC: In several ways. Go to these websites:
BCCR www.bccr.org - click on Advocacy
NYSBCN- www.nysbcnen.org - click on Public Policy
NBCC www.natlbcc.org - click on Public Policy

Join us for our annual visits to our New York State Legislators each Spring. BCCR charters a bus for this trip. It is an experience you’ll never forget!

Attend the NBCC Spring Advocacy Training Conference in Washington DC.

Join our Advocacy Committee. We meet at noon on the second Tuesday of every month at the BCCR.

So there you have it, Liz, ready for another cup of coffee?

Expressing your opinion to your Legislative Representative helps determine what these decisions will be. The more interest expressed in a bill or a funding initiative, the greater the chance of movement through each legislative body.

Phyllis Connelly, NBCC Field Coordinator and BCCR Leader with Sharon Ford-Watkins, NBCC Staffmember at the NBCC Conference in Washington DC, April 2007

Fran Visco, President of NBCC with some of the members of the Rochester delegation, April 2007
Our Fundraising Friends...

Rochester Women’s Council of Realtors Helps BCCR

A Western Charity Roundup hosted by the Rochester Women’s Council of Realtors was held in October at Casa Larga. The event, sponsored by Wells Fargo Home Mortgage and Forbes-Capretto Homes, featured a fashion show, as well as live and silent auctions.

Beneficiaries of the Roundup were BCCR, Gilda's Club of Rochester and Women Helping Girls Make Choices. BCCR was thrilled to receive a check for $10,000 following the event. BCCR Executive Director Holly Anderson and Chairwoman Joyce Wichie thoroughly enjoyed themselves as the Fall fashions were previewed.

It was Janet Clark, a member of the Rochester Women’s Council of Realtors, who first brought our mission of advocacy, education, outreach, support and research to their attention. BCCR has been the recipient of this annual fundraiser for the past three years.

We are so honored to have been selected as a beneficiary by such an esteemed group of women!

A Retirement Party raises money for The Breast Cancer Coalition of Rochester

Jim Rothfuss recently retired as the Monroe County Chief Fire Investigator for the Sheriff’s Office. With that his wife Sheila, a 2005 Breast Cancer survivor, volunteer and committee member for BCCR decided long ago, that they wanted a retirement party for Jim to mean something.

“The BCCR family is warm and gracious and I am grateful to have such an organization in our community. Holly and Kathy were instrumental in their support and guidance when I needed it (and continue to need it). I couldn’t think of a more appropriate way to say ‘thank you’”

2007 Bowling Tournament

The Fifth Annual Bowl for the Cure was held on Friday, February 16th at Clover Lanes. United States Bowling Congress/Rochester WBA Director Kathy O’Neill was proud to announce that this year’s benefit was a tremendous, inspiring success that broke records!

Ninety-three teams stepped up once again to show their love and support for those coping with a Breast Cancer diagnosis.

A total of $7,954.00 will be split with Susan G. Komen Breast Cancer Foundation and the Breast Cancer Coalition of Rochester. This is over $1,000 more than last year!

Thank you once again for an outstanding 5th anniversary of Bowl for the Cure! To date, over $23,000.00 has been raised with this annual tournament.

Save the date for next year - February 15th, 2008
Our 5th annual Tee’d Off at Breast Cancer Golf Tournament will occur on Monday, July 23rd at Shadow Lake Golf Club. Once again, the day includes a full 18 holes of golf, lunch at the turn, and a steak dinner to wind up the day. Raffle gifts and prizes will add to the fun!

Whether you’ve never held a golf club or are a seasoned pro, our golf tournament is for you! Your participation supports the people in our community and their families who live with breast cancer every day.

Please contact Barb at the Breast Cancer Coalition at (585) 473-8177 for registration details, sponsorship opportunities or to make a donation. Our website, www.bccr.org, also has information.

Hope to see you there!

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It’s ARTrageous!

The 2007 ARTrageous Affair, that is. BCCR’s annual Fall Gala is slated for Saturday, October 6th, 2007 at the Crowne Plaza Hotel, a new venue for the event. We are celebrating BCCR’s 10th anniversary of exceptional advocacy, education, research and support!

This year’s theme is gardens - anything you can place in the garden, plant in the garden or hang in the garden is welcome. Sculpture, garden gates, birdhouses, benches, birdbaths, fountains, mirrors, statuary, tables, chairs, hanging furniture like hammocks, garden seats or any item for an indoor or an outdoor garden is welcome. Anything that is three-dimensional and can be used in a garden is what we are looking for. Use your imagination!

Cindy Miller will be the entertainment at the Crowne Plaza. Cindy is from upstate New York and earned a Master’s Degree from the Eastman School of Music. Her professional engagements have ranged from intimate clubs to large stadium/concert performances, and as guest soloist with symphony orchestras.

This year, the focus is on increasing our attendance. We are looking for table captains, who do not have a financial commitment to BCCR but are encouraged to fill a table with friends, family members, co-workers, and/or clients.

Save the date - Saturday, October 6, 2007 Rochester’s Crowne Plaza, 6pm Details to follow!
Terri Schmitt would have enjoyed seeing Mark Siwiec take the podium in a white Easter Bunny suit at the Fourth Annual Terri Schmitt Legislative Reception, “An Evening Out with our Decision Makers”, held at the Breast Cancer Coalition on March 15th. According to Mark, Terri had a great sense of humor and loved laughing with friends and family. There were many of Terri’s friends and family members in attendance and plenty of smiles and nods while Mark spoke. He delivered a wonderful tribute to Terri, who was an early BCCR member and Co-Chairwoman of the Board of Directors from 2000-2002. Terri, also a former Rush town supervisor, instilled all she did for BCCR with her energy and her tireless work.

Melisande Bianchi, Chair of the Advocacy Committee, introduced the event.

One of the highlights of the evening was the presentation of a proclamation from a representative of New York State Governor Elliot Spitzer to BCCR Director Holly Anderson. The proclamation praised BCCR for its outreach to people with breast cancer and noted its 10th anniversary this year. Another highlight was seeing Democrats and Republicans alike sing a wonderful rendition of “Happy Birthday” to County Executive Maggie Brooks, whose birthday was the next day.

Most of all, there were many legislators or their representatives present and all were interested in showing their support for the Breast Cancer Coalition and the women and men it supports through its services. Rochester Mayor Bob Duffy, County Executive Maggie Brooks, representatives from Senators Hillary Clinton and Charles Schumer, and many other local legislators were present. The response from politicians from both sides of the aisle was heartwarming!

We thank our Advocacy Committee, including Advocacy Committee Chair Melisande Bianchi, Lila Bluestone, Phyllis Connelly, Aimee Erwin, Pat Foucht, Jean Lazeroff, Bev Levy, Eileen McConville, Patsy Robinson and Rebecca Solomon, BCCR Executive Director Holly Anderson and many volunteers who, once again, made this event a great success!
“Easter Bunny” being introduced by Holly Anderson

Mark Siwiec aka “Easter Bunny”, delivering tribute to Terri Schmitt

Legislative Reception Photos

BCCR Executive Director Holly Anderson with Monroe County Legislator Willie Lightfoot

Mel Bianchi, Monroe County Executive Maggie Brooks and Holly Anderson

Rochester Mayor Bob Duffy and Bonnie Turner, representative for Assemblyman Joe Errigo

Jack Connelly measuring up to Monroe County Legislator Ciaran Hanna
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 non-traditional support group, in that there is no facilitator but plenty of support, 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 10 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 14 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.

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!

Men’s Night
Facilitated by Jay Nittoli, MSW, this group is for men whose wife, daughter, mother or significant other has 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!
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!

Jewelry Making

Jewelry making, including glass bead making, is the latest program that we are offering. Beading is relaxing and reduces stress. Marilynne Lipshutz of Studio 34 has generously offered her studio and the instructors have donated their time to teach a variety of classes, such as making a polymer heart pin or a beaded bracelet. These are one session workshops, approximately two hours long with a maximum of 10 breast cancer survivor students per class. The classes are project oriented and students will wear home a completed piece of jewelry!

Please contact Marilyn Lipshutz at 585-737-5858 for more information!

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!

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 by 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!
Mary Jo was first diagnosed with breast cancer in 1992. She found the lump while doing breast self-exam. She then had a lumpectomy and radiation followed by chemotherapy. After about three years of remission, the cancer metastasized to her spine. With more treatment, the cancer remained contained for a few years, but then metastasized again.

Mary Jo was one of the early members of BCCR, joining in 1997. She could always be counted on to volunteer for whatever tasks where needed for BCCR, i.e., meeting with Dr. Jennifer Griggs, mailing newsletters, selling pink carnations at the mall or walk in a Cancer Walk. She was also very active in the Park Ridge Auxiliary. She had many friends and cherished them all. She made each person she ever met feel so special and made each family member feel the same way. Everyone who met her will never forget her. She was a great wife and a terrific mother and grandmother and we were all so important to her. She always did things to show what we meant to her. She met regularly with other women and helped them cope with their fight against breast cancer.

Holidays were a favorite time for her, Halloween and Christmas being among her favorites. She could have won awards for her costumes. When she dressed as Cruella d’Vill, the penguin from Batman, or a wicked witch, the neighbors always visited our home to see her dressed up. Our Christmases were always memorable. She made our stockings more exciting than our presents!

Mary Jo was happiest when she was with her family. Nothing was an imposition when it came to her husband Prisco, her children and her grandsons Joey and Mark. She was always so proud of her daughters Patty and Paula, and her son Mark. She welcomed her sons-in-law Joey and Paul into the family as if they were her own and Paul’s Tyler as if her were her own grandson.

Her life was full and she enjoyed every moment. She loved to read murder mysteries, watch the old Charlie Chan movies, listen to trivia on Legend 990, and, of course, going to the casino to spend Prisco’s money. Every Thursday found her with her closest friends playing cards and having lunch. Mary Jo always attended church and it was her strong faith that helped her to fight so hard.

On September 30, 2006, Mary Jo lost her battle with breast cancer and we will never be the same. She lived as she died, with dignity and grace. Mary Jo was beautiful on the outside and the inside. The large number of people who attended her calling hours was a true testament to how she touched so many lives.

She will be missed by all her family, friends and her BCCR friends. Her family Prisco, Mark, Patty, Paula, Joey and Paul would like to extend our deepest appreciation to all who showed their support and were a friend to our beloved Mary Jo. 🖤

This memorial was submitted by Mary Jo’s family, prefaced by “When asked to write about our Mom, we all go together and shared memories of what we would like you to know about her.”

Thank you for sharing Mary Jo - BCCR
Deep Peace...A Gaelic Blessing

Deep peace of the running wave to you;
Deep peace of the flowing air to you;
Deep peace of the quiet earth to you;
Deep peace, deep peace.

Deep peace of the sleeping stones to you:
Deep peace of the wandering wind to you;
Deep peace of the flock of stars to you;
Deep peace, deep peace.

Deep peace of the Eastern wind to you;
Deep peace of the Western wind to you;
Deep peace of the Northern wind to you;
Blue wind of the South to you;

Pure red of the whirling flame to you;
Pure white of the silver moon to you;
Pure green of the emerald grass to you;
Deep peace, deep peace.

Deep peace of the running wave to you;
Deep peace of the flowing air to you;
Deep peace of the quiet earth to you;
Deep peace, deep peace...

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@bccr.org.

We look forward to hearing from you!
**Programs Update**  by Kathy Reilly

The fourth Wednesday of every month is a date that should be circled on your calendar if you want to be well informed about breast cancer. Our educational seminars are always on that date from 7 to 9 pm. In May, Dr. Gary Lyman presented *Fingerprints, Footprints and Decision Making*, which covered decision making regarding chemotherapy treatments. In June, we will be hearing from a nationally acclaimed author, Kim Carlos, who, with three other young women undergoing breast cancer treatment, wrote the book, *Nordie's at Noon*.

On July 25th we will be having a Family Picnic. We have a pavilion reserved at Ontario Beach Park and it will be a time for the rest of your family to meet the friends that you’ve made at the Breast Cancer Coalition. We all know that breast cancer is a family affair, so this seems like an appropriate way for us all to get together.

We have been taping our seminars with the help of Kathy Raeside, Programs Committee member. Another member, Sherri Finke and her husband Ron have transferred them to DVD format. We have several previous programs on DVD that you can borrow from our Resource Center and view in the comfort of your home.

Since March 25th we have participated in the “Eat Well, Live Well Challenge” sponsored by Wegmans. We are committed to helping our survivors continue to live a healthy life, hopefully free of breast cancer. We counted our steps with the goal of 10,000 per day and ate our five cups of fruits or vegetables daily. This challenge ended on May 20th, but I’m sure that we’ll do this again in the future.

All programs at BCCR are free and we offer everything from support groups to gentle yoga and writing workshops to empower women after their breast cancer diagnosis, so check out the list of programs on pages 16 and 17 and join us!

---

**Omitted but not forgotten...**

The following names were omitted from our Thank You list in the last issue. We were and are very thankful for their contributions to the 2006 ARTrageous Affair!

**Artists**
- Deb Bolcko
- Bridget Grant
- Pattie Katchmar
- Barbara Wheat
- Patty Willerton

**Committee Members**
- Melisande Bianchi
- Phyllis Connelly
- Mary Jane Elliott
- Kelly Reed
- Nancy Ellison Sweet

**Setup Help**
- Sharon Carr
- Daniel Garver
Poetry...

Listen

Don’t speak to me in false reassurances.

Truth is the scalpel that wounds and heals.

Touch my hands, see into my eyes, let me know you are there.

Between the pages of the truth listen.

I have felt fear grow

as mountain springs bubble and mutter incomprehensible then gather and flood the plain before moving on to the faceless sea.

The landscape now alien, changed.

Stand alongside as I take this and make it my own.

This poem was written by Pat Battaglia, our Newsletter Coordinator.

Embrace Your Sisters is a recently launched group effort that exists to provide emergency funding for women with breast cancer when insurance does not cover their costs.

Embrace Your Sisters can be contacted through the mail at PO Box 162, Honeoye, NY 14471, by phone at (585) 727-4623 or through their website at www.embraceyoursisters.org.
Donations from October 2006 to March 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.

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Jane Beamish
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- Rachael Chase
- Ms. Catherine Ciardi
- Ms. Teresa A. Claffey
- Ms. Darlene A. Coffaro
- Ms. Rita F. Cohen
- Dr. & Mrs. Anthony Colarutolo
- Mrs. LaTasha M. Collins
- Ms. Mary Kay Colon
- Tina Conibear
- Ms. Sandy Cooper
- Ms. Wendy A Cortese
- Roger Couch
- Ms. Rebecca J. Cox
- Mrs. Lisa J. Craig
- Ms. Nancy J. Cross
- Thomas & Lisa Culhane
- Mr. John Currie
- Ms. Robin R. Cuzzupoli
- Mr. Michael J. Dailey
- Amy M. Dann
- Mrs. Marlene A. Dattilo
- Ms. Adelina Davin
- Mr. Raymond W. Dearcup
- Ms. Patricia A. Dell’Anno
- Ms. Kathryn P. Dennis
- Ms. Lorraine Dennison
- Mr. Jon R. Dertinger
- Mrs. Sheila M. DeSimone
- Mrs. Carol A. DiCesare
- Ms. Debbie L.
# Breast Cancer Coalition of Rochester
## 2007 Seminars

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Event Title</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>January 24th</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Utilizing Complementary Modalities in the Treatment of Breast Cancer: Acupuncture, Reiki and Yoga”</td>
</tr>
<tr>
<td><strong>February 28th</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Women Partnered With Women: Removing Barriers in Breast Cancer Care”</td>
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<tr>
<td><strong>March 28th</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Lymphedema: Risk and Management”</td>
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<tr>
<td><strong>April 20th</strong></td>
<td>1:00-5:00 P.M.</td>
<td>“Advanced Breast Cancer: Tools for the Journey”</td>
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<td></td>
<td>Reservations for this half-day Seminar are required</td>
</tr>
<tr>
<td><strong>April 25th</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Fertility &amp; Pregnancy Following a Diagnosis of Breast Cancer”</td>
</tr>
<tr>
<td><strong>May 23rd</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Fingerprints, Footprints &amp; Decision Making: Exactly what is Genotyping?”</td>
</tr>
<tr>
<td><strong>June 27th</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Young Survivors: Kim Carlos, Author of “Nordie’s at Noon”</td>
</tr>
<tr>
<td><strong>July 25th</strong></td>
<td>6:00 P.M.</td>
<td>No Seminar</td>
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<td>Please join us for a Family Picnic at Ontario Beach Park!</td>
</tr>
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<td><strong>August 22nd</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Long Term Effects of Breast Cancer Treatment”</td>
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<tr>
<td><strong>September 26th</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Breast Cancer Updates: Physician Panel of Experts”</td>
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<td><strong>October 24th</strong></td>
<td>7:00-9:00 P.M.</td>
<td>“Lives Touched, Lives Celebrated”</td>
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<td><strong>December 6th</strong></td>
<td>6:00-9:00 P.M.</td>
<td>“Annual Holiday Open House”</td>
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All Seminars are free and open to the public. If noted, reservations are required.

**BREAST CANCER COALITION OF ROCHESTER**
840 University Avenue
(Between Culver and Goodman)

**Questions? Contact the BCCR at 473-8177**
**Wear our new pins proudly!**

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.

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**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.

Name
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City State Zip
Phone
Fax
E-mail

- $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 cannot afford to make a donation at this time but would like to be on your mailing list.

I would like to make an additional gift of $ 
In
- Honor of
- Memory of

Please send acknowledgement to: (name and address)

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

Amount Enclosed $ 
Credit Card No.
Expiration
Signature
Name on Card

Remember the BCCR Library:
Browse, Borrow, Read!

Breast Cancer Coalition of Rochester
840 University Avenue
Rochester, New York 14607
(585) 473-8177

Gifts of $100 or more receive a free Comfort Heart.
This photo is from our Pink Ribbon Run and Family Fitness Walk, held on Sunday, May 13th.

It was a great event with record attendance and record funds raised!

More Pink Ribbon news and photos will appear in our Summer issue of Voices of the Ribbon.

Save the Date!
BCCR Family Picnic
Wednesday, July 25th, 6 pm
Ontario Beach Park
Food, Entertainment, Fun!

Voices of the Ribbon
Published Quarterly by the
Breast Cancer Coalition of Rochester

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Fax 585-473-7689
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