Time has gone so quickly and I have to pinch myself as a reality check when I realize how far we have come. The progress and growth over the last ten years has been the result of hard and long hours by many, many people dedicated to eradicating breast cancer and helping those who have been affected by this disease.

The grassroots of the present day movement go back to 1993 when 2.6 million signatures were collected nationwide to present to President and Mrs. Clinton requesting $2.6 billion research dollars to be spent by the year 2000 on breast cancer research. 1997

On July 2, 1997 thirteen women met at my home to organize the Breast Cancer Coalition of Rochester (BCCR) and become a member organization of the National Breast Cancer Coalition. We collected the necessary $100 from the members present so we could begin functioning.

First items of importance were getting a telephone listing and voicemail, a post office box and a checking account.

Present at that meeting were: Judythe Roth, Harriet Susskind Rosenblum, Maurine Johnson, Marcia Gitelman, Linda Gottwald, Shirley Falvo, Mary Jo D'Angelo, Carmella Richards, Janet Smith, Jackie Buck, and Kathy Chiavoroli. At the August meeting officers were elected: Sylvia Cappellino, Chairperson, Kathy Chiavoroli, Vice Chair, Recording Secretary, Jackie Buck, Corresponding Secretary, Harriet Susskind Rosenblum and Shirley Falvo and Judythe Roth as Treasurer. By the September meeting, we had designed brochures, posters and business cards, all made on my computer so... continued on page 5
Every year in the United States, over 192,000 women will hear the alarming words “you have breast cancer.” As someone who has heard these words firsthand, I know that one of the perpetual questions in those first weeks following a new diagnosis is “why did this happen?” Our brains work overtime. Worrisome thoughts crowding our minds during business meetings, in grocery store check-out lines, on treadmills at the gym, and while lying in bed at night. Quiet moments of reflection are interrupted by thoughts like, “I didn’t exercise enough.” I drank more than three glasses of wine per week.” My diet could have been better.” “I didn’t breast feed.” We can drive ourselves and our loved ones crazy with our speculation. Somewhere in our own analysis we may wonder about our genes. We worry about our children, especially our daughters.

The National Cancer Institute estimates that 5-10% of women newly diagnosed with breast cancer will have a hereditary form of the disease. Alterations in certain genes, BRCA1 and BRCA2, are the genes scientists have discovered make a small population of women more susceptible to breast and ovarian cancers. Scientists are attempting to identify genes that may help us understand genetic predisposition to other cancers. Isn’t this good news?

Maybe, but maybe not. In the case of breast cancer, if 5-10% of those diagnosed have a genetic form of the disease, it follows that 90-95% do not have it. As patient advocates, some of us are becoming concerned about the recent push to “get tested”. More and more, we are hearing of women referred for genetic counseling and testing. In the majority of instances, these referrals seem appropriate. Lately, however, some of these referrals aren’t making sense, leading advocates across the country to question what might be happening.

“Wouldn’t you feel better knowing one way or another?” is a common refrain heard from friends and family members. As a breast cancer survivor with children, I am interested in discovering what may have caused my breast cancer. What mother wouldn’t want to spare her children that legacy of fear? As a breast cancer advocate however, I have a responsibility to the constituency we serve to provide information that will help women make informed decisions about their care.

To understand the issue more fully, one needs to have an understanding of risk.

According to the National Cancer Institute, the likelihood that breast and/or ovarian cancer is associated with BRCA1 or BRCA2 is highest in families with a history of multiple cases of breast cancer, cases of both breast and ovarian cancer, one or more family members with two primary cancers, or an Ashkenazi (Eastern European) Jewish background. It is important to keep...
in mind that not every woman in such families carries an alteration in \textit{BRCA1} or \textit{BRCA2}, and not every cancer in such families is linked to alterations in these genes. Most importantly, even if it is discovered that one has the mutation, this does not mean one will actually get breast or ovarian cancer.

There are numerous risks and benefits associated with genetic testing (see Figure 1) and this column is not meant to encourage or discourage women from exploring these risks and benefits with their care providers. That being said, those living in the aftermath of a breast cancer diagnosis are particularly vulnerable, and potentially exploitable, to suggestions that we “get tested”.

The National Cancer Institute provides excellent information about \textit{BRCA1} and \textit{BRCA2} testing on their website listed below. If you do not have access to the Internet, please call the National Cancer Institute at 1-800-4-CANCER for this information, or call (585-473-8177) or write to us and we will mail you a copy of this information.

We will be taking a closer look at the referral, counseling and testing processes in the next few months.

Stay tuned.

Source

\begin{figure}[h]
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\caption{Figure 1}
\end{figure}

\textbf{Did you miss Dr. Langstein’s presentation in October - “New Techniques in Reconstruction”?}

\textit{Don’t worry...}

\textit{The entire presentation is on DVD and available in our Resource Library for you to view.}

\textit{Stop in and treat yourself to some very valuable information.}

\textit{Borrow a book while you’re there!}
Think Before You Pink, sponsored by Breast Cancer Action, encourages consumers to ask questions about breast cancer fundraisers so that your money goes where you want it to go.

Their website, www.thinkbeforeyoupink.org, has a “Parade of Pink” that lists the various fundraising campaigns and how much of your donation goes to the cause you support.

This kind of resource is a valuable one in a time when pink ribbons are everywhere and it’s hard to discern which organizations live up to their marketing promises.

Put a bookmark on this website and make your pink dollars count!

Save the Date - the 2007 Pink Ribbon Race and Family Fitness Walk coming this May 13th!

Why We Walk

There’s an empty seat at the dinner table
Where a mother used to sit.
She was 34 years old, full of life and dreams
And two small kids.
There’s a young man with a tear in his eye and a pink ribbon on his coat
In memory of the only love he’d ever known.

There’s a lady looking in the mirror without a single strand of hair,
She barely recognizes the woman standing there.
She’s waging a silent war against an enemy inside
And putting up the fight of her life.

That’s why we walk.
We walk to remember.
We walk to celebrate.
That’s why we walk.
Leaning on each other
And holding on to faith.
For those who are gone and those who live on
We honor them all
And that’s why we walk.

She lays in a cold white room in a baby blue paper gown,
Anticipating what the X-rays might have found.
Then she hears the words that always stop you on a dime
And prays that they found it in time.

That’s why we walk.
We walk to remember.
We walk to celebrate.
That’s why we walk.
Leaning on each other
And holding on to faith.
For those who are gone and those who live on
We honor them all
And that’s why we walk.

For life, for love, for one another,
For him, for her, there’s strength in numbers.

Join us as we walk on Sunday, May 13th, 2007!

These lyrics, written by and used with the permission of Julie Vassar, accompany a song written by her husband Phil Vassar. The song can be heard on the CD that is included with the book Why We Walk, edited by Deb Murphy with photographs by Paula Lerner, published by Lionhart Books, Ltd. Available in our wonderful Resource Center.

Do you have a few volunteer hours a month to help us distribute our Comfort Hearts to offsite locations?
Please contact Barb at 473-8177 for more information.
we could be ready to have a display table at the Highland Hospital Luncheon, where Dr. Susan Love was speaking on breast cancer. We were ecstatic when Dr. Love mentioned our newly formed group in her presentation.

By now, membership was growing. Joining us were Susan DeBlase, Jo Braitman, Cynthia Craig, Nancy Infantino, Jean MacArthur, Joyce Paley, Maxene Greenfield, Marie Siracuse and Judith Waldert.

We were a very busy group establishing our goals, setting up bylaws, writing grant proposals, benchmarking with other NYS breast cancer organizations. We also met with attorneys Robert Nassau and Catherine Foerster at Boylan, Brown et al, who were donating their time and expertise to help us with our 501(c)3 incorporation. We were meeting at Valley Manor Apartments, who were so gracious to donate a meeting site for us once a month. Our first fundraiser was November 1, 1997 at Eastview Mall, a “Pink Carnation Sale” chaired by Marie Siracuse that netted us about $1,500. Local florists donated all the flowers. We also received our first Grant from Senator Alphonse D’Amato through Kraig Siracuse for $5,000. Wow, it really felt like we were getting a “Jump Start”. In December, the Rochester Area Foundation granted us $2,500 to help us establish ourselves as the only organization devoted solely to breast cancer advocacy in the Rochester area. This was a wonderful way to end our first six months of 1997.

1998

Judith Waldert became Chairperson and Harriet Susskind Rosenblum became Vice Chair. Other officers remained the same. As past Chair, I continued to be actively involved from my winter home in Florida, utilizing email and telephone. The many new members this year included Kathy Clark, Terri Schmitt, Lenora Colaruoto-lo, Deborah Hall, Isabelle Scalise, Marcia Rocco, and Amy Zicari.

Our group’s efforts now focused on establishing communication between our members and the community. We utilized mailings, voice mail and outreach efforts at health fairs, writing articles for the newspaper, luncheons and speaking engagements. We wrote and passed bylaws, and voted to set aside a percentage of all donations into a BCCR Breast Cancer Research Fund for a future research grant.

May 1998 saw five members of BCCR travel to Washington D.C. for the National Breast Cancer Coalition Annual Advocacy and Training Conference. It was awesome to see hundreds of people come together to discuss all the issues surrounding breast cancer. We learned a great deal about breast cancer advocacy and came away fired up with many ideas for our group and how we could best serve people with breast cancer. Four women bunking in one hotel room was quite an experience also. We met with other groups from New York State and made plans to start the NY State Breast Cancer Network.

Within our own community we collaborated with many groups and businesses: Cancer Action, Highland Center for Women, the Strong Memorial Cancer Research Department, Women’s Health Partnership, Cornell’s Breast Cancer Environmental Risk Factors (BCERF), and the American Cancer Society. We were the benefactors of a wonderful fundraiser at People’s Pottery, which brought in over $5,000, thanks to Jim and Carla Froehler. We received donations from Shear Ego, Lakeshore Kiwanis, Natapow Foundation and the Locust Hill Women’s Association. We continued to enjoy Wilmorite’s generosity in allowing us the use of their malls for our “Pink Carnation Sale”.

The year ended on a sad note as we lost one of our founding members

Continued on page 7
New York State Senator James Alesi, of the 55th Senate District, is this year’s recipient of the Advocate’s Spirit Award, which was awarded in a ceremony at the ARTrageous Affair on October 7th, 2006.

From the time of the Breast Cancer Coalition of Rochester’s incorporation in December 1997, Senator Alesi has assisted the Coalition in their effort to provide services and support to those living with a diagnosis of breast cancer. The Senator was instrumental in the opening of the Coalition’s first offices on Park Avenue in June 2000 and continues to be instrumental in the Coalition’s ability to meet the needs of an ever-expanding breast cancer community.

Breast Cancer Coalition of Rochester’s Executive Director Holly Anderson states, “Over the past decade, the Senator has been one of our most reliable and fervent supporters, always listening, sharing constituents’ concerns, and offering words of wisdom along with careful expertise. Upon expansion of the Coalition’s offices and the addition of support services, as well as listening to numerous legislative concerns, Senator Alesi has seen to it that the breast cancer community’s collective voice is being heard.”

The Senator represents the 55th District of New York and the Monroe County towns of Chili, East Rochester, Henrietta, Irondequoit, Mendon, Penfield, Perinton, Pittsford, Riga, Rush, and Wheatland, as well as portions of the City of Rochester. However, according to Anderson, “This is a New York State Senator who truly represents us all.”

Past recipients of the Advocate’s Spirit Award:
2005 - Jennifer Griggs, MD, Former Director of the Comprehensive Breast Cancer Center at the James P. Wilmot Cancer Center, University of Rochester
2004 - Wende Logan Young, MD, Director of the Elizabeth Wende Breast Clinic in Rochester.

Reiki Treatment and Breast Cancer... one person’s perspective
by Pat Battaglia

Nothing can prepare you for the shock of a breast cancer diagnosis. It was in the spring of 2004, when I got the results of my mammogram and biopsy; I had breast cancer. I reeled from the shock. It felt as though the rug had been pulled out from under me and I was falling into fear and uncertainty. I have always tried to maintain a healthy lifestyle and have nursed five babies, so I was confident that my risk of getting this disease was somewhere around zero. But there are so many unknowns in life, and I suddenly found myself plunged into a place where I had to come to an acceptance of the situation while gathering information about my disease and its treatments. There were vital decisions to make, and they needed to be made quickly, during an emotional and confusing time.

“I could feel the warmth and healing energy coming through Mary Joan’s hands, and I began to feel I had the strength to face whatever was ahead of me.”

I’ve known Mary Joan Deutschbein for a long while, from the time when our children were small and we were La Leche League Leaders, and onward into years of home schooling. When I told her of my diagnosis, she offered her services as a Reiki provider, which I gratefully accepted. I didn’t know much about Reiki, or what a Reiki session was actually like, but I understood the premise that it involved a gentle type of massage and work on the energy field surrounding the body. I was intrigued by the possibilities that it opened for me in dealing with my cancer. The standard medical approach to treatment involves an array of very effective methods to eradicate cancer cells, but these treatments have other effects which can compromise overall health. Reiki seemed to me to be a way to deal with the effects of both the cancer and the treatment; a gentle David in the face of a Goliath.

It became clear early in my breast cancer journey that a mastectomy was the best surgical option for me. With the knowledge of impending surgery foremost in my mind, I had my first session with Mary Joan. I was feeling betrayed by my body and fearful about losing a part of it when Mary Joan arrived at my home (she and her

Continued on next page
suddenly. Shirley Falvo died of a heart attack at our November meeting. This hit us all very hard. She was a loving and important person to us all.

1999

This year stands out as a year when big decisions had to be made: decisions about how big we were going to become and our need for an office and staff. It was becoming more and more difficult to have open programs for the community, general meetings at Valley Manor and smaller committee meetings at local restaurants.


As newsletter editor, I became very busy with our goal of four newsletters a year. Our first newsletter was printed in the spring with printing donation and reduced fees gratefully accepted from Park Printers who also printed our stationery, brochures and donation envelopes, all of which I designed on my computer.

Our organization’s goals were stated as breast cancer awareness, education, advocacy and research.

Our mission statement was: “To make eradication of breast cancer a priority through education and advocacy, to empower women and men to participate fully in decisions relating to breast cancer and to promote and focus research into the causes, prevention, treatment and cure of breast cancer.”

We participated in our first statewide Lobby Day with other members of the newly formed NYS Breast Cancer Coalition. Two of our members participated as reviewers on the New York State Health Research Science Board for breast cancer grants. We lobbied for support of the DOD $175 million for research, Centers for Disease Control treatments for low income women, nondiscrimination for genetic testing, and the Women’s Rights and Cancer Act which gives women the right to a second opinion, right to reconstruction and right to choose the length of hospital stay. We promoted the new breast cancer stamp and the NY State Tax Check-off for breast cancer research money.

Sadly, many of our early members have been lost to the disease: Shirley Falvo, Nancy Infantino, Terri Schmitt, Carmella Richards, Mary Jo D’Angelo, Harriet Susskind Rosenblum, Isabelle Scalise, Joan LaRose, and Delores Mancuso.

Sylvia Cappellino is the Chairperson Emeritus of BCCR. Next Issue: BCCR History, Part II - The New Millennium. A new home, more funding, new directors and a big race await BCCR!

Reiki Treatment and Breast Cancer

My sessions with Mary Joan became something I looked forward to during my post mastectomy period, through lymph node surgery and recovery, and onward through chemotherapy. Always, they were a relaxing time for me and I came away from them with a sense of inner calm and rightness about what was happening to me. During chemotherapy, we scheduled sessions to coincide with the time just before treatment, when I had recovered from the effects of the previous treatment enough to begin feeling somewhat normal, and was dreading the prospect of the upcoming treatment with every fiber of my being. Mary Joan described the changes in my energy field in ways which made perfect sense to me. The first combination of drugs produced what she described as small ripples in my energy field, like the surface ripples on water in a pool. The second drug
Reiki and Breast Cancer, continued from page 7

produced a deeper effect, as though the water was being churned from its depths. Being able to visualize this brought me an understanding of what was happening within my being. I still dreaded treatments, but after my reiki sessions, I felt the inner strength to face them.

After chemo ended, Reiki sessions continued to help me achieve a sense of inner balance and rightness about my body as I regained my strength and adjusted to my new normal. Normal for me now is to live with one breast and limited mobility in my left arm. It is to live with the knowledge of how easily the scales of inner balance and health can be tipped and we can slip unawares into a life-threatening disease. It is also the knowledge that we each have within us the means to right this balance and achieve health, whatever the prognosis and however uncertain the situation may seem.

I am fortunate in that I’ve been able to return to full health. I am equally fortunate to know Mary Joan. With her help, I’ve come through cancer treatment with a belief that true healing comes from within, and a knowledge of how I can access that healing. She is a true healer in this regard.

Thank you, Mary Joan. ☮

Pat Battaglia is our Newsletter Coordinator and a member of the Board of Directors of BCCR.

Poetry ...

Cancerchemo by Eileen Collins

You have always been noticed
Always high functioning
And often time consuming.
If you saw it you had it fast
When you feel, the moment is a flashpoint
Everything worked so well.
Sometimes I forgot you/I are the same
Like the rest of nature so unpredictable
Yet so constant
I was in love with you before anyone else
The bridge of my reality is
Magic in connection
But common in experience
Sad to see/feel the damage.
New reality was so sudden
Instant old age
No time for practice. ☮

Are you a breast cancer survivor? Do you like to write?
Send in your writing (poetry or prose) to Voices of the Ribbon - All submissions will be considered.
Forward all writing to Holly Garver, Editor, at hbg@bccr.org or mail to 840 University Avenue, Rochester, NY 14607
Residents of New York in need of physical therapy (PT) now have a “direct access” option open to them. After 25 years of lobbying on behalf of their patients, the New York Physical Therapy Association was recently successful in getting the “Consumer Choice To Direct Access” Bill passed. On July 26th, Senate Bill S.3169 was signed into law and New York became the 43rd state to allow patients direct access to physical therapy. The law took effect in November.

While the bill does not allow the unrestricted direct access that advocates had hoped for, the NYS version is still one of the least restrictive in the country. In New York, therapists delivering direct access services must be practicing for at least three years, and if they have not earned a Doctorate in Physical Therapy, must refer the patient back to the MD after 10 visits or 30 days (whichever comes first). Physical Therapists are also required by law to inform their patients, in writing, that direct access services may not be covered by their particular insurance company. Even with the present restrictions, local therapists still hail the law as good health care policy.

The two largest area health care insurers both remain plan-specific as to whether patients can self-refer and be reimbursed, depending on allowed coverage. Excelitus will reimburse on a plan-eligible basis; Preferred Care stopped requiring referrals in June, although limits still apply in some plans. In all cases, the physical therapists must be plan providers.

For Breast Cancer patients, who often deal with problems such as lymphedema (swelling of the arm, primarily after a lymph node dissection), shoulder and other joint-related problems, this new direct access to care is another step in removing barriers that some patients encounter in accessing the health care system.

“No consumers have more choice,” says Sue Callan-Harris, of Callan-Harris Physical Therapy in Rochester, who has treated Breast Cancer patients for over 20 years. “Currently, patients find out about treatment options by word of mouth and then ask their doctor for a referral. Sometimes they don’t know what to ask for. In the PT assessment, there is a clear description of the problem and a plan for treatment.”

Not only does the change enhance consumer choice, but patients will find it more time efficient and less costly. Direct access will help prevent delays in starting therapy, thus leading to better outcomes. Patients of physical therapists in New York State are one of the last groups to benefit from self-referral. Most other states have enjoyed direct access for years.

After her mastectomy and reconstruction, Linda King’s experience was typical of many women. At 53, removal of lymph nodes left her with mild lymphedema and, despite diligent exercising, limited and painful shoulder mobility. After PT treatment, Linda’s symptoms improved. However, she felt as though it took longer and was more intensive than it needed to be.

Said Linda, “Cancer patients have enough to deal with in making treatment decisions, and I think being able to get PT at the first sign of trouble will be a welcome change for many patients.”

Sue Callan-Harris providing lymphedema care

Patients should check with their carrier to ensure their specific plan will reimburse self-referred costs.

Join us for “Lymphedema - Concerns and Treatments” with Victoria Nugent, NP and Sue Callan-Harris on Wednesday, March 28th, at the BCCR center on 840 University Avenue.
Does Contacting Your Representative Really Matter?
A conversation between Liz Rich and Phyllis Connelly over a cup of coffee...

LR (Liz Rich): So Phyllis, tell me again why you e-mail me with these urgent requests to get in touch with my Congressperson or State legislator?

PC (Phyllis Connelly): (Chuckle). I know, Liz, people wonder just what can be so Urgent "Make a phone call? What difference can that make? Besides, I am very busy." Or, “I am not comfortable doing this sort of thing.” Please believe me, the Urgent email request only comes at a pivotal point in the process of getting an important bill enacted into law. (Last month, there was an article in Voices of the Ribbon by Jean Lazeroff, which described this process in our state government. The process is very similar at the national level). Calls from the general electorate make the difference at various junctures of this process. Introduction, gaining bi-partisan sponsorship, committee action, chamber floor vote, and Conference Committee action are some of the most important steps in this chain of events where action makes or breaks the flow.

LR: Can you give me one example of the importance of making this kind of call?

PC: Recently the staff of the National Breast Cancer Coalition was following a particular bill as it started going through the long process. The lead sponsors of the bill were preparing to introduce it to the floor of the House of Representatives. Before this would happen, bipartisan co-sponsorship was needed. NBCC alerted the Field Coordinators and an Action Alert was sent out to inform you of the name and number of the bill, a description of its general content and what action was needed on the part of your representative. As a result, all 4 of our area Representatives signed on as co-sponsors. One of these representatives was new to Congress and unaware of this piece of legislation. His staff person thanked us for bringing it to their attention, as they agreed it was a good bill and he was proud to work toward its passage.

LR: It always seems that when you send me an email it is “hurry up and do it now!” and I don’t always feel I know how to do what you want. Can you tell me a little more about what your emails are asking me to do and why?

PC: Well, sometimes it is just to call a legislator’s office or click on a site to send an e-mail. Previously, calls had been routinely made to staff of lead sponsors to learn if there is any movement likely to be taking place. If so, the nature of the movement dictates the action. Strategy is decided and an email goes out to those on the Action Alert team labeled Urgent because a prompt response is important. Outlined in the message will be what is considered the most effective action to take in order to get the desired results. Most often, it is asking you to make a very quick phone call to the office of one or two of the prominent legislative players. The Action Alert includes a suggested message, succinctly stating what it is we are asking our legislators to do. If you are calling as a constituent, mention that. Otherwise, you are calling because you have a vested interest in the outcome of this piece of legislation (and you want your voice added to the others coming from around the state of country). Someone in reception (or an answering machine) takes your message. Some people prefer sending their message as an email. The messages received on that issue are tallied and reported to the legislator, indicating the level of interest.

LR: How do you decide what you want us to do?

PC: An annual agenda is adopted by the Board of Directors of the NBCC and by the Advocacy Committee of New York State Cancer Support & Education Network (NYSBSEN). BCCR is a member of both organizations and joins forces with them to work toward accomplishing their goals. Both organizations have staff and/or members tracking each agenda item and will contact us after determining the most appropriate and effective action. Since BCCR is non-partisan, we work to secure support of our representatives on both sides of the aisle.
If legislators understand the significance of the bill and that the issue is important to voters back home, they are much more likely to take the action we request.

LR: Do we need to know who our representatives are?

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

Monroe 585-753-1550, Genesee 585/344-2550, Wayne 315/946-7400, Orleans 716/396-4005, Niagara 716/438-4040 or 4041, Erie 716/858-8891, or call the BCCR and someone on the Advocacy Committee will help you.

LR: What can I do to help BCCR?

PC: Join our Advocacy Alert Team! Simply call BCCR (473-8177) or email info@bccr.org and ask to be added to the Action Alert team.

(Don’t have access to e-mail? We will be happy to give you an “alert” call.) You will receive this Action Alert when action is deemed important and timely. This happens only 4 or 5 times a year. Granted, the Breast Cancer and Environmental Research Act scenario this past year was an exception. (sigh). If you were in favor of the bill and the suggested action, you would call or email the offices of one or two state or federal representatives with a brief message.

LR: How much information will we be getting pertaining to the issues we are calling or emailing about?

PC: As little or as much as you want.

Many people want the least amount necessary. I try to be brief. The Action Alert from Washington, which is included in the message you receive, does give quite a bit of background information. Or just reply to the e-mail and ask anything you wish to know.

LR: How will we know who to contact and how to reach them?

PC: That detailed information will be in the Action Alert message. It is also important to be aware that a timely response is critical.

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
NYSBCSEN www.nysbcsen.org - click on Public Policy

NBCC www.natlbcc.org - click on Public Policy.

Join us for our Annual visits to our State Legislators. We visit locally this coming year and next year, we’ll take a large group aboard a bus. Attend the NBCC 4-day Advocacy Training Conference in Washington DC every Spring. Join our Advocacy Committee. We meet at noon on the second Tuesday every month at the BCCR office. Or, volunteer to be on a “as needed” basis. Contact the office for details: 585-473-8177.

LR: What do you hope to accomplish by informing people about the need to be involved in this way?

PC: An increase in the number of people on the Action Alert list, resulting in our legislators hearing from more of us. It is important that our political representatives know what issues are important to our members and friends and why. Remember, our government decides research monies and public policies. If we do nothing to shape and influence these decisions, these monies will not be allocated or authorized and policies to our liking will not be instituted. The more interest expressed in a bill or a funding initiative, the greater the chance of passage.

LR: I am really impressed with all the work the Advocacy Committee does to make sure that members of the BCCR stay on top of legislative issues that affect us. I’m glad for the opportunity to participate in the process.

PC: I feel the same way, Liz. Now, how about another cup of coffee? ☕️
**End of the Year UPDATE on the National Scene**

The lame duck session of the 109th Congress failed to act - TWICE

In the wee hours of Saturday December 9th, the 109th Congress ended without passing the Breast Cancer and Environmental Research Act (BCERA). It is difficult to accept that this bill was not enacted considering it had such overwhelming Congressional support. The American public, including so many of us in the Rochester area, also clamored for its passage but leadership ignored us and Congress did nothing. Congress had the opportunity to help shed light on some answers about the causes of breast cancer but failed to do so.

Additionally, we are left waiting until February to learn what the appropriation will be for the Department of Defense Breast Cancer Research Act after Congress adjourned without making any decision.

Disappointing? Disconcerting? Frustrating? Yes, yes, and yes!

Be assured however that we are not giving up this fight! The National Congress. We will again press for this very important piece of legislation as well as keeping the DOD funding in the budget at the Senate level.

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**Mark Your Calendars!**

Meet author Kim Carlos on Wednesday, June 27th from 7-9 when she comes to BCCR to discuss her book *Nordie’s at Noon*, about the personal stories of four women who are “too young for breast cancer”.

**Wednesday, June 27th - 7 to 9 pm**  
**BCCR - 840 University Avenue**  
**Rochester, NY 14607**

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**Bowl for the Cure coming in February 2007!**

The Fifth Annual *Bowl for the Cure* is slated for Friday, February 16th at Clover Lanes on Monroe Avenue in Pittsford. The tournament is designed to be both a tribute to lost friends and family and a strong show of support for those currently dealing with breast cancer. Bowl for the Cure will have three flights, starting at 6:30 and 9 pm with Party Bowl at 11pm. Cost to participate is $20 per person.

The Benefit format is 3-6-9, which means that the bowlers in those frames are given a free strike. Teams are made up of three bowlers each and do not need to be sponsored. Their only requirement is to have a good time! Bowlers move lanes after each game. Prizes and other surprises will be given out throughout the evening. It is expected that there will be room for 150 teams, but early signup is encouraged, as there were waiting lists for last year!

Funds raised by the 2007 Bowl for the Cure will be split between the Susan G. Komen Breast Cancer Foundation and the Breast Cancer Coalition of Rochester. Please contact Kathy O’Neill for more information at 254-2983 or bowlkat@aol.com.

Sign up to be a part of a great evening of fun and fundraising! Get a team together and support BCCR!
A Survivor Speaks ... Linda Gaylord

When her breast cancer diagnosis came in the summer of 2005, Linda was retired and living a full and active life. During the time of her treatment, she was forced to slow her hectic pace. Now that treatment is finished, she has found new contentment in a more relaxed manner of living. Linda is a regular at Brown Bag Lunches and attends our Voices and Vision group, where the depth of the inner peace gained since her experience with breast cancer has found expression and touched the hearts of all who hear her. A delightful sense of humor lends balance and perspective to her insights. Linda and her husband have two daughters, four grandchildren and one great-grandchild. She reminds us that life is still full when you stop and take the time to smell the roses. This piece was written in response to a writing prompt, “In 2007, I welcome...”

2007........

This year I welcome into my heart the positive attitude I recently discovered. I welcome the thought of continuing good health and the ability to sustain a smile and good feelings toward all. I welcome the opportunity to learn more about my disease and use that information in a positive way. I feel an overwhelming need to share what I learn and what I know. I know I’ll be anxious to see how this manifests itself.

I welcome gratitude into my life for my many miracles and blessings. This year I will say goodbye to at least 20 pounds. 💭

Linda Gaylord

Nazareth College Raises Funds for BCCR

For the past eight years, the last Friday in October has been “Denim Day” sponsored by Lee Jeans. A charity was designated each year for the funds raised by this event.

In 2006, however, it was decided that Nazareth would donate to a local charity so that the funds would stay in town, and the Breast Cancer Coalition came to mind. The masterminds for the plan were Joanne Ciaciuch, a two-year survivor of breast cancer who works in Human Resources and Joanie Fitzgerald, who works in Office Services at Nazareth. Many others also became excited about the idea and joined in.

Each person who participated in “Dress Down for the Cause” paid $5 for the privilege of wearing jeans that day. The President of the college gave his approval for the plan and was the first to pay his fee! Raffle tickets were sold for 42 donated prizes that included: scarves, kitchen towels, Post-It Notes, “Tastefully Simple” products and other things, mostly in a pink theme. The children who attend daycare at Nazareth drew all the raffle winner tickets.

As a result of this fundraiser, more than $1400 was raised for BCCR! One student, Greg Hyde, took a jar around and collected $95 in change. Everyone at the Breast Cancer Coalition is most grateful to Greg and to Nazareth for their donations! 🎉
An ARTrageous Evening!

Our deepest thanks to our committee members who worked so hard to make the ARTrageous Affair a success!

**Paula Martin & Marlene Dattilo — Co-Chairs of the Event**
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We thank our artists who generously donated their work to the ARTrageous Affair!

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Continued on page 21
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Special thanks to our Gold Sponsors!
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. Our sessions are ongoing in 5-6 week intervals. You can join them at any time! The class starts at 6:30 p.m. and finishes at 7:45 p.m. The class is limited to 10 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!
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 about joining!

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 call 585-473-8177 for information on the next classes!

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 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.

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

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

This new and exciting program gives people with breast cancer an opportunity to explore and express their feelings by writing. Meeting twice a month, this warm and supportive group is led by a survivor who is also a writer. Not only is journaling proven to be very therapeutic for breast cancer survivors, but this program is getting rave reviews! Register and check the Upcoming Events Calendar on page 26 the dates of the new seminars.

Please call 585-473-8177 for information on upcoming seminars!
The Program Coordinator’s Report ...

2007 should be an exciting year for programs at the Breast Cancer Coalition of Rochester! On the fourth Wednesday of every month we have an educational program and this year’s line up is very diverse. There should be something of interest for everyone!

On February 28th we are presenting a panel focusing on the unique issues faced by women diagnosed with breast cancer who are partnered with other women. The gay community seems to have an unusually large number of women with breast cancer and they face special problems. We will be focusing on the personal, medical and legal issues that this segment of our population deals with. This program, like all of our programs, is open to the public.

In March our topic is Lymphedema. Victoria Nugent NP, who is a nurse practitioner with Genesee Surgical Associates, will answer such questions as how to recognize the symptoms of lymphedema, who is at risk, what can be done to prevent it and many more! Also speaking at this program will be Sue Callan-Harris. She is a physical therapist and breast cancer survivor, and she specializes in the treatment of lymphedema. If you have concerns about lymphedema, this is a program that will give you the knowledge to reduce your risk, and if you do have it, to manage your symptoms.

Don’t forget that Brown Bag is every Friday at noon and you can stop by and visit, no matter how long its been since your diagnosis. We also have on going programs such as Gentle Yoga, which is at 6:30 on Monday evenings and Voices, and Vision, a writing workshop open to all cancer survivors. Those who have participated in this program have commented that it helps them to delve deep within themselves and deal with their innermost feelings.

We are also putting together a wellness program! Since being overweight is thought by some to be a risk factor for breast cancer, it seems logical that we would strive to help our community of breast cancer survivors to exercise and lose weight! Therefore, we are in the process of forming a daily walking program! More news of this will follow!

Hope I see many of you at our programs this year!

Curves in Mendon - an active fundraiser for BCCR!

The Curves in Mendon, which is not only an exercise place but also a meeting place for women, has become active in fundraising. They are regular contributors to the Breast Cancer Coalition. Their fundraising activities have included catering pies for Thanksgiving and holding a raffle for a wall hanging. Until the end of 2006 their funds were matched by the National Breast Cancer Coalition, making their efforts that much more fruitful!

The BCCR thanks Curves for their generosity!

We have the 2007 Women of Color Support Group Calendar “Live, Love & Laugh” available for purchase at the BCCR center, 840 University Avenue. Calendars are $13 each. Enjoy this lovely calendar, full of photos, information and tips for cancer prevention!
Friends Remembered ...

I will not die an unlived life
I will not live in fear
of falling or catching fire.
I choose to inhabit my days,
to allow my living to open me,
to make me less afraid,
more accessible;
to loosen my heart
until it becomes a wing,
a torch, a promise.
I choose to risk my significance,
to live so that which came to me as seed
goes to the next as blossom,
and that which came to me as blossom
goes on as fruit.

Dawna Markova, from I Will Not Die an Unlived Life

Cynthia Brown
Nancy Schneider Carey
Joanne Mammano Glenday
Karen Hooker Norton
Diane Small

Save the Date!
Please mark your calendars for the

Breast Cancer Coalition of Rochester’s
Fourth Annual
Terri Schmitt Legislative Reception

Thursday, March 15, 2007
4:00 – 7:00 P.M.
840 University Avenue

Meet with members of the Breast Cancer community in
a relaxed, open forum.

Light refreshments
Brief program
Please call 585-473-8177 with any questions.

Young Survivors Soirée

Young survivors are treated to pedicures by Elaina Cosner and Kelly Morgan at
our recent “Young Survivor’s Soirée”. This evening event is held quarterly as a way
for young survivors to socialize and share their experiences with other young
survivors.
A Winter Recipe!

Here is a soup recipe that is sure to keep you warm and satisfied during cold winter days. It is low in fat and calories, too! It is modified from a recipe of Martha Stewart’s and is a big family favorite. I often double the recipe to feed a larger group.

Cauliflower Curry Soup

Serves 4
Prep time: 45 minutes

Ingredients:
1 head cauliflower (about 2 ¼ pounds), cut into florets (about 6 cups)
2 tablespoons vegetable oil
Salt & Pepper to taste
1 tablespoon butter, margarine or oil
3 medium onions, sliced 1 inch thick, preferably mild, sweet onions
1 ½ teaspoons curry powder
6 cups canned chicken, beef or vegetable broth (I often mix them)
2 tablespoons chopped fresh parsley (optional)

1. Preheat oven to 450°. In an extra-large (2 1/2 gallon) zip-lock bag, place cauliflower, oil, salt and pepper. Seal and shake to coat the cauliflower. Spread out on baking sheet and bake until the florets turn brown, about 25 minutes. Check it every few minutes, turning cauliflower over as needed to brown.
2. In a medium to large saucepan, melt butter (or add oil) over medium-high heat. Add onions and cook until soft, about 5 minutes. Stir in curry powder, cauliflower, and broth. Cover and bring to a boil. Uncover, lower heat and simmer 5 minutes.

3. Using a slotted spoon, transfer about 3 cups cauliflower and onion pieces to a bowl and set aside. Put remaining cauliflower florets into a blender, food processor or use an immersible blender; add 1 teaspoon salt and process until smooth. Stir this puree into the broth in the pan and reheat if necessary. Put whole florets and onions back in the soup. Top with parsley if desired. Serve hot with fresh bread!

Per serving: 187 calories 10.3 grams fat; 6.8 grams protein; 20.5 grams carbohydrates. 

Contributed by Holly Garver, Newsletter Editor

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- William King, Esq.
- Lori Leftowitz
- Locust Hill Country Club Pro Shop-Steve Barber
- Mary Maggio
- Josephine Marinetti
- Sondra McFarlane
- Mill Creek Golf-Mark Walley
- Rosann Milne
- Sandy Monahan
- Monroe Pro Shop-Jim & Sue Mrva
- Carol Moran
- Morgan Stanley
- Oggi Domani-Jen
- Oggi Domani-Suzanne
- Orange Glory- Jacquelyn Powers
- Penfield Country Club-Denny Forster
- Penfield Racquet Club
- Perinton Picture Framing
- Barb Pifer
- Wesley Pluta
- ROC Boxing & Fitness Center
- Savastano’s Pizzeria & Bakery
- Robert Scheidt
- Scruples-Lauren Grinnell
- Scott Seeman
- Susie & Greg Smith
- Judy Sloan
- Sorella’s & Company-Soon Pollet
- Starbucks Coffee-Pittsford
- Tantalo Photography
- Madeline Uttaro
- Webster Golf Club
- Kristen Wondrack
- Wright Wisner - Don Miller
- Zeller Corporation

United Way Donations – Donor Choice #2334

- Stacey Albert
- Colleen Husted
- Candice Kraemer
- Lori & Tom McJury
- Jill Mountain
- Judith Palmer
- Yvette Simons

*We sincerely regret any errors contained in this listing. Please call BCCR at 585-473-8177 or email at info@bccr.org with any changes. Thank you!*
Upcoming Events & Programs

Breast Cancer Coalition of Rochester  
2007 Seminars

**January 24th  7:00-9:00 P.M.**  
“Utilizing Complementary Modalities in the Treatment of Breast Cancer: Acupuncture, Reiki and Yoga”

**February 28th  7:00-9:00 P.M.**  
“Women Partnered With Women: Removing Barriers in Breast Cancer Care”

**March 28th  7:00-9:00 P.M.**  
“Lymphedema: Risk and Management”

**April 20th  1:00-5:00 P.M.**  
“Advanced Breast Cancer: Tools for the Journey”  
Reservations for this half-day Seminar are required

**March 25th  7:00-9:00 P.M.**  
“Fertility & Pregnancy Following a Diagnosis of Breast Cancer”

**May 23rd  7:00-9:00 P.M.**  
“Fingerprints, Footprints & Decision Making: Exactly what is Genotyping?”

**June 27th  7:00-9:00 P.M.**  
“Young Survivors: Kim Carlos, Author of “Nordie’s at Noon”

**July 25th  6:00 P.M.**  
No Seminar  
Please join us for a Family Picnic at Ontario Beach Park!

**August 22nd  7:00-9:00 P.M.**  
“Long Term Effects of Breast Cancer Treatment”

**September 26th  7:00-9:00 P.M.**  
“Breast Cancer Updates: Physician Panel of Experts”

**October 24th  7:00-9:00 P.M.**  
“Lives Touched, Lives Celebrated”

**December 6th  6:00-9:00 P.M.**  
“Annual Holiday Open House”

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
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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$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 $

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

Shop for BCCR Merchandise

We have many lovely things that can be enjoyed and benefit the Breast Cancer Coalition. What could be better? Check our website for items available, call, or visit us at 840 University Avenue, Rochester, NY (585-473-8177)

Online ordering through Paypal is now available!

Comfort Hearts – These beautiful pewter hearts offer comfort to many. - $10

Wear one of our new boxing glove pins to show you are part of the fight against breast cancer! In brown. $3

Pink Ribbon Magnet Tins - $5

Bracelet of Hope – Handmade glass & sterling bracelet in a gift bag - $20

Bookmarks –Made by local artists Kim Kircher & Dorothea Hillis.
Available in gold or silver finishes.
$5 small, $10 large

Pink Jelly Bracelet – very popular! - $2

We have pink ribbon car magnets again too! $2 each

Remember the BCCR Library:

Browse,
Borrow,
Read!
Breast Cancer Coalition of Rochester
840 University Avenue
Rochester, New York 14607

Non Profit Information

We are listed in the “Organizations Not Subject to United Way’s Review” section of the 2004 United Way Donor Designation Form. Please select Choice #4 on your United Way form.

Our organizations non-profit identification number is 2334.

Our organization can only continue to do our work with your generous support. We are, at present, the only independently operated organization focused specifically on Breast Cancer in the Greater Rochester Region. When you donate to our organization, 100% of the donation is focused on Breast Cancer issues and 100% of your donation stays in the Rochester area. Each dollar donated is 100% appreciated by those of us working towards the eradication of Breast Cancer.

As you know, we are a grassroots organization dedicated to eradicating Breast Cancer through action and advocacy. We formally organized as a 501(c)(3) not-for-profit organization in 1997. We are a member organization of the National Breast Cancer Coalition and the New York State Breast Cancer Network.

Voices of the Ribbon
Published Quarterly by the
Breast Cancer Coalition of Rochester
Tel. 585 473-8177
Fax 585 473-7689
E-Mail: info@bccr.org

Errata
In the Autumn issue of Voices of the Ribbon, we published erroneous information about aromatase inhibitors (AI). Women taking an AI are not routinely given bone enhancing drugs. The Breast Cancer Coalition is committed to providing women with accurate and timely breast cancer information. We offer our deepest apologies for the misinformation and will continue to strive to bring you information you can depend on.