



# CRAAB!

## Capital Region Action Against Breast Cancer!

Vol. 12, No. 4 • Fall/Winter 2010

## YAY! 2<sup>nd</sup> NYSBCN Supported Bill is Now Law!

by Margaret Roberts



After being the object of intense advocacy on behalf of New York State Breast Cancer Network (NYSBCN) member organizations and our Tier Four Coalition partners, Governor David Paterson signed this essential legislation, A8278A (Kellner et al.) and S5000A (Duane et al.), into law on October 1, 2010. The NYSBCN, of which CRAAB! is a founding member, is proud to have worked with our Tier Four Coalition partners to put this important protection into place.

The *Prescription Drug Out-of-Pocket Cost Limitation Act* prohibits insurers and health maintenance organizations from creating specialty tiers within their prescription drug formularies. These specialty tiers force patients to pay a percentage of the cost of certain high-priced drugs, rather than a fixed amount, as a co-payment for a prescription drug. Specialty tiers most often apply to drugs needed by people suffering from life-threatening and/or chronic illnesses, thus requiring people with these conditions, even though insured, to pay hundreds or even thousands of dollars a month for vital medication.

The Network chose this bill for its 2010-2011 Legislative Agenda to protect NYS health consumers from this unfair and dangerous practice. With the signing of the bill we are assured that these abuses can never happen in New York State. Thank you to all NYSBCN members for making this happen!

Visit [www.nysbcn.org](http://www.nysbcn.org) for more information; plan to participate in the next NYS Breast Cancer Advocacy Day on March 15, 2011.

## Save the Dates!

**FEBRUARY 25, 2011**

**Pink Zone Game**

11<sup>th</sup> Annual Breast Cancer Awareness Basketball Game and Reception at Siena College.

### Spring Lecture Series

**TUESDAY, APRIL 5, 2011**

**The benefits of various exercise programs to improve quality of life for survivors**

with Dr. Karen Mustian, Ph.D., M.P.H., FSBM; Assistant Professor and Director of the University of Rochester Medical Center, Physical Exercise, Activity and Kinesiology Clinical Research Core Laboratory in the Department of Radiation Oncology in the University of Rochester Cancer Center.

**TUESDAY, APRIL 12, 2011**

**Potential prevention of breast cancer through nutrition, including Vitamin D**

with Dr. JoEllen Welsh, an Empire Innovations Professor at the Gen\*NY\*Sis Center for Excellence in Cancer Genomics at the University at Albany.

Look for the flyer in your mailbox announcing the dates for winter CRAAB!-sponsored classes, which are without charge to participants.



## Walk On!

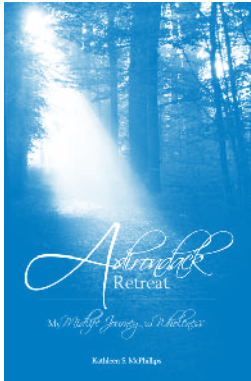
Some members of Team CRAAB! celebrate after the Susan G. Komen Northeastern New York Race for the Cure in Albany on Oct. 2.

## CRAAB!

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# Book Review



## Adirondack Retreat: My Midlife Journey to Wholeness

**Kathleen S. McPhillips**  
**88 pages**  
**Publisher: BookSurge**  
**Publishing (November 14, 2009)**  
**Reviewed by Wanda Easter**  
**Burch, CRAAB! Board Member**

I met Kathleen McPhillips at Great Camp Sagamore presenting yoga instruction as part of the Creative Healing Connections team for Arts and Healing Retreats for women surviving chronic illness. I present dream workshops for the retreats and always begin with introductions where we share our dreams for our lives. Kathleen lives her dream in her work as a Reiki master, writer, yoga instructor, and spiritual advisor. Her presence seems to bring a soothing magic that is meditation in action.

She is a breast cancer survivor whose not-so-easy life story is one of leaving her family, leaving her home, and overcoming overwhelming health and family challenges. Her choices led her to the Adirondack mountains where she sought a place of reflection and refuge and found in that place new friends and new purpose. A friend once told me that living well was all about soul. Kathleen followed the call of her soul and regained her health and her life.

*Adirondack Retreat* is bathed in poetry, poetic prose and extraordinary seasonal photographs of life in the Adirondack mountains, each word and each image, bracketed by the seasons, a reflection of Kathleen's journey to spiritual and physical wellness. Just as the winter recedes into a mud season that Kathleen finds rejuvenating and bursting with energy, she enters her own "spring":

*Every cell  
 Of my being is vibrating,  
 resonating with life  
 as I acknowledge  
 full surrender  
 to being one with All.  
 I see myself, my humanity and God  
 everywhere in everything...  
 my journey continues.*

Tragedy and injury brought her to a place where she sought love and healing, finding it in basic spiritual truths such as: loving ourselves before we can love others; always walking forward in health because that is God's intent for our lives; and seeking spiritual wholeness in all of creation and seeing creation as a mirror of our inner lives. Through the ages, the Adirondack mountains have been a place of healing; spaces of mountains, woods and water became a safe space for Kathleen to rediscover her life, her life's purpose, and the powerful healing energy that allows purpose to move beyond oneself and become a gift for others.

This is a quiet little book that is designed to take its readers out of the dark places and losses in their lives into a place of healing and reclamation of purpose and Soul.



Suzanne Hagadorn, Program Coordinator of the CSP Partnerships of Fulton and Montgomery Counties, and CRAAB!'s newsletter editor and representative to the Partnerships, Cara Anaam, exchange ideas at the St. Mary's Hospital Breast Cancer Awareness Luncheon, held October 24. CSP Partnerships offer free screenings for breast, cervical, and/or colorectal cancers for men and women who qualify. For more information on how to contact your local CSP, see our website, [www.craab.org](http://www.craab.org).

### CRAAB! OFFICERS and EXECUTIVE BOARD MEMBERS for 2009-2010

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*Newsletter design & layout by Rogers Design*



# President's Corner

by Joan Sheehan

● October 5, 2010

The lecture by Dr. Linda Miller, PT, CLT was entitled *“Don't Lift More than 5 Pounds and Other Myths Following Breast Cancer Surgery”*. She explained the physiology of the lymphatic system, the pathophysiology of breast cancer lymphedema and insights into current research that encourage the development of safe, effective exercise programs.

**Such a program would include deep breathing, flexibility, resistive and aerobic exercises.** Dr. Miller's advice was to “re-condition the arm through a controlled and gradual exercise program” inclusive of these three types of exercises. If the limb is used as a barometer of response to exercise and if proper steps are taken while the exercise is performed, there seems to be no reason why a return to a full, active lifestyle cannot be expected after the onset of lymphedema, claims Dr. Miller.

Studies presented in her talk provided evidence-based conclusions that supported

*Continued on page 4.*

The last leaves have fallen and the dust has now settled on the flurry of fall activities for Breast Cancer Awareness. In this edition we share some photos with you from wonderful events that left us exhausted and exhilarated at the same time. CRAAB! is exceedingly grateful to the organizations we partnered with: St. Peter's PT Department; ToLife; Siena College's Sister Thea Bowman Woman's Center; Samaritan Hospital and the Susan G. Komen for the Cure, Northeastern New York Affiliate. We thank the organizations we conducted workshops for or who invited us to be present at an event. But remember, even though there is a frenzy of activity one month of the year, we are here for you in all twelve!

## Highlights from Fall Lectures ...



Top left: CRAAB! members, Siena faculty and students enjoyed dinner with Dr. Gayle Sulik after her Oct. 26<sup>th</sup> lecture on her new book, *Pink Ribbon Blues*, at Siena College.

Top right: Attendees were able to visit 13 exhibits by local cancer organizations and service providers, and Samaritan Hospital's breast cancer screening and treatment services at "A Woman's Journey," held at the Hilton Garden Inn in Troy on Oct. 27<sup>th</sup>.



Left: On October 15<sup>th</sup> Alison Lechowicz, proprietor of the Clifton Park Outback Steakhouse, is joined by Janice Pastizzo, owner of Fit For Life Wellness Center and Joan Sheehan, President of Capital Region Action Against Breast Cancer (CRAAB!), for a breast cancer fundraiser, "Luncheon for a Cause," to benefit ACS, the Susan G. Komen for the Cure, Northeastern New York Affiliate and CRAAB! All employees graciously donated their time to serve the lunch and there were many raffles and silent auction items to win!

this statement. Dr. Miller, a dynamic and humorous speaker, related complex information in easily understood terms that dispelled several myths surrounding lymphedema. Three studies were cited in her talk. (*J Clin Oncol* 27, 2008, *SportsMed* 35(6) 2005, *JSurg Oncol* 74, 2000, *J Clin Oncol* 21:3, 2003, *J Clin Oncol* 24, 2006, *N Eng J Med* 2009; 361:664-73. Dr. Miller shared the following implication from the data presented: **Exercise can be performed safely by women who have lymphedema or who are at risk for lymphedema.**

Evidence is becoming overwhelming in favor of breast cancer survivors engaging in physical activity as part of their long-term care plans. **CRAAB! offers yoga, pilates, Healthy Steps and Resist-A-Ball classes as important adjuncts to those plans. Check your mailbox for the winter flyer with class schedules.** Also remember to take advantage of Mary Ibbetson's free exercise program offered in partnership with the Ciccotti Center in Colonie every Monday from 5:30 to 7 p.m. She'll meet you in the lobby.

### ● October 26, 2010

CRAAB! was happy to be a sponsor, along with the Sister Thea Bowman Women's Center and other academic departments of Siena College, of the lecture presented by **Dr. Gayle Sulik relating to her new book, Pink Ribbon Blues.** The key theme was what it means to "pink" breast cancer, and Gayle presented both the positive and negative aspects of pink ribbon culture.

On the positive side are increased visibility and awareness about breast cancer; solidarity; making the disease a priority for research; allowing consumer input for research; improved treatment and the myriad support services developed over the past two decades. On the negative side, using the pink ribbon as a symbol for fundraising and marketing has become a boon for corporations, pharmaceutical companies and breast cancer organizations that profit from selling and marketing pink ribbon programs, making billions of dollars each year. Some devote only a small percentage of what they collect to breast cancer research, and/or don't disclose which research centers they are donating to or what kinds of research are being done.

The use of the pink ribbon is now a world-wide phenomena, and has been promoted to raise awareness or "publicize" breast cancer in a way that many women, including some cancer survivors, find inconsistent with and in some cases, insulting to their own experiences with the disease. Pink ribbon culture has become overtly sexualized, fantasized, and infantilized with the emphasis on sexy ads, balloons, children's toys, happy faces and endless encouragement to "shop for a cure," so that now breast cancer shares the products and symbols of a fun party. This has led to a counter-culture that asks: How are the funds raised *really* being used? Who or what is profiting from this billion dollar pink ribbon marketplace? Are the products bearing a pink

ribbon truly safe? Should we care whether the money is going to pharmaceutical companies and academic centers for new chemotherapy treatments, or to research centers that are investigating environmental causes and prevention methods?

**Gayle's book was reviewed in the New York Times on Tuesday, October 26,** alongside the book that Nancy Brinker, founder of the Komen for the Cure Foundation, co-authored with a professional writer. The reviewer cited Gayle's book as describing the "how-it-is" actual story of the breast cancer movement, and Ms. Brinker's book as being the "wish it were" and inspirational story, and told us not to read one without the other. Contact CRAAB! for copies of Gayle's book.

### ● October 27, 2010

**CRAAB! collaborated with Northeast Health/Samaritan Hospital's Women's Center, to present the program, "A Woman's Journey."** Before dinner at the Hilton Garden Inn in Troy, NY attendees were able to visit 13 exhibits by local cancer organizations and service providers, and Samaritan Hospital's breast cancer screening and treatment services. Over 170 people registered for this event, and there was a waiting list.

The guest speaker was **Dr. Donna Bacon, MSW, Ph.D., who is the Outreach Coordinator for Sisters United in Health and a professor at Nassau Community College.** Dr. Baker told her poignant personal story of being a breast cancer survivor in a family marked by both continual loss and remarkable fortitude. Her mother died from breast cancer at age 37, when Dr. Bacon was only four years old. This shattering event was followed by the deaths of her great-grandmother, her grandmother and uncle, which left teen-aged Dr. Bacon and her twin sister homeless, with no source of income.

Dr. Bacon, a brilliant student, doubled up on high school classes and entered college early, went on to get a Masters degree, then earned her Ph.D. soon after finishing her last treatment for breast cancer, with which she had been diagnosed at age 34. Two years later her twin sister was diagnosed with breast cancer, and both are now in remission. As Dr. Bacon modestly explains, her mission is now to help others, by encouraging everyone to get screened, do self exams and stay informed about risk factors and their health.

**Dr. Bacon delivered a strong message about risk reduction strategies, encouraging us to keep body fat down, not to smoke, drink only in moderation, exercise, avoid products with carcinogens, stay informed about environmental links to cancer, and build a support system of like-minded friends.** Dr. Bacon received a standing ovation for her honesty, her amazing strength and the courageous way she never gave up on herself, fought for her education and advocated for herself and her sister through diagnosis and

*Continued on page 7.*

From  
This  
Nurse's  
Perspective:

by Kim Baker, M.S., R.N.,  
CRAAB! Vice President

I've been attending an inspiring Wellness Program entitled "Origins of Health Series" and would like to share with you some of the valuable information presented by Mark Pettus, M.D., Chief of Medicine at St. Peter's Health Care Services.

Dr. Pettus is a strong proponent of the principles of epigenetics: that our genes alone do not determine our health or disease but rather our genes and the environment combine to influence how the gene is expressed. As Dr. Pettus so aptly states, "Our genes load the gun. Our environmental inputs pull the trigger."

Cancer, for example, has been thought to be linked to genetic mutations; that the genes themselves have become abnormal and irreversibly damaged. (With breast cancer, only 5-15% of cases are attributed to *hereditary* genetic mutations). Scientists now are beginning to realize that there might be other changes occurring that are related to epigenetic damage – modifications to chromosomes that alter gene-expression patterns – and that some types of cancer, diabetes, heart disease, high blood pressure, depression and auto-immune diseases may be caused entirely by epigenetic damage.

The key feature involved appears to be the number of times a cell has divided. As we age, our stem cells divide more frequently to replenish damaged aging tissue. Each time that the cell divides, there is a chance that epigenetic damage or injury can occur; therefore, anything that causes the cell to divide more frequently (or age) is an associated risk factor for disease. Smoking/cigarette exposure is an example of an environmental factor that can cause tissue injury. The lung of a smoker is 20 years older than the lung of a non-smoker. Sun exposed skin is another example of the changes that can occur to cells that have been damaged by an environmental factor.

Less obvious is the damage caused by environmental toxins or carcinogens such as Perfluorochemicals, otherwise known as Teflon, Scotchgard, Stainmaster and Gore-Tex and found in carpets, on clothing, on fast-food

# Don't Ask Why but Rather Why Not!

wrappers, and on the lining of pet food bags. Also troublesome is Bisphenol-A, a synthetic estrogen found in some hard plastic water bottles, canned infant formula, canned foods and cash register receipts. According to a new report from the President's Cancer Panel, "environmental toxins also play a significant and under-recognized role in cancer, causing 'grievous harm' to untold numbers of people."

But unlike genetic damage that is irreversible, epigenetic damage can, at times, be reversed or halted. With intervention, epigenetic repair can occur *without* the use of the treatments and medications that are often as toxic to healthy cells as the diseases they aim to treat. By taking control of your life and making the behavioral and attitudinal changes required to reduce tissue injury and aid in healthy tissue repair, you are bettering your chances of staying well, avoiding disease and, most importantly, reversing damage that has already occurred. Change does come at a cost and requires challenging and mindful work.

As Dr. Pettus states, "I passively accept less and consciously choose more" and although change is difficult, "current scientific evidence supports the idea that our primal mind-body systems are designed to adapt in ways that reward and reinforce positive emotions, thoughts and effective behavioral change." In other words, we have the capability of changing those difficult deep rooted thoughts and behaviors that may be causing "bad" health into healthier thoughts and behaviors that reduce the risk of age-related disease. As you start to make changes, you will begin to feel better and as you begin to feel better, the more you will want to change! Dr Pettus recommends making changes in four areas of your life.

*General guidelines are as follows:*

## Nutrition

- Reduce the number of high glycemic load calories e.g. breads, pastries, desserts, bagels, potatoes, sugar-sweetened drinks, chips, pretzels and candies. Also have fewer trans-fats and commercially processed vegetable oils/meats, red meats.

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# RECENT RESEARCH

Capital Region Action Against Breast Cancer



Fall/Winter 2010

*From Jessica Werder, M.P.H.*

*This report is made possible through a grant from the Susan G. Komen for the Cure Northeastern New York Affiliate. Please note that while the studies listed below are both scientifically and methodologically sound, caution should be taken in drawing conclusions from any one study. You can access this column in previous newsletters at [craab.org](http://craab.org).*

## Household Chemicals and Breast Cancer Risk

### Background and Recent Evidence:

Since 1994, the Silent Spring Institute in Massachusetts has been conducting a study known as the Cape Cod Breast Cancer and Environment Study.<sup>1</sup> The study has collected information from over 2,000 women, some with breast cancer and some without. Most recently, in July, the group released a study examining the links between household chemicals and breast cancer risk.<sup>2</sup>

Information was collected, via interview, about women's past experience using certain household cleaning products, air fresheners and pesticides, measuring frequency of use. In the first study ever to assess breast cancer risk and household cleaning products, researchers found a 2-fold increase in breast cancer risk among those women who reported the highest use of cleaning products and air fresheners; they found no association between reported pesticide use and breast cancer risk, which is consistent with previous studies.<sup>3,4</sup>

### Implications:

A number of household chemicals contain substances, such as endocrine disruptors, that have been linked to breast cancer, lending weight to the findings of this study.<sup>5,6</sup> However, researchers in epidemiology often point to *recall bias* as a potential weakness. The term refers to a situation in which someone is likely to remember something differently, based on a current outcome. In this study, it might be assumed that women who develop cancer remember using more chemicals in the past than they actually did, because they believe that chemicals may be responsible for their illness.

To address this concern in this particular study, researchers also asked study participants about their beliefs regarding what might contribute to cancer. They found that women with cancer who reported high use of household chemicals were more likely to believe that chemicals contributed to cancer risk. But, they also found that women who developed cancer and had a family history of cancer were more likely to believe that family history contributed strongly to cancer risk.

Researchers point to this fact as evidence that, while recall bias may exist, it may also be that women simply form their opinions based on their experiences. Epidemiology and science are important, but so is a person's intuition. In light of the possibility of recall bias in this study, more research should be conducted to examine the relationships between household chemicals and breast cancer risk, a connection that many women see as obvious.

## Novel Cancer Drug Trials: Olaparib

### Background and Recent Evidence:

PARP Inhibitors are a very recent class of cancer drugs which block the action of PARP, an enzyme that helps DNA repair itself.<sup>7</sup> By preventing cancer cells from repairing their damaged DNA, the drugs help ensure the death of these specific cells, and appear to be particularly useful when used to target BRCA1 and BRCA2 cancers, where the cancer mutations seem to affect DNA repair. In July, researchers published data from a clinical trial for the drug Olaparib, a PARP inhibitor.<sup>8</sup> Designed as a "concept trial," in which researchers could evaluate the "efficacy, safety, and tolerability" of the drug, the recent trial looked at 54 women with BRCA1 or BRCA2 mutations and advanced, recurrent breast cancer. The women were given three rounds of chemotherapy and then split into two groups; one group was given Olaparib while the other was not. Researchers then monitored the women for adverse effects and an *objective response rate (ORR)*, or the number of women in whom the cancer shrank or disappeared after treatment. The researchers found that women taking Olaparib had an ORR of 41%; those not taking the drug had an ORR of only 22%, when looking at

decreased tumor size. They also found that while side effects did exist, they were consistent with other cancer medications and included such things as headache, nausea and anemia.

### Implications:

As one of the first human trials of a PARP inhibitor, this recent research suggests that drugs such as Olaparib may be effective in targeting BRCA1 and BRCA2 breast cancers. The researchers also published data to suggest that Olaparib may also be effective in treating BRCA1/BRCA2 ovarian cancers.<sup>9</sup> In a comment published in the same journal, a scientist notes that these findings add weight to the new genetic-targeting approach that many cancer therapies are taking.<sup>10</sup> Additional clinical trials will need to be done to look at life extension as the key outcome of treatment, not just decreased tumor size or time to recurrence.

## New Origins for BRCA 1 Breast Cancer Cells

### Background and Recent Evidence:

The human breast has a gland system that is comprised of two different kinds of cells: “basal cells” and “luminal cells.” Basal cells include cells that are similar to skin cells and stem cells; luminal cells include milk-secreting cells and some cells that bind to hormones. It has traditionally been thought that most BRCA1 breast cancers arose from mutations in basal cells, and many cancers are labeled as “basal-like,” because they appear to share characteristics of basal cells.

In a recent study, however, scientists suggest that BRCA1 breast cancers start from mutations in luminal cells.<sup>11</sup> The researchers determined this after experiments in which they purposefully altered both basal cells and luminal cells in rats. They found differences in the resulting cancers. Rats with altered basal cells developed rare, aggressive tumors that are not often seen in humans. Rats with altered luminal cells, however, developed “basal-like” cancers that were very similar to BRCA1 cancer in humans.

### Implications:

It may be difficult to understand why such a distinction is important, but it does, in fact, have large implications for the ways in which scientists and physicians think about BRCA1 breast cancer prevention and treatment in women with this mutation. Knowing exactly what kinds of cells give rise to certain cancers allows scientists to explore new, targeted, and sometimes genetic, approaches to cancer prevention and treatment.

1. Silent Spring Institute. Cape Cod Breast Cancer and Environment Study. August 30, 2010. <http://www.silent.spring.org/our-research/communities-high-breast-cancer-rates/cape-cod-breast-cancer-and-environment-study>. What is new and interesting about this study is the possible link with other household chemicals, such as cleaners and air fresheners. The authors state: “No epidemiological studies we know of have reported on the relationship between cleaning product use and breast cancer, and previous breast cancer studies of pesticides have been largely limited to organochlorine compounds.”

2. Ami R Zota et al. Self-reported chemicals exposure, beliefs about disease

causation, and risk of breast cancer in the Cape Cod Breast Cancer and Environment Study: a case-control study. *Environmental Health* 2010, 9:40.

3. Teitelbaum SL et al. Reported residential pesticide use and breast cancer risk on Long Island, New York. *American Journal of Epidemiology* 2007 15;165(6):643-51. Epub 2006 Dec 13. This study found a possible link between lawn pesticide use and breast cancer among women on Long Island, but noted no association between use of “nuisance-pest pesticides, insect repellents, or products to control lice or fleas and ticks on pets.”

4. Farooq U et al. Self-reported exposure to pesticides in residential settings and risk of breast cancer: a case-control study. *Environmental Health* 2010, 25;9:30 This trial was designed mostly to evaluate whether or not a drug works as predicted so the indicator used was *objective response rate*.

5. Rudel RA et al. Chemicals causing mammary gland tumors in animals signal new directions for epidemiology, chemicals testing, and risk assessment for breast cancer prevention. *Cancer* 2007, 109:2635-2666.

6. Fenton SE. Endocrine-disrupting compounds and mammary gland development: early exposure and later life consequences. *Endocrinology* 2006, 147:S18-24.

7. Rouleau M. PARP inhibition: PARP1 and beyond. *Nature Reviews Cancers* 2010, doi: 10.1038/nrc2812. Advanced online publication.

8. Oral poly(ADP-ribose) polymerase inhibitor olaparib in patients with BRCA1 or BRCA2 mutations and advanced breast cancer: a proof-of-concept trial. *Lancet* 2010; 376: 245 – 251.

9. Tutt A et al. Oral poly(ADP-ribose) polymerase inhibitor olaparib in patients with BRCA1 or BRCA2 mutations and advanced breast cancer: a proof-of-concept trial. *Lancet* 2010; 376: 235–44.

10. Rouleau M. PARP inhibition: PARP1 and beyond. *Nature Reviews Cancers* 2010, doi:1038/nrc2812. Advanced online publication.

11. Molyneux G. BRCA1 Basal-like Breast Cancers Originate from Luminal Epithelial Progenitors and Not from Basal Stem Cells. *Cell Stem Cell*, BRCA1 Basal-like Breast Cancers Originate from Luminal Epithelial Progenitors and Not from Basal Stem Cells. *Cell Stem Cell* 2010, 7: 403–417.

## President’s Corner *Continued from page 4.*

post treatment care. Her uplifting spirit and delightful sense of humor further enhanced her warm rapport with the audience. There was hardly a dry eye in the house, but also lots of smiles and laughter. We are so grateful to the Susan G. Komen for the Cure, Northeastern New York Affiliate and to Genomic Health that helped fund this program.

### An Important Partnership

In late September Margaret Roberts and I sat down with representatives from **the Center from Health, Environment and Justice (CHEJ) who informed us about their new Poison Plastic (PVC) Campaign.** The off-gassing of polyvinyl chloride (a.k.a. PVC or vinyl) is permeating our schools, from vinyl flooring to computers, to vinyl backpacks and other school supplies. CHEJ recently released their brand new interactive website – This Vinyl School – to uncover all the sources of vinyl in schools – and suggest safer alternatives. A few simple changes will protect students’ health, and ability to learn.

I bring this campaign to the attention of our readers because PVC is associated also with breast cancer and more can be learned about this connection on the CHEJ website. Please visit <http://www.chej.org/thisvinylschool>. You can click through a virtual animated school to identify where this dangerous plastic is hiding, and healthier products. There are many suggestions for parents, teachers and concerned community members on the web site. Mike Schade is the PVC Campaign Coordinator for CHEJ and can be reached at 212-964-3680 or by email to [mike@chej.org](mailto:mike@chej.org).

# NBCC Conference

Joan Sheehan, Kim Baker, Wanda Burch, and Carol Davis represented CRAAB!  
at the NBCC Annual Advocacy Training Conference in Washington DC from May 22-25, 2010.  
See the Summer/Fall issue if you missed Joan and Carol's reports.

## Wanda Burch

The National Breast Cancer Coalition has been training breast cancer activists to influence research, advance public policy and drive the adoption of quality standards in health care since 1995. One of the ways they do this is through PROJECT LEAD, an intense week-long course that teaches the science of breast cancer and the practice of advocacy. Several of the offered concurrent conference workshops were reserved as sessions open only to Project LEAD graduates. As a year 2000 Project LEAD graduate, I attended a special session on PARP Inhibitor Research updates. The science behind PARP inhibitors was charted for easier comprehension and questions were received on the research's potential as a significant new breast cancer treatment for patients with BRCA1 mutation and triple-negative breast cancer.

PARP – Poly (ADP-ribose) polymerase – is a protein involved in one of the many DNA repair pathways, more specifically that of single strand breaks. Normally, these breaks are repaired but if they go unrepaired a double strand break may occur. This would normally be repaired by another pathway, but, in BRCA mutation carriers, the pathway is altered. So if the PARP pathway is inhibited and the pathway is altered, repairs are not completed and there is cell death.

Addressed were concerns surrounding the small number of participants in the clinical trial and the speed of delivery of information. In response, the panel emphasized the excitement surrounding the research and the enormous potential of the outcome in the first clinical trial. In the patients studied, no treatment related adverse events have been observed. A trend towards inhibition of PARP activity was observed in the first cohort, and significant inhibition of PARP levels was observed in tumor biopsies from all three patients in the second cohort.

At this time, there are nine or more PARP inhibitor drugs in trials or close to trials. Two of them are in Phase 2 and 3 breast cancer trials: Olaparib, an oral AstraZeneca product, and Iniparib, an IV BiPar/Sanofi-Aventis product. Two more drugs are in Phase 1 and 2 trials, both oral Abbott products. These trials have different designs, have different inclusion criteria, have different endpoints. Some are used singly, others in combination. It is expected that some of these drugs will be approved within a few years if the mature trial results are as compelling as the initial reports.

The drugs aren't perfect despite the enthusiasm and excitement. Two potential problems are the enhancement of toxicity when used in combination and the development of resistance. The toxicity seems to be dependent on the particular drugs used, the dose and the schedule. Problems include fatigue, nausea, and anemia but occasional more serious problems. Some of the challenges are finding the right dose; the right duration of treatment, the right combination or use as single agent; the right sequencing of the drugs; the amount of PARP inhibition needed to produce a clinical

benefit; the optimal relationship between inhibition in tumor cells and effects in normal tissue; and most importantly, targeting the most sensitive population by means of predictive biomarkers.

In the new research world of personalized medicine and unraveling the DNA puzzle, new discoveries are made every day – and every cancer is different. Discovering these differences has expanded research and broadened thinking toward more innovative research for the next generation of scientists.

## Kim Baker

The 2010 NBCC Annual Advocacy Training Conference was an unforgettable opportunity. One of the highlights for me was a plenary session titled: *All Breast Cancer Is Not The Same: Rethinking Some Old Issues*. In this session panelists: George Sledge, M.D., Ballve Professor of Oncology, Indiana University; Laura Nikolaidis, M.S., Director of Research Programs for the National Breast Cancer Coalition; H. Kim Lyerly, M.D., Professor of Cancer Research and the Director of the Duke Comprehensive Cancer Center; and William Redd, PH.D., Vice Chairman of Oncology Sciences and Director of Cancer Prevention and Control at the Mount Sinai School of Medicine engaged in a fascinating discussion on the current need to manage the research, diagnosis and treatment of breast cancer not as one disease but, as Dr. Sledge described, as many criminals sharing the same boarding house needing to be approached differently and punished differently.

Panelists acknowledged that breast cancer is much more complex than it was once thought to be. Histological analysis alone is inadequate to predict clinical outcome and should be only one factor in identifying the optimal therapeutic strategy. Individual tumors often carry a specific footprint and emphasis is now shifting toward specific individualized clinical management. Laura Nikolaidis stated it is becoming more evident to clinicians all the time that there isn't a "one size fits all" formula for diagnosis and treatment and that the same needs to be translated into risk reduction and research.

Dr. Lyerly discussed the importance of reducing environmental cancer risk and the emerging belief that our DNA may be altered not only by what we eat and where we live but also by lifestyle choices made by our parents and grandparents. Lastly, Dr. Redd addressed the mind/body role by asking the question, "do emotions affect breast cancer?" He acknowledged that there are many theories, opinions and controversies, both in support of and not, on the role that stress has in the development of cancer and cited three studies that suggested a correlation between stress and increased development of cancer. All were in agreement, in the end, that stress can not be dismissed.

Dr. Sledge ended the session by referring to an encouraging study on the benefits yoga has on breast cancer patients. The

*Continued on next page.*

# April Educational Series

Sponsored by

CRAAB! and THE COLLEGE OF SAINT ROSE Physical Education Department

## Prevention, Exercise, Symptom Management and Improved Life for Survivors

The College of Saint Rose, St. Joseph's Auditorium  
5:30 p.m.

**Tuesday, April 5, 2011**

### ***The benefits of various exercise programs to improve quality of life for survivors***

With Dr. Karen Mustian, Ph.D., M.P.H., FSBM; Assistant Professor and Director of the University of Rochester Medical Center, Physical Exercise, Activity and Kinesiology Clinical Research Core Laboratory in the Department of Radiation Oncology in the University of Rochester Cancer Center.

Dr. Mustian will present a program on her research into aerobic exercises, yoga, and tai chi for symptom management in the cancer patient.

**Tuesday, April 12, 2011**

### ***Potential prevention of breast cancer through nutrition, including Vitamin D***

With Dr. JoEllen Welsh, an Empire Innovations Professor at the Gen\*NY\*Sis Center for Excellence in Cancer Genomics at UAlbany. In 1994, Welsh was named a senior scientist at the W. Alton Jones Cell Science Center in Lake Placid, N.Y., focusing her research efforts on vitamin D and breast cancer.

Dr. Welsh will speak on her research examining the role of the vitamin D pathway in normal mammary gland development and the role it plays in a woman's susceptibility to the development of cancer.

Dr. Ann Neilson, Director of Physical Education at Saint Rose, says she "is delighted to sponsor an in-depth educational series that brings together people of different ages and life experiences to have a meaningful dialogue about possible ways to reduce this disease's impact on our society."

- College students will gain knowledge about the possible preventive measures and health benefits of exercise and be enabled to establish healthy behaviors early in life.
- Nursing students will, in addition, be able to pass on this important information to their future patients.
- Breast cancer survivors, including those with metastatic disease, will be introduced to practical ways to reduce stress and sleeplessness, and regain their energy, strength and stamina after debilitating treatments.

CRAAB! thanks the **Susan G. Komen for the Cure, Northeastern New York Affiliate** and all of you – CRAAB!'s generous donors – for making this unique education series possible.

**To register for either or both of these special lectures, call CRAAB! at 518-435-1055.**

## NBCC Conference *(Continued.)*

results were published Feb. 24 in a special physical activity issue of the journal *Psycho-Oncology*. The study involved 44 women with breast cancer; half were enrolled in a yoga program and half were put on a waiting list. After 10 weeks of classes, the yoga participants showed greater improvements in areas of mental health and positive emotions and spirituality than did the women still waiting to begin the yoga program. The yoga group reported, on average, a 50 percent reduction in feelings of depression and a 12 percent increase in feelings of peace and meaning. The

study participants also reported less fatigue while participating in the yoga program.

Through grants received from the Susan G. Komen for the Cure, Northeastern New York Affiliate and the NYS Department of Health Cancer Services Program CRAAB! is able to offer free yoga classes to breast cancer survivors at three convenient locations in Delmar, Schenectady and Amsterdam. Please call CRAAB! at 435-1055 for more information about these classes.

# Community Profile

This Community Profile is sponsored by a grant from the Community Foundation of the Greater Capital Region Assemblyman Robert Reilly Salary Fund.

by Diana Sponable and Jane McKinney

## Introduction

We met when Diana moved into the neighborhood. Jane noticed the pink ribbon magnet on Diana's car and introduced herself as a neighbor down the street and fellow cancer patient. We were being treated at the same time and quickly forged a friendship. Jane was already an active member of CRAAB!, which she had joined in memory of her mother and grandmother, both of whom had had breast cancer. She quickly introduced Diana. Together, we participated in several programs that CRAAB! offered, and shared many laughs and tears. Most importantly, the bonds we developed by sharing encouragement, strength, hope and positive energy with one another made us fast friends.

## Our experiences of cancer

Jane:

I was diagnosed April 22, 2008 with "Invasive Ductal Carcinoma, stage 1, no lymph node involvement, small tumor." The experience was surreal, but being a third generation survivor and being so involved with CRAAB! already, I knew I had to meet the experience head on. The oncologist offered me the option of having either a lumpectomy or mastectomy and to help make that decision ordered an Oncotype test of tissue taken at biopsy. The first tissue sample having been lost, my doctor had a second sample sent to the lab. The result was a score of 14 – right in the middle – where the test does not offer any guidance.

After further consultation with my doctor, I opted for a lumpectomy and radiation. I started radiation July of 2008 and was in increasing discomfort as a result of the treatments. At one of CRAAB!'s

programs I discovered that this discomfort was not common, which prompted me to go right back to my doctor. He immediately prescribed a course of antibiotics for several weeks and, when there was no improvement, I was started on steroids to treat the internal tissue damage from the radiation that was causing my pain. As this condition slowly improved, I began hormone therapies but experienced serious side effects. After trying several different drugs, I, with my doctor's approval, decided to stop taking them altogether. My medical team continues to monitor me closely, and my quality of life has been much improved.

Diana:

In January of 2007, a routine mammogram showed a cloudy area in my left breast. Having a family history of breast cancer, I was called back for further testing. The consultation resulted in further mammograms that resulted in my being given a clean bill of health.

In September 2007, I felt a small lump in the same breast and rushed to see the doctor. Another mammogram was ordered but at a surgical practice this time because of family history. The new doctors thought the results were inconclusive and warranted an MRI. After having that, I wasn't even home yet when the hospital was calling – I needed to undergo an ultrasound immediately. The MRI and subsequent ultrasound clearly showed a tumor in the same area questioned in January – my cancer was never visible on mammogram – even the day of the surgery.

On October 29, 2007, I was diagnosed with "a 1.1 cm invasive breast cancer tumor." I was given much the same treatment options as Jane, and chose a lumpectomy with chemo followed by radiation.

Chemo was a difficult decision, especially since if the diagnosis had been made in January, as it should have been, the chemo



Jane McKinney and Diana Sponable

would not have been recommended as the tumor would have been much smaller. Having three boys in middle school, I wanted to exhaust all the medical options offered, reasoning that would give me a better chance of being around to see them grow up. I too had an Oncotype test which scored right in the middle and therefore offered little guidance. I opted for the recommended four rounds of chemo with Taxotere and Cytosan followed by radiation; I'm now taking Tamoxifen. Having my boys made me keep a positive outlook so that we could keep our lives as normal as possible rather than letting them be consumed by my cancer.

### *The value of friends*

Our friendship is so important in the healing process! We laugh, we bitch, we compare notes, and we spend a lot of time with others who have been through cancer. Being around long-term survivors (there are several 20+ year survivors at CRAAB!) is so inspirational. We spend a lot of time at CRAAB! events – walking at the Crossings on Tuesdays, Healthy Steps on Thursdays, a variety of lectures. The great thing about these events is that every generation is represented and the camaraderie is ageless. Cancer brings people together in a way that most people will never understand. Sharing good times and bad times with those fighting the disease gives us hope for the future and really puts things in perspective.

### *What we learned*

Both of us found our cancers ourselves – accidentally. Listen to your body. Find a doctor you like, trust and can communicate with. Most importantly, be your own advocate. No one knows your body like you do. Doctors, nurses, technicians – they're all human – and humans make mistakes. Follow your inner voice if you think something needs to be tested or checked. Don't settle for an answer if you're not fully satisfied by it.

CRAAB! is a great place to get information because they offer such a variety of classes, programs and lectures. Those newly diagnosed will find CRAAB! to be an exceptional resource giving both well-researched information and the support of experienced survivors. Their events bring women of all ages and stages of treatment together yet the focus at these events is not cancer. It's about celebrating life after cancer!

We both strongly feel that there has been so much good that has come from this journey – the support and strength we receive from others, and the amazingly strong women we've met along the way. Cancer has given us much more than it has taken.



## A Nurse's Perspective

*(Continued from page 5.)*

- Add green-leafy, colorful red and yellow veggies, brown rice, blueberries, apples, grapes and cherries to your diet.
- Eat Omega-3 fish oils (2 grams EPA/DHA), nuts, avocados, whole grains, nutrient rich, high-fiber foods, organic meats and dairy.
- Vitamin D, 2000-5000 units/day to reach target blood level of 40+
- Probiotics, at least 10-20 billion strains/day.
- Eliminate food allergens/sensitivities e.g. gluten and dairy.
- Reduce drinking alcohol.

## Activity and Movement

- Start by adding 10-15 minutes of activity three times per week appropriate to your current condition. Even simple activity can bring about change.
- Take a walk in the park, work in your garden, join CRAAB!'s *Walking for Wellness Club*.
- Join a Pilates group, practice a resistance exercise. CRAAB! offers both, and more!
- Dance to your favorite music, alone or with someone you love.
- Exercise your brain with reading, puzzles, or journal writing.

## Mindfulness and Meditation

- Reduce stress and anxiety by practicing activities such as meditation, yoga, prayer and/or tai chi. CRAAB! offers three yoga & meditation classes.
- Incorporate laughter into your life.
- Don't underestimate the value of positive thought.
- Take a walk, ride a bike, sit under a tree, read a poem, keep a journal, enjoy a pet.
- Improve sleep hygiene: establish a sleep pattern by going to bed at the same time every night; reduce stimulation from tv's and computers at least one hour before sleep; keep computers and tv's out of the bedroom; add melatonin as a bedtime supplement as our natural circulating levels drop as we age.

*Continued on page 12.*

CRAAB! Board member and volunteer, Nancy Guest, gets the information table ready at the Community Block Party, held in September. It was sponsored by the **New Jerusalem Home of the Saved Church** in Albany and offered direct access for community members to the many agencies and services represented at the Block Party.



At the Komen Race, CRAAB! team members, parent Angela Kowalski and retired teacher Helen Tomaso, reunite. Reminiscing about their friendship at Roessville Elementary School, they discover that they now have something more in common!



# Thank You!

## **We welcome new members!**

Diedre Fitzgerald  
Angela Kowalski  
Michelle Lo

## **We are grateful for your donations! In Honor Of:**

All Cancer Survivors by Dawn Crouch  
Joan Sheehan by Angela Kowalski  
Joan Sheehan's birthday by her friends

## **Special Donations:**

Boscov's Department Store

## **Have you moved lately? Changed your phone number? Switched to a new email provider?**

If your contact information has changed, please send your current address/phone/email to CRAAB! so that we can continue to keep you updated on the latest programs and services we offer.

## **A Nurse's Perspective** (Continued from page 11.)

### **Social/Relationships and Positive Emotional States**

- Build and strengthen your support system.
- Make time for special friends and family, cuddle with a loved one, hold a baby, and call a friend.
- Join a social group – book club, card group.
- Volunteer for a favorite cause.
- Watch a favorite funny television show or movie.

More information may be found online at <http://www.savvypatient.com/index.html>.

Although there is much more to be learned about the mechanisms by which epigenetic alterations occur, this field has emerged as an important new area for research. I will bring you updated information and recommendations as I continue to explore this exciting topic.