



# CRAAB!

Capital Region Action Against Breast Cancer!

Vol. 12, No. 2 • Spring/Summer 2010

## CRAAB! Represented at EPA Roundtable

**M**argaret Roberts, along with her colleagues on the NYSBCN Environmental Committee, Karen Miller of Huntington Breast Cancer Action Coalition and Laura Weinberg of Great Neck Breast Cancer Coalition, were invited to the EPA Region 2 “Environmental Roundtable,” in New York City on April 16<sup>th</sup>. They also attended a focus group beforehand led by one of the EPA’s retired executives who wanted to learn how the EPA could best interact and communicate with grassroots and community organizations throughout the state.

At the Roundtable, Region 2 Director Judith Enck informed the diverse group from environmental and health organizations about new developments and on-going projects of EPA Region 2 (which includes New York, New Jersey, Puerto Rico and the Virgin Islands) and listened to the concerns of all the attendees, most of whom shared ideas to advance their main issues.

Karen Miller brought up the need for renewed efforts to remove lead in children’s products that are used everyday such as crayons and jewelry. She also expressed everyone’s hope and expectation that the EPA will now base its practices on science and evidence-based information, and not on politics. Laura Weinberg spoke about the need to have the EPA chemical screening process include studies of endocrine disruptors (EDs) and chemical effects on mammary gland development, as well as the need for a policy to determine if replacement

*Continued on page 5*



*CRAAB! is extremely grateful to have been chosen as a recipient of the Assemblyman Reilly’s Salary Fund managed by the Capital District Community Foundation. In February, CRAAB! Board members (from left) Francine Frank and Claudia Longo, and President Joan Sheehan, joined John Scherer, CDC Grant Committee, Assemblyman Robert Reilly, Karen Bilowith, CDC President and CEO, and Graham Jones, CDC Grant Committee, to accept the award.*

## CRAAB!

### Annual Meeting

**O**n the evening of April 27, 2010, the CRAAB! Board of Directors met in the office at 125 Wolf Road for its Annual Meeting as required by its by-laws. A motion was made and carried to change the titles of two elected officers from two Co-Presidents to a President and a Vice President, an option allowed under the aforesaid by-laws. The slate of candidates was presented, accepted, and then voted upon. Joan Sheehan will continue as President with Kim Baker being elected to serve as Vice President. Sally Heritage became the Treasurer while Michelle Ray continued as Secretary.

Bonnie Spanier, who was a co-founder of CRAAB! and has served with distinction as Co-President, will continue to serve as Board Member Emerita and as Consulting Scientist to the Board and the newsletter.

## CRAAB!

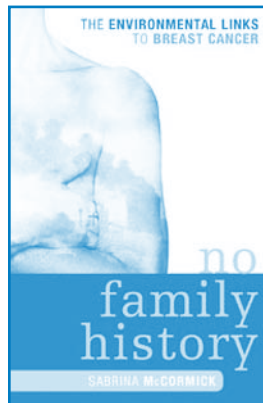
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# Book Review

## No Family History: The Environmental Links to Breast Cancer

By *Sabrina McCormick, Ph.D.*  
Review by *Debbie Marchesini*



What is the more important goal – finding a cure for breast cancer, or preventing the disease from developing in the first place? Both are vital, but the one that makes the most news (and raises the most money) is Finding THE Cure. This book, however, talks about the other issue – preventing the disease from occurring in the first place. Preventing breast cancers means discovering what factors cause them to develop, and then eliminating as many of these as possible. Genetic factors come into play in only a small percentage of breast cancer diagnoses, so other factors have been active in the majority. This book looks at the environmental links to breast cancer that are ignored at our peril.

While working for CRAAB!, I've spoken with many women who were shocked that THEY could receive a diagnosis of breast cancer. These were women who were in otherwise good health; they ate right, exercised, took vitamins, and had no family history of the disease. The questions that immediately jump to my mind are: Why are these women developing breast cancer? And: Can this happen to me?

Dr. McCormick's book focuses on a number of studies of "cancer clusters" – areas in the United States that have significantly higher numbers of women with breast cancer. She gives special attention to the Long Island Breast Cancer Study Project, which was a multistudy effort investigating whether environmental factors were responsible for breast cancer in Suffolk and Nassau counties (Long Island), NY, as well as in Schoharie County, NY, and Tolland County, CT. Researchers were to look at environmental factors, such as the effects of electromagnetism and home pesticide use, along with exposures to the many different chemicals found in everyday life. The debate over which factors would be included in the study brought together several organizations, including the West Islip Breast Cancer Coalition, the Huntington Breast Cancer Coalition, the Southampton Breast Cancer Coalition, Sister Support and One in Nine. In the end, all of the groups were disappointed by the number of "inconclusive" test results from the project.

Studies such as this one that try to investigate environmental causes of breast cancer are complicated. Determining the level of exposure to various chemicals throughout a person's life is challenging. I now wonder about the level of pesticides in my own body; I remember the trucks that drove around at night spraying for mosquitoes when I was a child. How much of that pesticide remains in me? Will I have health issues as I get older for something that happened early in my lifetime?

It is hard to determine which toxic agent is having a particular harmful effect. We are exposed to many chemicals each day; obvious ones such as car exhaust, and not-so-obvious ones, such as dust embedded deep down in our living room carpet. How can we study the effects of a single toxin on our bodies when we are exposed to so many others during the course of a day? This was the dilemma that confronted the Long Island Breast Cancer Study Project. Researchers were unable to pinpoint which environmental factor was the culprit in causing a particular breast cancer. There were too many factors intermingling within the bodies of these women. And what if the interaction between or among these factors was implicated? Studies have already identified possible classes of culprits: parabens, pthalates, polycyclic hydrocarbons and pollution. Further research is needed to provide women with information on ways to reduce their risks by limiting their personal exposure to them while as a society we work to eliminate them from our environment. I hope they hurry – I have a daughter.

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

President ..... Joan Sheehan  
Vice President ..... Kim Baker  
Secretary ..... Michelle Ray  
Treasurer ..... Sally Heritage

Board Members ..... Wanda Burch, Francine Frank,  
Brenda Ginardi, Nancy Guest, Janet Hotis,  
Michele Keleher, Claudia Longo

#### Staff:

Newsletter Editor ..... Cara Anaam  
Office Manager ..... Deb Marchesini  
Liaison to NYSBCN ..... Margaret Roberts  
Outreach/Program Coordinator ..... Margaret Roberts

*Newsletter design & layout by Rogers Design*



# President's Corner

by Joan Sheehan

*A picture is worth a thousand words!*



CRAAB! was honored by the Capital District Tobacco-Free Coalition as a Tobacco-Free Champion. Margaret Roberts (left) and I gratefully received our plaque from the Coalition's Project Coordinator, Theresa Zubretsky. Photo by: JoanHeffler.com



Senator Hugh Farley visits with Cara Anaam and Wanda Burch at the Community and Family Wellness Day in Amsterdam.



CRAAB! members enjoying the reception that preceded Lunafest.

I want to take this time to express my gratitude to Bonnie Spanier, co-president with me for CRAAB! for the past eight years. This past year she was conducting CRAAB! business and consulting with me from a distance and will continue to provide assistance using the miracle of the internet! Her knowledge of issues and scientific background keep us focused on evidence-based medicine. I would not be able to take on my current position without her guidance and support. I look forward to working with newly-elected officers Kim Baker, Vice President, and Sally Heritage, Treasurer.

Member Cay McEneny retired from the CRAAB! Board in late December. Her viewpoint as a survivor, knowledge of environmental issues and willingness to serve as an advocate have been a great asset to the Board. You may remember, Cay also served for several years with distinction as our Outreach/Program co-coordinator. Cay is a Master Gardener for Albany County and so continues to work for the community.

As the warmer weather approaches, come and walk in the park, attend or volunteer at the **CRAAB! Golf Tournament** on June 21 and/or the **Tennis Tournament** on July 17. There's something for everyone to be sure! 🦀

## Burch Given Prestigious Award



After 35 years as the site manager of Johnson Hall State Historic Site in Johnstown, NY Wanda Burch is retiring and on Saturday, March 20, friends and colleagues gathered to honor the contributions she has made to the site, the community, and to understanding the history of early New York. In recognition of Wanda's outstanding service, Carol Ash, Commissioner New York State Office of Parks, Recreation and Historic Preservation announced she had been selected to receive the L.L. Huttleston Special Achievement Award for 2010, the agency's highest award. Commissioner Ash wrote, "Your commitment is total, your life incredibly full." We congratulate her on this well-deserved recognition!

Wanda, among other activities, will continue to serve on the **CRAAB! Board**, paddle with **Hope in the Boat** and work with **Creative Healing Connections**, of which she is a founding member. Her life in retirement promises to still be incredibly full.

# Radiation Exposure

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

**H**ave you ever questioned whether there is any harm in receiving radiation from the medical imaging procedures ordered by your physician? Recently, we have seen much discussion in the press regarding unwanted exposure to radiation from medical imaging. This article will explain the controversy involved and what the U.S. Food and Drug Administration, FDA, is doing to address this issue.

“Radiation” describes a process in which energy waves travel through a medium with the ability to penetrate various types of materials. Radiation can be classified as non-ionizing or ionizing based on the amount of energy involved. Visible light, radio waves, and microwave radiation are examples of non-ionizing radiation and come from the lower part of the electromagnetic spectrum. Ionizing radiation involves more energy and is used in both radiation therapy and x-ray. Ionizing radiation has enough energy to potentially cause damage to DNA and consequently cause mutations or cancer.<sup>(1)</sup>

The dose of radiation used in a procedure depends on the density of the body tissue and the type of medical imaging used. For example, the radiation dose associated with a CT abdomen scan is the same as the dose from approximately 400 chest X-rays. The following chart compares various types of procedures as to how much radiation they deliver to an average adult.

**Table 1. Radiation Doses from Various Types of Medical Imaging Procedures**

Type of Procedure	Average Adult Effective Dose (mSv)	Estimated Dose Equivalent (No. of Chest X-rays)
Dental X-ray	0.005 - 0.01	0.25 - 0.5
Chest X-ray	0.02	1
Mammography	0.4	20
CT	2 - 16	100 - 800
Nuclear Medicine	0.2 - 41	10 - 2050
Interventional Fluoroscopy	5 - 70	250 - 3500

In Table 1, the average adult effective doses from various study types are compared to the average adult effective dose from a posteroanterior chest x-ray (0.02 mSv). (Mettler, Jr. FA, et al., July 2008.)

Unlike an x-ray that uses high energy ionizing radiation, ultrasound imaging uses high-frequency *sound*

waves to view soft tissues such as muscles and internal organs and magnetic resonance imaging (MRI) uses low level *radio* waves and magnetic fields to produce images.

While there is some disagreement over the extent of the cancer risk associated with exposure to radiation from medical imaging, there is broad agreement that steps can and should be taken to reduce unnecessary radiation exposure. On Feb. 9, 2010, the FDA, **unveiled an initiative to reduce unnecessary radiation exposure from medical imaging.** The initiative follows an investigation that revealed “206 patients who had been exposed to excess radiation at Cedars-Sinai Medical Center in Los Angeles over an 18-month period. Since then, the FDA, working with state and local health authorities, has identified at least 50 additional patients who were exposed to excess radiation of up to eight times the expected level during their CT perfusion scans.”<sup>(2)</sup> **The FDA is advocating the universal adoption of principles of radiation protection known as the “three-pronged initiative.”** This initiative targets three types of medical imaging procedures: computed tomography (CT), nuclear medicine studies, and fluoroscopy. These types of *ionizing radiation*, can increase a person’s lifetime cancer risk.<sup>(3)</sup>

## Three-Pronged Initiative

1. Promote the **safe use** of medical imaging devices by careful optimization of the radiation dose used during each procedure.

2. Support informed clinical decision-making with **appropriate justification for ordering** each medical imaging procedure.

3. Increase patient awareness of exposure by ensuring that every exam conducted is the *right* imaging exam, at the *right* time, with the *right* radiation dose. The patients should be exposed to a radiation dose that is **no more or no less** than what is necessary to produce a high-quality image and

have available *tools to track their personal medical imaging history.*

Additionally, **the FDA is developing new initiatives to ensure that patients receive safe medical imaging:**

*Continued on next page.*

1. Patient medical imaging card to serve as a way for patients to keep track of their own medical imaging history and that can be used as a tool to share with their physicians.
2. National dose registry of imaging procedures. A dose registry would pool data from many imaging facilities nationwide, capturing dose information from many imaging studies. This would help to define diagnostic reference levels, validate levels that do exist, and provide benchmarks for health care facilities to use in individual imaging studies.

Unfortunately, we do not know how often patients are exposed to unnecessary radiation during procedures, but according to a March 2009 report by the National Council on Radiation Protection and Measurements (NCRP), the U.S. population's total exposure to ionizing radiation has nearly doubled over the past two decades.<sup>(4)</sup> Unnecessary radiation exposure may be the result of performing an exam without appropriate clinical justification, or the use of more radiation than needed to create a high-quality image. The amount of unnecessary radiation a patient receives can also vary in its effect. A patient who receives a small amount of radiation may experience no immediate signs or symptoms, but the radiation may have damaged the DNA in the tissues that were exposed, increasing the risk that cancer may develop at that site in the future.<sup>(5)</sup>

The acting director of the FDA's Center for Devices and Radiological Health assures us that progress is being made in the investigation of excess radiation exposure.

As always, **a balanced public health approach seeks to support the benefits to be gained through the use of medical imaging while keeping exposure at a minimum.** Continue to follow your doctor's recommendations if you need to have a medical imaging procedure done, but also be sure to advocate for yourself by staying informed and asking questions as needed.

Reference:

1. <http://www.fda.gov/Radiation-EmittingProducts/RadiationSafety/RadiationDoseReduction/ucm199996.htm>
2. FDA Makes Interim Recommendations to Address Concern of Excess Radiation Exposure during CT Perfusion Imaging. 2009 (December, 7) <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm193190.htm>
3. <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm200085.htm>
4. In the early 1980's, the U.S. population's per capita exposure to ionizing radiation from all sources was 3.6 mSv. By 2006, that figure had risen to 6.25 mSv. (National Council on Radiation Protection and Measurements, *NCRP Report No. 160*, March 2009, pp. 242-243.)
5. White Paper: Initiative to Reduce Unnecessary Radiation Exposure from Medical Imaging Page Last Updated: 02/16/2010 <http://www.fda.gov/Radiation-EmittingProducts/RadiationSafety/RadiationDoseReduction/ucm199994.htm>

chemicals used in manufacturing are indeed *safer alternatives* and not carcinogens or EDs. She also stated that the drinking water contaminant candidate list (CCL) needs to be updated to include EDs and Bisphenol A (BPA).

Because our NYSBCN groups educate the public about environmental and health connections, my remarks centered around the need for greater public awareness about chemical policy reform and EPA's work in general. I think the public could benefit by having more *showcase* projects in Region 2 that highlight communities where environmentally sound practices are taking place. I also suggested that EPA projects could have a more holistic focus so that multiple green initiatives could be addressed at once at each project location; for example, when safer pest management is taught at day care centers, they could also present information on toxic-free toys, cleaning products and building materials. We also discussed the EPA's recent review of BPA.

During the meeting Ms. Enck and her staff took many notes and provided solid information about everyone's concerns. It's great to know that the EPA is now led by such dedicated and competent environmentalists who value science and community organizing. For more information, please visit [www.epa.gov/region2](http://www.epa.gov/region2).

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## Update: Gene Patents

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

In the Winter/Spring 2010 newsletter, I reported on a lawsuit against a company called Myriad Genetics. Myriad Genetics patented the two breast cancer genes BRCA1 and BRCA2, and by doing so, no one else can legally test for them, look at them, or even develop potential therapies that are based on them without Myriad's consent. The lawsuit charges that the patents on two human genes associated with breast and ovarian cancer are unconstitutional and invalid. The case had its first federal court hearing on February 2 before Judge Robert Sweet of New York, who was presented with impassioned arguments on both sides. On March 29, Judge Sweet made a precedent-setting ruling that patents on genes associated with hereditary breast and ovarian cancer are invalid. The judge wrote that the patents on the breast cancer genes had been improperly granted because human genes are indeed products of nature. Seen as a victory for hereditary breast and ovarian cancer testing, the ruling also calls into question the patents held on approximately 2,000 human genes and could have a far reaching effect by opening up medical research. Myriad Genetics is appealing the decision.

You can learn more about the case at [aclu.org/brca](http://aclu.org/brca) or by watching the April 4, 2010 CBS 60 Minutes segment: Should Firms Be Able to Own Your Genes? at [cbsnews.com/stories/2010/04/01/60minutes/main6354069.shtml](http://cbsnews.com/stories/2010/04/01/60minutes/main6354069.shtml)

# RECENT RESEARCH

CRAAB!

TIPS

Capital Region Action Against Breast Cancer



Spring/Summer 2010

From Jessica Werder, M.P.H.

*This report is made possible through a grant from the Susan G. Komen for the Cure, Northeastern NY. Please note that, while the studies listed below are both scientifically and methodologically sound, they are examples of promising cancer research at the level of genes and molecules and have not yet been translated into available treatment options.*

## PARP Inhibition

### Background and Recent Evidence:

In March, the Journal Nature Reviews Cancer published a piece in which the authors reviewed over forty years of research on a group of enzymes (proteins that encourage specific chemical processes) known as poly(ADPH-ribose) polymerases or PARP.[i] PARP has most recently emerged as an enzyme of particular interest in the cancer community due to its special role in DNA repair. PARP is activated when a strand of DNA breaks inside the cell and a long line of processes are initiated that eventually lead to mending the DNA strand. There are other enzymes that assist with the repair of damaged DNA, but cells in BRCA1 and BRCA2 mutant cancers rely primarily on PARP to repair their DNA. These particular cancer cells, therefore, are especially affected if PARP is turned off or inhibited, and are prone to die as a result. [ii]

Because of these and other findings, many pharmaceutical companies have created drugs known as PARP inhibitors, which weaken the normal functioning of the enzyme in hopes of killing the cancer cells. There are two approaches to using the drugs. The first involves targeting specific kinds of cancer whose cells are known to be sensitive to the lack of PARP enzyme. The other approach involves combining PARP inhibitors with DNA-damage-causing therapies, such as ionizing radiation and certain chemotherapies, where damage is deliberately inflicted on cancer cells. The elimination of PARP in these instances means that the cells will not be able to repair themselves and will likely die.

### Implications:

The immediate implication for the treatment of breast cancers of the ongoing clinical trials of these drugs is the possibility of a new class of targeted therapies for BRCA1 and BRCA2 mutant cancers. However, the authors do caution that there is much research yet to be done. As the drugs are blocking the normal function of DNA repair, there is the possibility that other cancers may arise, or that the primary cancer may recur in the long-run. There must also be investigations into other long-term effects on the cardiovascular system and on memory, in both of which PARP enzymes have been shown to play a role.

## Poverty Linked to Cancer

### Background and Recent Evidence:

Women of lower socioeconomic status have been noted to have poorer outcomes when diagnosed with breast cancer than those from higher socioeconomic classes.[iii] In a recent study, researchers attempted to uncover a biological explanation for this difference. To do this, they investigated the gene known as p53, which is normally responsible for the death of cells that exhibit abnormal growth. However, in cells with p53 mutations, the gene does not perform its usual function and cells can continue to grow abnormally, developing into cancer.

In the recent study, researchers looked at 246 women diagnosed with breast cancer in England.[iv] The women were followed between 1997 and 2001, during which time data were collected on the women's diagnosis, cancer type, treatment, surgical procedures and survival. In addition, each of the women was assigned a "deprivation rating" which corresponded with their address/postal code and effectively assigned them to one of 10 socioeconomic categories.[v] Scientists also examined DNA from each woman's tumor to look at the p53 gene.

Researchers found that women in the lowest socioeconomic ranking were significantly more likely to have a

mutation in this gene. Looking specifically at those women with a mutation, researchers found that 70% of women in the lowest socioeconomic class died as a result of cancer, while only 28% of those in all others classes died. A similar relationship was found regarding relapse, with more “deprived” women being much more likely to have cancer recurrence. The authors also examined the women for differences in treatment regimens, finding that differences in treatment did not account for the large discrepancy in death and relapse rates.

## Implications

The authors of this study have identified a possible biological mechanism that accounts for the known differences in breast cancer outcome between women of different socioeconomic classes. They have illustrated that p53 mutations play a serious role in cancer occurrence and possibly outcomes in women of lower socioeconomic classes. They point to the fact that past studies have demonstrated a significant relationship between stress-induced inflammation (the result of constant stress that comes with poverty), the p53 gene and cancer. In addition, it is possible that women from lower socioeconomic classes have greater exposures to environmental contaminants[vi], less access to antioxidant rich fruits and vegetables[vii] and participate in less exercise[viii]. Poverty is not genetic and therefore not directly related to cancer mutations; there must be social and environmental factors that lead to a higher rate of p53 mutations among impoverished women. The authors call for further research on the relationships between these factors to help identify the reasons that poorer, disadvantaged women have such a high occurrence of mutations and such a poor prognosis once cancer has developed.

## Tumor Self-Seeding

### Background and Recent Evidence:

Traditionally, cancer growth is categorized into two phases: primary cancer growth and secondary metastasis, in which cancer cells spread from the site of origin and cause cancer in other parts of the body. However, for a few years, researchers at Sloan-Kettering Memorial Hospital have been challenging this notion and advocating the theory of Tumor Self-Seeding[ix]. The theory suggests that not only do circulating cancer cells float around the blood stream and infect other parts of the body, but that these cells can also re-colonize the original tumor and help it expand at a faster rate[x]. In the December, 2009 issue of *Cell*, these same researchers published an article with direct evidence to support their theory.

In the study, the scientists inoculated mice with human breast and lung cancer cells to effectively create a tumor.[xi] They first injected labeled cells (these cells were treated with

a protein that glows under certain conditions and is therefore distinguishable from other cells). These labeled cells were used to form a donor tumor, which would release circulating cancer cells into the bloodstream. They then injected unlabeled cells to form a recipient tumor. After 60 days, the researchers examined the recipient tumors. What they found was that in over 80% of the cases, the recipient tumor had significant numbers of labeled cells from the donor tumor which had traveled through the bloodstream and colonized the recipient tumor. This showed that circulating tumor cells actually colonize existing tumors and that they are in fact more aggressive and provoke tumor growth, invasion and metastasis once they have circulated through the blood stream and returned to the original tumor or colonized another.

### Implications:

The authors suggest that the new model of cancer growth may help account for some situations that, to date, have not been fully explained or understood in clinical oncology. For example, it is still not fully understood how anaplasia (when cells cease to have the normal characteristics of surrounding cells and stop associating with them) happens and why it results in a poor prognosis. It may be because circulating cancer cells have returned to the original tumor and re-colonized it, resulting in a very disorganized cellular environment full of fast-growing, aggressive cancer cells. In addition, it may help to explain why recurrence happens after a tumor is removed (because of circulating cancer cells re-colonizing the original site) or why secondary tumors become much more aggressive after a primary tumor is removed. If cancer cells could be blocked from self-seeding, it may be possible to halt the aggressive growth and metastasis of certain tumors. However, creating such drugs will be difficult and time consuming.

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[iv] Baker L. p53 mutation, deprivation and poor prognosis in primary breast cancer. *British Journal of Cancer* 2010, 102: 719-726.

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[vii] Casagrande S. Have Americans Increased Their Fruit and Vegetable Intake?: The Trends Between 1988 and 2002. *American Journal of Preventive Medicine*: 2007, 32: 257-263

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[ix] Langreth R. The mathematics of cancer. *Forbes*, March 15, 2010. [http://www.forbes.com/forbes/2010/0315/opinions-health-cancer-larry-norton-ideas-opinions\\_2.html](http://www.forbes.com/forbes/2010/0315/opinions-health-cancer-larry-norton-ideas-opinions_2.html)

[x] Norton, L. Is cancer a disease of self-seeding? *Nature Medicine* 2006, 12: 875-878.

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# Advocacy in Action

by Margaret Roberts

## Access to Care: Taking Charge

On March 9, CRAAB! members joined breast cancer advocates from 25 organizations across New York State for the 12<sup>th</sup> Annual New York State Breast Cancer Network Education & Advocacy Day. During the morning educational program, Mark Scherzer, Attorney and Access to Health Insurance Advocate, spoke about “What’s Next in Health Care Reform for New Yorkers.” His presentation was an excellent summary of what he expected to be in the new Health Care Reform package and how it would specifically affect cancer survivors. He explained that New York State has one of the most comprehensive health insurance coverage systems in the country, thanks to a series of reforms started in the 1990s and advocated by New Yorkers for Accessible Health Coverage (NYFAHC), which have resulted in NY being the “gold standard for access.” Even so, New York’s policies are not as comprehensive or cost-reductive as they could be, and to rein in costs over time, to provide insurance coverage to millions of Americans, and to address the fragmented and inconsistent health insurance systems across the country, widespread reform was needed at the federal level. He made the following points:

- ▶ The percentage of uninsured citizens varies by state: for example, in New York, 15-16% of the population (2-3 million people) are uninsured; in



Top: Patsy Robertson of Breast Cancer Coalition of Rochester (BCCR) with Hope Nemiroff of Breast Cancer Options (BCO) in Kingston.

Middle: Students of New Visions in Kingston who have attended several Advocacy Days with BCO.

Bottom: Students from Rochester, NY attending Advocacy Day with BCCR.

Texas, over 25% are uninsured; and in Massachusetts, less than 5% of people are uninsured.

- ▶ States in which free market systems of insurance predominate and which have few or no state insurance programs in place, have the most uninsured people.

- ▶ Under 5% of the US population gets insurance coverage on their own; most people have insurance through their employer. Under the new law, most people will still maintain their health insurance through their employers; their premiums may be reduced after specific reforms take place while their coverage will probably be expanded.

Mr. Scherzer stressed that the new law, the “Patient Protection and Affordable Care Act,” is “not a government takeover of healthcare,” and in fact insurance coverage policies will still be sold and administered by private insurance companies, not government agencies. He outlined four issues addressed in the bill (which has now been signed into law): Accessibility, Affordability, Comprehensiveness, and Quality of Care, and explained how each would be implemented and how each compared with New York’s current state regulations. (For further information about his presentation, please contact CRAAB! or [nysbcscen.org](http://nysbcscen.org), the New York State Breast Cancer Network.)

## Bringing Issues to Legislators

During the afternoon session, we visited our state legislators to discuss our **support for the “Prescription Drug Out-of-Pocket Cost Limitation” bills (A8278A, S5000A)**. These **prohibit health insurers and HMOs from creating within their prescription drug formularies specialty tiers that could be used to force patients to pay a percentage of the cost of high-priced drugs, rather than a fixed amount or co-payment**. To strengthen our voice in support of these bills, the New York State Breast Cancer Network (NYSBCN) joined the Tier 4 Coalition and thereby partnered with other organizations focused on chronic diseases such as MS, leukemia & lymphoma, HIV/AIDS, lupus, psoriasis and others for which costly drugs are often required. The Tier 4 Coalition will continue to work together throughout the year to ensure these bills get passed and rising costs do not prevent those with chronic diseases such as cancer from getting the drugs they need.

We also spoke to our legislators about two issues involved in eliminating from the environment potential carcinogens and toxic chemicals linked to breast cancer. We first shared with them the research on **Bisphenol A (BPA), an endocrine-disrupting chemical that imitates the hormone estrogen**. Laboratory animal studies have shown that BPA can alter the expression of hundreds of genes, with effects varying among specific tissues and the timing of the exposure. Even at low doses it causes cell proliferation, mammary tumors and lesions in lab animals, interferes with normal immune function, and affects male reproductive systems causing adverse changes to testes, testosterone, and sperm development. It also has been linked to early puberty, type-2 diabetes, obesity and heart disease.

We called for **restricting BPA in children’s products, such as baby bottles and toddler drinking cups, for using safer alternatives to BPA in those products, and for labeling products that are BPA free so that the public has a clear choice in the marketplace**. While it has been shown that about 93% of the US population tests positive for BPA, research confirms that babies have up to eleven times higher levels of BPA in their bodies than do adults because they have greater exposure to BPA and a reduced ability to metabolize it. Children contain higher concentrations in their bodies than do adolescents who have higher levels than adults. In January, 2010 the U.S. Food and Drug Administration declared that BPA affects human development and said it is working to take the chemical out of infant formula cans and baby bottles. While some manufacturers have already eliminated it from their products and some retailers have agreed to eventually remove products with BPA from their store shelves, it is still found in hundreds of products we use on a daily basis.

Secondly, we asked our representatives to develop and **support legislation that requires state agencies to purchase commodities, services, and technologies that minimize potential adverse impacts on public health and**

**the environment, using specified criteria that include a prioritized list of toxic substances**. This requirement, parts of which were previously implemented by Executive Order by Governors Pataki and Spitzer, reflects a necessary precautionary approach to public health policy.

NYSBCN’s *Breast Cancer Advocacy and Education Day* begins the year-long shared mission of 25 breast cancer and health-related groups to educate our legislators and the general public about issues that negatively impact our health and the need for new policies and solutions. If you would like to join us, please contact CRAAB!

## Women’s Health & the Environment

On March 22, CRAAB! co-sponsored with Clean New York, Learning Disabilities Association of NYS, NYS Nurses Association, NYS United Teachers and Assemblywoman Linda Rosenthal, **The Symposium on Women’s Health & the Environment: Science and Solutions**. The symposium addressed scientific evidence linking women’s health with the environment, current policy and market trends towards safer materials and *sustainable chemicals* (sustainable chemicals and methodologies use renewable and/or recycled products that leave a reduced environmental footprint or impact – ex. Bio diesel fuel from plant sources). The conference illustrated how legislators, health advocates, nurses, teachers and others can work together to support policies, based on current research and empirical evidence, that protect women’s health and the environment. **Keynote speaker, Peggy Shepard**, Executive Director of WEACTION for Environmental Justice, was joined by fellow speakers – Dr. David Carpenter of the University at Albany and Dr. Maricel Maffini of Tufts University, **and by state legislators** – Assemblywoman Linda Rosenthal, Assemblywoman Crystal Peoples-Stokes, and Senator Bill Perkins.

Clean New York’s website: [clean-ny.org](http://clean-ny.org) has a summary report on the Symposium, including the actual power point presentations by Dr. Carpenter and Dr. Maffini, who in addition to her talk on the harmful affects of bisphenol A (BPA), presented the power point of Dr. Janet Gray of Vassar College who could not attend the event that day. The panel of advocates – Kathy Curtis (Clean New York), Cecil Corbin-Mark (WE ACTION), and Margaret Roberts (CRAAB!) closed the event with a comprehensive look at the advocacy scene in New York and nationally; they discussed in some detail the opportunities for actions on issues surrounding BPA, the New York Child-Safe Products Act and the reform of the federal Toxic Substances Control Act.

As is evident from this article, CRAAB! is active on your behalf within the advocacy community. Thanks to everyone involved with these important events.

# COMMUNITY PROFILE

*The Community Profile is a place for survivors to reflect on personal choices they made on their journeys through cancer to healing, the lessons they learned, and how they are changed.*

## Lessons I Never Learned In School ...

*by Astrid Duerr*

**M**y past experiences did not prepare me, while taking my regular morning shower on Feb. 29, 2004, for finding a lump in my right breast. Without any forewarning it had popped up over night and sent me into an emotional turmoil. I'd always had very regular menstrual cycles and, grasping at straws, was hoping it would "go away" after my next period. Needless to say, it did not!



Well known in our neighborhood as "Mrs. Healthy," I thought that I was the least likely candidate to develop any type of cancer due to my healthy lifestyle: daily power walking; organic, unprocessed foods; no smoking; almost no alcohol (My husband always teased me: "One or two tablespoons today?"); and no family history of cancer. I even breast fed our two boys for their first 11 months. However, in spring of 2004, after I'd had my very first mammogram, several biopsies and an MRI, we as a family had to face the harsh reality that I had DCIS Stage 1 breast cancer. Before this I had not known that there were different kinds of breast cancer, that, if such a diagnosis were made, I would have to deal with not only my gynecologist but with different oncology specialists, and how nerve-racking it would be to wait for test results, how exhausting it could be to tell my family and friends the same scenario over and over again.

Both while growing up in Germany and living for over seven years in Australia where I was trained as a clinical aromatherapist, I had always treated the minor illnesses I experienced with herbal and other natural remedies. With that mindset, I totally refused the suggested conventional medical route (mastectomy for sure and then, depending on the tumor pathology, chemotherapy, radiation, and tamoxifen) and tried to get rid of the cancer with a special diet and a natural remedy, which had helped a friend who had lung cancer. After six months the tumor had not shrunk but grown, so I did decide to accept surgery. During this discernment process I realized that you can face an illness alone and with others, but in the end nobody does the walking but you. Decisions about treatments

are very personal and, I firmly believe, should be respected by your family and friends as well as by your doctors, as mine were. I experienced what for me was the overwhelming outreach of friends and neighbors who provided daily dinners for my entire family for two months, so I could recover from the mastectomy. Having always been a very private person who could deal with everything herself (I thought), I learned to accept, and to even ask

for, help.

After the surgery, I continued with natural treatments and supplements supervised by an internist and was declared cancer free almost one year to the day after I had found the lump. Life was great for almost two years – until I felt another growth in the scar tissue and then another "cherry pit" in front of my neck. The cancer had returned with a vengeance. Within three months, which was three years after my initial diagnosis, I could feel the cancer-filled lymph nodes going up the side of my neck. This was the most traumatic period I had ever experienced in my life – I was so scared and worried about what would happen to our two boys if I died. I kept it a secret from them until another MRI confirmed that the cancer had spread to my sacrum. Now the feared chemotherapy seemed to be no longer one option among several, but the only hope I had to survive Stage IV breast cancer. I had read a lot about the toxicity of chemotherapy and its likely side effects, so I was very scared having to do it now.

I had already seen three different oncologists who all recommended the same treatment – aggressive weekly chemotherapy, radiation, more surgery – and gave no real hope for it all to be successful anyway. Because I was no longer keeping my situation so private, a friend of mine recommended another doctor who was a breast cancer specialist and I found the oncologist who would save my life. He very thoroughly analyzed my previous test results and images then decided to take the path to hormonal therapy and not go to immediate chemotherapy. This option was presented to me on my birthday – I was in tears of happiness that I did not have to go through

*Continued on next page.*

chemotherapy. Instead I was put into immediate menopause to starve the cancer, which was both estrogen and progesterone driven. In addition to monthly Lupron shots (no longer necessary since I had my ovaries removed last year) and Zometa infusions, I began taking one aromatase inhibitor pill daily. This treatment put me into remission and I had another clear scan in February, 2010.

Having used essential oil blends for many years, they were my main emotional and mental support to keep me from falling into and staying in the hole of fear and desperation. Even though I still have my moments and am extremely nervous when waiting for the next scan results, I know that the aromatic oils help me tremendously to ease this frightening journey.

After moving to New York, I was desperately looking for a breast cancer support group and found CRAAB! with Joan Sheehan. Even before we met in person, she gave me names

of local doctors and called me later to recommend the Life Coaching Class with Dr. Patricia Ford. Those weekly meetings were so comforting because, for the first time ever, I could talk about my feelings without needing to explain them, since all the other participants had also dealt personally with breast cancer. I joined the Pilates class at Fit for Life with Janice Pastizzo, also sponsored by CRAAB!, and it now provides a weekly grounding for me.

Breast cancer has taught me more than any degree course or teacher ever did: two big lessons I've shared with others are: 1) the importance of always getting at least a second opinion from a non-affiliated doctor, i.e. a doctor who does not come recommended by the initial doctor; 2) to have your hormones checked annually regardless of age. My journey has made me much more compassionate about other people's struggles and has opened many new doors for me, especially spiritually.

## CRAAB! Receives Donation from Amoena USA

Every year since 2003, Amoena USA Corporation, the world-wide leader in post-breast surgery products, has celebrated breast cancer awareness month by commissioning an artist to design lapel pins which are sold to raise funds for breast cancer support organizations. CRAAB! is pleased to be the recipient of funds raised this past year. On Thursday, April 8, 2010, at Marra's Pharmacy in Cohoes, Amoena presented \$1,000 to CRAAB! that we will use to fund our free Yoga & Meditation classes for cancer survivors. CRAAB! and Amoena have a shared goal to provide better quality of life for women following breast surgery. Marra's Pharmacy in Cohoes provides products by Amoena and other companies, and has four certified fitters on staff. Marra's also carries many products and will bill insurance companies that offer coverage for these. CRAAB! is grateful for Amoena's continued support, and we are happy to pass it along to survivors who attend our Yoga classes!



*Christina Rotondo (right), Territory Manager for Amoena USA Corporation, presenting donation to Margaret Roberts at Marra's Pharmacy boutique.*

## Genes, Germs and the Environment

*Report by Francine Frank, Ph.D.*

On April 15, 2010, I attended a lecture by John A. McLachlan, Weatherhead Distinguished Professor of Environmental Studies and Director of the Tulane/Xavier Center for Bioenvironmental Research, and sponsored by the School of Public Health of the University at Albany. The lecture, *Genes, Germs and the Environment*, examined three theories for understanding the causes of disease, and highlighted the intricate interactions among genes, germs, and environment in the understanding of cancer.

Dr. McLachlan focused on the many environmental estrogens, some produced by plants, others synthetic, such as DDT, PCBs and Bisphenol A, which are known to interact with the endocrine system. Those endocrine disruptors are factors relevant to the relatively new concept of epigenetics, which refers to changes in appearance or gene expression caused by mechanisms other than changes in the underlying DNA sequence. Evidence points to many examples of heritable changes without DNA damage (i.e., no mutation), as external signals become internalized. Research into this area is leading to a theory of epigenetics and an attempt to tie gene interaction networks to the ecosystem.

The talk ended with a summary of important theories: the germ theory of disease is well established, universal and predictive; genetic analysis is 150 years old, universal and predictive. Dr McLachlan believes that we can soon develop an epigenetic theory that is predictive of the effects of the environment on health.

I have only touched on a few of the topics covered by Dr. McLachlan. The related website is very good, especially the "learnings" section: <http://e.hormone.tulane.edu>.

*We invite you to become a member of CRAAB!. Call us at 518-435-1055 or contact us at [craab.org](http://craab.org).*



**CRAAB! RECEIVES KOMEN GRANT-**  
Margaret Roberts (left) accepts a check from Lynette Stark of the Susan G. Komen for the Cure Foundation. The grant will fund REAP the Benefits II, which includes support for the Recent Research newsletter column, and the support services Life Coaching at Gilda's Club, Medical Massage In Your Own Home, Yoga in Schenectady and Amsterdam, and Resist-A-Ball classes in Albany;

and also a project in partnership with the Adirondack Rural Health Network and the Clinton Essex Franklin Library System to develop and distribute Risk Reduction Information Cards with facts about nutrition, exercise and screening locations in the North Country; and a partnership with Northeast Health and the Women of Color Support Group to plan a Community Health Forum.

# Thank You!

## **We welcome new members:**

Helen Bosart  
Annie Graham Cosgrove

## **We are grateful for your donations!**

### **In memory of:**

Ann Egan by Maureen Luca  
Donald Short by Brenda Ginardi  
Donald Short by Nancy Guest  
Donald Short by Joan Sheehan

### **In honor of:**

Dr. Janet Gargiulo by Janet Britt  
Lisa Kordyjak by Harriet Rothstein

## **Special donations:**

Amoena

## Save the Date!

Call CRAAB! at 435-1055 for more information/to register.

### FUNDRAISERS

#### **3<sup>rd</sup> Annual Golf Tournament**

Take a Swing at Breast Cancer  
Town of Colonie Golf Course, Colonie  
**June 21**

#### **4th Annual Tennis Event**

Action Against Breast Cancer  
Albany Tennis Club, Albany  
**July 17**

### CRAAB! SPONSORED CLASSES

#### **Yoga & Meditation in Amsterdam**

United Methodist Church, Golf Course Road, Amsterdam  
Thursdays at 5:45 p.m.  
**May 6 to June 24**  
Led by James Meehan

#### **Resist-A-Ball Classes for Breast Cancer Survivors**

Plaza Fitness, Stuyvesant Plaza, Albany  
Mondays at 6 p.m.  
**May 17 to June 28**  
Led by Randi Jurus

### FOR SURVIVORS

#### **Casting for Recovery**

Wiawaka Holiday House Retreat, Lake George  
**August 13-15**

For more information about the fly-fishing program or to learn how to apply for the retreat, please email [info@castingforrecovery.org](mailto:info@castingforrecovery.org).

#### **Summer program for cancer survivors**

Peaceful Acres Horses, Inc, with a grant from the NENY Komen Foundation, is hosting weekend retreats in August and September for women recovering from breast cancer. Offering meditation, yoga, nutrition information and equine-assisted learning activities. More information available on [www.peacefulacreshorses.com](http://www.peacefulacreshorses.com) or by calling 518-887-3178.