



# CRAAB!

## Capital Region Action Against Breast Cancer!

Vol. 13, No. 1 • Winter/Spring 2011

### CRAAB! Receives Large Health Education Grant for “True Burden” Project

by Margaret Roberts, CRAAB! Program Coordinator and “True Burden” Project Director



Capital Region Action Against Breast Cancer (CRAAB!) is pleased to announce that we have received a two-year grant of \$150,000 from the New York State Health Research Science Board under the Patricia S. Brown Breast Cancer Education Community-Based Demonstration Projects. We will develop educational materials, including power points, brochures and website applications, on risk factors for breast cancer, and deliver them to students at five colleges in the Capital Region, including Albany Medical

College and Maria College of Nursing, and to several community groups. Albany Medical College will also post the materials on their website and use them for educational programs in upstate rural communities through their physician/educator program with the NYS Area Health Education Center System (AHEC).

The project, entitled “True Burden,” will explain the known or established risk factors for breast cancer, along with the growing body of research that links environmental and lifestyle factors to cancer. These factors are not well known by the public nor widely publicized by many cancer organizations, and may contribute to the United States and Western nations having 6 times the rates of breast cancer as undeveloped countries. The title “True Burden” references a quote from Dr. Lasalle D. Leffall, Chair of the President’s Cancer Panel, in the 2010 report, *Reducing Environmental Cancer Risk: What We Can Do Now*. He wrote, “The panel was particularly concerned to find that the *true burden* of environmentally induced cancer has been grossly underestimated.”

“... the true burden of environmentally induced cancer has been grossly underestimated.”

CRAAB! is working with Dr. David O. Carpenter, Director of the Institute for Health & Environment and Professor of Environmental Health Sciences & Biomedical Sciences at the University at Albany, and a participant in the President’s Cancer Panel meetings; Dr. Roxana Moslehi, Assistant Professor of Epidemiology and Statistics, School of Public Health at UAlbany; Dr. Bonnie Spanier, Associate Professor Emerita, University at Albany and former Co-

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### Save the Dates!

#### Yoga Classes

##### March 2, 9

Led by Mary Sloan, LCSW, LMT, RYT  
Wednesdays, Noon – 1:15 p.m.  
The Yoga Loft, 540 Delaware Avenue, Albany  
\*Funded by NYSDOH Cancer Services Program

##### March 2, 9, 16

Led by Vicki Braunstein  
Wednesdays, 5:30 – 6:30 p.m.  
Congregation Agudat Achim,  
2117 Union Street, Niskayuna  
\*Funded by Komen Foundation

##### March 3, 10, 17, 24, 31

Led by James Meehan  
Thursdays, 5:45 – 6:45 p.m.  
United Methodist Church,  
Golf Course Road, Amsterdam  
\*Funded by Komen Foundation

#### Healthy Steps™

#### Moving You to Better Health with the Lebed Method

##### March 3, 10, 17, 24, 31

Led by Diane Levesque-Kopecki, RN, MS, CLM  
Thursdays, 6 – 7:00 p.m.  
HopeClub, One Penny Lane, Latham  
\*Funded by NYSDOH Cancer Services Program

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## CRAAB!

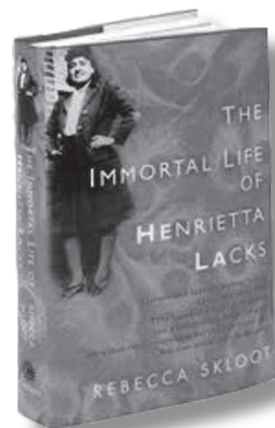
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## Book Review

### The Immortal Life of Henrietta Lacks

by Rebecca Skloot  
Reviewed by Melinda Kowaleski,  
CRAAB! member



Henrietta Lacks, the great-great granddaughter of slaves, her family and her immortal HeLa cells have played a critical role in the understanding of cancer, medicine, bioethics and racism in American history. Science writer Skloot describes how cancer cells taken from a poor, southern, African-American woman led to one of medicine's most important achievements. Skloot weaves three different story lines into a magnificent history and social commentary: the life of Henrietta Lacks, the history of her HeLa cells, and the author's own relationship with the Lacks' family, especially Henrietta's daughter Deborah.

Born in 1920, Lacks was diagnosed in 1951 at the age of 30 with cervical cancer and sought treatment at Johns Hopkins University in Baltimore, MD. A biopsy was performed, and, without her knowledge or permission, cell specimens of Lacks' carcinoma were removed, "standard procedure" at that time. The cancer samples were delivered to Dr. George Otto Gey, head of tissue culture research at Johns Hopkins.

Like many researchers hoping to find a cancer cure and understand cell growth, Gey had been unsuccessful for three decades in attempts to grow malignant and normal human cells in tissue culture. Henrietta Lacks' cervical cancer cells continued to grow aggressively, replicating exponentially. Henrietta died six months later, leaving a husband and five children, never knowing that her cells had been taken, replicated and used in one of the most important discoveries in modern medicine, an immortal cell line for cancer research.

HeLa, named by Gey after Henrietta Lacks, were the first cancer cells ever to be grown outside the human body. Gey sent Henrietta's cells to any scientist who requested them for cancer research. The Tuskegee Institute set up facilities to mass-produce Henrietta's cells, and began shipping 20,000 tubes of HeLa, about six trillion cells, every week. A multi-billion dollar industry selling human biological materials with enormous potential for medical and biological research was born.

As early as 1954, HeLa cells were used by Jonas Salk to develop the polio vaccine. Since then the cells have been used in research for cancer, AIDS, leukemia, influenza, Parkinson's disease, among others. HeLa cells were sent on the first NASA space missions to understand zero gravity. HeLa cells were the first ever cloned. Important cancer medications like Vincristine and Tamoxifen may be traced to

HeLa. HeLa cells have generated multi-billions of dollars in profit for medical researchers who patented Henrietta Lacks' tissues. Today, there are approximately 11,000 patents. Since 2001 alone, five Nobel Prizes have been awarded for research in which they played an important part.

The mystery of why Henrietta Lacks' cervical cancer cells became immortal in a culture remains, although there are clues. Scientists have found that exposing cells to certain viruses or chemicals can influence growth. Lacks had the HPV virus, other infections and lived near Bethlehem Steel in Maryland, known for environmental cancer-causing asbestos. Cancer cells become more abnormal genetically as they divide, so in theory one of her original cervical cancer cells was able to survive and continue

replicating – the origin of immortal HeLa cells.

Skloot states, "This was very frightening, particularly for Deborah. The science had a very scary sci-fi quality to it, so she had a very hard time distinguishing what was reality and what wasn't when it came to science. She worried that there were clones of her mother walking around that she might bump into. And she worried that what the research scientists were doing to her mother's cells somehow caused her mother pain in the afterlife. She'd say, 'If scientists are shooting my mother's cells to the moon and injecting them with chemicals, can she rest in peace?' For her, these existential questions were really difficult."

The Lacks' family remains upset about issues of money, proprietary rights and the fact that many have profited from their mother's cells, though they have not; they themselves cannot afford healthcare, the greatest irony. The Lacks family is hopeful that biotech companies and scientific institutions that may have profited from HeLa cells will recognize and honor Henrietta Lacks' contributions to medical science.

The core controversy of the Henrietta Lacks' story is that an individual's property was taken and used without

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#### CRAAB! OFFICERS and EXECUTIVE BOARD MEMBERS for 2010-2011

President ..... Joan Sheehan  
Vice President ..... Kim Baker  
Secretary ..... Michelle Ray  
Treasurer ..... Sally Heritage  
Board Members ..... Wanda Burch, Francine Frank,  
Brenda Ginardi, Nancy Guest,  
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Office Manager ..... Deb Marchesini  
Liaison to NYSBCN ..... Margaret Roberts  
Outreach/Program Coordinator ..... Margaret Roberts

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## President's Corner

by Joan Sheehan

### A New Year

The officers, Board members and staff of CRAAB! hope that our readership had a successful move from 2010 to 2011! I was just getting used to writing 2010 and now it is just as hard getting used to writing 2011! We thank all our members who were able to respond to our challenge grant in December, and I assure you the money raised will be carefully spent. All of our exercise classes are in full swing and appreciated by all who are able to take advantage of the classes we offer.

The 11<sup>th</sup> Annual Breast Cancer Awareness Event known as the **Pink Zone Game** was held on February 25. The Siena Women's basketball team in their pink uniforms played a terrific game and the event was a huge success for CRAAB!. We wish to thank all who helped make it so and will have a full report in the next edition of our newsletter.

### You're Invited

On March 15, 2011, CRAAB! will once again join many other grassroots breast cancer organizations from across the state as part of the New York State Breast Cancer Network to advocate for our 2011 legislative agenda. This year the title of the **Advocacy Day is The NYS Susan M. Cohen Education and Advocacy Day** in tribute to our past leader, Susan Cohen, who passed away in December and who was a driving force in the Network. Please read our tribute to Susan that can be found on page 9. We will be lobbying our

state legislators in favor of two bills. The first is **The Cancer Oral Chemotherapy Equity Bill**. This is an act to amend the insurance law, in relation to policy coverage of chemotherapy treatment. The second is the bill to **Restrict Bisphenol A in Thermal Store Cash Receipts**. More details can be found on page 12.

I remind everyone about the two special lectures we have planned in April at the College of Saint Rose, St. Joseph's Auditorium. Mark your calendar for **April 5 at 5:30 to hear Dr. Karen Mustian**, Assistant Professor and Director of the University of Rochester Medical Center. Dr. Mustian will present a program on her research into **aerobic exercises, yoga and tai chi for symptom management in the cancer patient**.

On **April 12 we will hear from Dr. JoEllen Welsh**, an Empire Innovations Professor at the Gen\*NY\*Sis Center for Excellence in Cancer Genomics at UAlbany. Dr. Welsh will speak on her research examining **the role of Vitamin D pathway in normal mammary gland development and the role it plays in a woman's susceptibility in the development of cancer**.

### National Lead Update

It has been awhile since CRAAB! reported on the Community Concerned about NL Industries (CCNL). See the newsletter article in Vol. 10, No. 1 Winter 2008. I am happy to say that, after much hard work by officers and activists Anne Rabe, Sharon Herr and Tom Ellis, a major victory was achieved in 2010 when the NYS Department of Health agreed to CCNL's request to conduct both a health study of residents

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## Save the Dates!

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### Life Coaching for Breast Cancer Survivors

**March 2, 9, 16**

Facilitated by Linnea Korotitsch, LCSW-R, CWC, CASAC  
Wednesdays, 6-7:30 p.m.  
HopeClub, One Penny Lane, Latham

### Pilates Classes

**March 4, 11, 18**

Led by Janice Pastizzo  
Fridays at noon  
Colonie Community Center,  
1653 Central Avenue, Colonie  
\*Funded by member donations.

### Educational Programs at the College of Saint Rose

**April 5** - Dr. Karen Mustian  
"Exercise and the Cancer Patient"

**April 12** - Dr. JoEllen Welsh  
"Nutrition and Breast Cancer"

### Medical Massage

By Mary Beth Halayko  
Call CRAAB! to make an in-home appointment.  
\*Funded by the Komen Foundation and NYSDOH Cancer Services Program

### NBCC's Annual Advocacy Training: "Changing the Conversation"

**April 30-May 3**

Washington, D.C.  
Call CRAAB! for information.

### Survivor Navigation

A Survivor Navigator (who will at no time offer medical advice) will act as your personal health advocate to help you create your own survivorship plan by providing emotional support and mentoring. Call CRAAB!.  
\*Funded in part by NYSDOH Cancer Services Program

### March 15

The NYS Susan M. Cohen Breast Cancer Education and Advocacy Day  
(See back page for details.)

From  
This  
Nurse's  
Perspective:



# What's It All About?

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

A very good friend asked me recently, "Why are you so involved with CRAAB! when you've never had breast cancer nor has anyone in your family?" It is true that I have never had *any* type of cancer nor do I have a strong family history of breast cancer. As someone who has had health issues since age 14, there are organizations I could give my time to that support people with health issues similar to my own. The question caused me to stop for a moment – not because I didn't know the answer, but because I wanted to make sure my words would ensure my friend understood why I feel so passionately about my work with CRAAB! This is what I tried to explain.

Although breast cancer does on occasion affect men, breast cancer is a woman's disease, not just limited to women who have had breast cancer or women who have risk factors, but **every** woman's disease. All women are at risk just by being a woman; and all of us know that if not ourselves, then our mothers, our daughters, our sisters or our friends could be diagnosed at any moment.

The more I do this work the more passionate I become, because I've realized that it's not just about cancer; it's bigger than that. It's about health, every woman's health, with or without cancer, and it's about **primary prevention of the underlying causes of disease!** It calls upon us all, collaboratively, to examine the environmental inputs in our lives such as diet, nutrients (including air and water), exercise and stress, and make the lifestyle changes that will improve our health.

The advocacy movement will undoubtedly continue to advocate for new and more effective treatment options and all of us at CRAAB! will continue to support that movement, but we also support interventions that will **ELIMINATE** breast cancer from occurring in the first place. Over the last 20 years, the National Breast Cancer Coalition (NBCC) has changed the world of breast cancer by creating new partnerships, collaborations, research funding opportunities and avenues for access to quality care. On September 20, 2010, NBCC launched a bold new initiative – a call to action for policymakers, researchers, breast cancer advocates and other stakeholders to **END** breast cancer by 2020!

It's time to move beyond awareness to action, peel back the pink to see what's really happening in research, treatment, prevention and cure. NBCC asks that we all become educated, "speak up on behalf of women and men everywhere and take action to end this disease." You can begin by helping the people you know distinguish between the falsehoods and the facts about breast cancer! NBCC has explained the following Myths and Truths in their publications and on their website:

- **MYTH:** Monthly breast self-exams save lives
- **MYTH:** Mammograms prevent breast cancer
- **MYTH:** Mammograms can only help and not harm you
- **TRUTH:** When breast cancer shows up on a mammogram, it may have been in your body for 6-10 years
- **TRUTH:** Breast cancer mortality rates are declining
- **TRUTH:** We don't know how to prevent breast cancer
- **MYTH:** Most women with breast cancer have a family history of the disease
- **TRUTH:** Risk of breast cancer increases with age
- **TRUTH:** Most people think they have a higher risk of breast cancer than they actually do
- **MYTH:** Every breast cancer is the same
- **MYTH:** Everyone who has the BRCA 1 or BRCA 2 gene mutation will get breast cancer
- **TRUTH:** The mortality rate from breast cancer is higher for African American women than for Caucasian women

- **MYTH:** There are drugs that can prevent breast cancer
- **MYTH:** With new treatments we can now cure breast cancer
- **MYTH:** Once diagnosed with breast cancer, it's very important to make treatment decisions immediately
- **TRUTH:** You should question your doctor
- **TRUTH:** Your tax dollars fund a significant amount of breast cancer research
- **MYTH:** All breast cancer research is good
- **MYTH:** My Senators and Members of Congress have no role in what happens in breast cancer research and treatment
- **TRUTH:** I can influence what happens in Washington D.C. about breast cancer
- **MYTH:** The media accurately reports breast cancer science
- **TRUTH:** I can educate myself
- **TRUTH:** I can make a difference

Find more at <http://www.stopbreastcancer.org/know/31-myths-and-truths/>



The State Employees Federated Appeal (SEFA) offers a convenient way for NYS employees to support a network of local, national and international community services all year long through the annual State-authorized fund raising effort. The NYS Environmental Facilities Corporation sponsors a number of events as part of the annual kick-off of the SEFA campaign as a means to raise awareness.

This year one of the events included a special "jeans day" on November 23<sup>rd</sup> to benefit CRAAB. For a \$5 contribution employees were entitled to wear jeans that day to work. The EFC raised a total of \$220 with this event to benefit CRAAB. Pictured wearing their jeans on the 23<sup>rd</sup> are (l to r) Mike Hale, Lance Crossett, Amy Grant, John McDonald (Joan Sheehan's nephew) Paula Ruff, Paul Valente, Katie Brennan, Judy Spadaro, and Judy Avent.

## Book Review *continued from page 2.*

permission. The argument is that just because it was standard practice at the time does not mean that there was nothing wrong with it. Abuses of patient consent dating back to slavery that came to light in the 1970s forced changes in laws and practices in regard to informed consent. The mistrust within African-American communities toward the medical establishment is sometimes undeniably well-founded. Rebecca Skloot expertly expresses how the story of the Lacks family, past and present, is inextricably connected to the dark history of experimentation on African Americans, the birth of bioethics, and the legal issues relating to ownership of our "selves."

As no system for informed consent was in place in 1951, Lacks' doctors acted within the rules of their time. According to Skloot, today it is illegal for a researcher to take a sample for research without informing the patient. However, the tissue samples that are left behind in a hospital from biopsies, blood tests, and other procedures may be disposed of as a hospital sees fit according to today's standard consent form. For additional insight on patents and research, please read Kim Baker's article in the Winter/Spring 2010 CRAAB! newsletter entitled "The ACLU Asks: Are Patents on Breast and Ovarian Cancer Genes Unconstitutional?" and the "Update" in the Spring/Summer 2010 issue.

In January 2010, Rebecca Skloot founded The Henrietta Lacks Foundation which provides financial assistance to individuals who have made contributions to scientific research without their knowledge or consent. The Foundation gives those who have benefited from biological contributions including scientists, universities, corporations, and the general public a way to show appreciation. Skloot donates a percentage of her book proceeds to the foundation and the Lacks' family will receive compensation for acting as consultants on the upcoming HBO film produced by Oprah Winfrey.

Skloot concludes, "It's clear that the public and the courts believe new guidelines and regulations are necessary, but any new oversight must not slow the progress of science." I would recommend this book to any reader because Rebecca Skloot successfully brings a complex scientific and ethical subject down to earth and intertwines the real personalities of the Lacks family into a story that is fascinating, entertaining, spiritual and profound.

To learn more about Henrietta Lacks, HeLa and the Lacks Family:

[www.rebeccaskloot.com](http://www.rebeccaskloot.com), [www.lacksfamily.com](http://www.lacksfamily.com),  
[www.henrietalacksfoundation.org](http://www.henrietalacksfoundation.org)

## Jeans for CRAAB!

# RECENT RESEARCH

Capital Region Action Against Breast Cancer  Winter/Spring 2011

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 exercised in drawing conclusions from any one study. You can access this column in previous newsletters at [craab.org](http://craab.org).

## Hormone Therapy

### Background and Recent Evidence

The Women's Health Initiative was a venture launched by the National Institutes of Health in 1991.<sup>1</sup> Enrolling over 161,000 participants, the study aimed to answer questions regarding cardiovascular disease, cancer, and osteoporosis in postmenopausal women who had no signs of these diseases. To achieve this aim, the study took three tracks: 1) a clinical trial to examine new approaches to disease prevention; 2) an observational study to identify predictors of disease and; 3) an analysis of selected programs focused on developing healthy behaviors.

Over 60 scientific publications resulted from the 15-year study, including a number of publications reporting data from the Hormone Therapy Trial (a part of the larger clinical trial) conducted to examine the effects of estrogen-progesterone hormone therapy (HT) on women aged 50-79. After almost 6 years studying HT, the initiative confirmed what had been suspected from previous, smaller studies: estrogen-progesterone HT presented an increased risk for developing invasive breast cancer.<sup>2</sup> They also found that women on HT had more frequent delays in breast cancer diagnosis, which often resulted in late-stage cancer, and had an increased risk for certain cardiovascular issues, including heart problems and blood clots.<sup>3</sup> **Following this discovery, the study was ended to prevent further negative effects to participants' health.** Though it was known that breast cancer risk increased with the use of HT, no data was ever published on women's mortality.

This year, researchers finally published that data, over 12 years after the start of the original trial. The results were recently published in the *Journal of the American Medical*

*Association*.<sup>4</sup> Data suggest that the trend observed in the original study remains consistent as women get older: women who received HT are more likely to develop breast cancer. But the data also show something more. **Women who received HT in the study had a higher rate of breast cancer-related death** than did the women not treated with HT. **Women receiving HT also had higher rates of death from any cause after a breast cancer diagnosis.**

### Implications

When the initial results were released from the WHI Hormone Therapy Trial, HT use in the United States fell dramatically. This decreased use has often been given credit for falling rates of breast cancer in recent years. However, some physicians still employ the use of HT for women who have passed menopause. **These results should further underscore the significant, negative effects that HT can have on women's health.**

## Fatalism and Latina Cancer Screenings

### Background and Recent Evidence

It has been well documented that a number of barriers prevent minority women from carefully following cancer screening recommendations. One recent review article looked at prior studies and compiled a list of these barriers: low income, lack of health insurance, poor knowledge about cancer screenings, language barriers, transportation issues, embarrassment, and little trust in the health care system.<sup>6</sup> Identifying such barriers is important to both physicians and health educators alike, because they must be overcome if women are to make healthy, informed decisions. Ideal health environments aim to reduce these barriers.

In another recent publication, researchers identified and examined a barrier common among Latina women: fatalism. Fatalism refers to the idea that events in life are the result of fate and, therefore, cannot be changed. When referred to in the context of health screenings, fatalism is often viewed in a negative light. Women who are influenced by the idea of fate may tend to think that cancer is not preventable, nor is it curable once detected. This may limit women's inclination to

seek out cancer screenings and treatment.

Published in the *International Journal of Behavioral Medicine*, the report examined 11 separate studies that had looked at the connection between fatalism and Latina women's inclination to seek out cancer screenings. In general, the researchers found that fatalism appeared to have a negative effect on Latina's health behaviors.<sup>7</sup>

### Implications

Cultural beliefs and personal attitudes are important components of an individual's motivation in making decisions. Identifying the particular attitudes that may negatively impact a woman's decision to seek out cancer screening is an important first step in designing health promotion programs. Such programs can empower women and encourage them to be pro-active about their own health. They are particularly important for women who face enormous barriers in making healthy decisions for themselves.

## Oral Contraceptives

### Background and Recent Evidence

Many studies have been done to assess the relationship between oral contraceptives (birth control) and a woman's risk for breast cancer. From these studies, conflicting results have been published. Some studies link oral contraceptive use with an increased risk of breast cancer.<sup>8</sup> Others suggest that women at higher risk, such as those who carry the BRCA1/BRCA2 gene and women with a family history of cancer, may be more vulnerable to the risk posed by hormones in oral contraceptives.<sup>9</sup> Yet, other studies conclude that use of oral contraceptives presents no additional risk for breast cancer among women with these recognized risk factors.<sup>10,11</sup>

A recent study by a team of researchers at the Harvard School of Public Health may shed some additional light on the matter. In the October, 2010 issue of the journal *Cancer Epidemiology, Biomarkers and Prevention*, the researchers published the results of their study on over 116,000 women, ages 25 to 42. They found that women who were using birth control at the time of the study had a moderately increased risk of developing breast cancer.<sup>12</sup> But they also found a more interesting result: women using a specific class of birth control, were *three times more likely to develop breast cancer*. This class of birth control is referred to as "triphasic" hormonal contraceptive. In triphasic birth control pills, the ratio and dose of estrogen and progesterin (hormones) per pill changes three times throughout the pill pack, or once every 7 days; biphasic pills change dose once during the month and monophasic pills have a constant hormone dose in every pill, throughout the entire three weeks of active pills. Triphasic birth control pills that used a kind of progesterin called levonorgestrel were the pills that resulted in the high risk for

breast cancer. The two specific triphasic brands assessed in the study were *Tri-Levlen* and *Triphasil*; among women who were currently using these two brands, risk of breast cancer was significantly elevated.

### Implications

This study may be the first on record to report risks associated with specific kinds of oral contraception. To date, studies have had conflicting results regarding the risk that oral-contraceptive use may pose in terms of breast cancer. This new information highly suggests that this may be because *different types of oral contraception pose different risks*. The immediate implications are for women who may be using a triphasic contraceptive with levonorgestrel as the progesterin (many women will need to ask their doctor about this). And, as always, women who already have an increased risk, such as those with familial breast cancer or who know they carry BRCA1/BRCA2 mutations, should be particularly careful. But the implications are larger than this. More drug-specific, long-term studies should be conducted to determine what, if any, risk a woman might acquire from using oral contraception.

<sup>1</sup> Women's Health Initiative. National Institutes of Health. December 12, 2010. <http://www.nhlbi.nih.gov/whi/index.html>.

<sup>2</sup> Chlebowski R, et al. Influence of estrogen plus progesterin on breast cancer and mammography in healthy postmenopausal women: the Women's Health Initiative randomized trial. *Journal of the American Medical Association* 2003, 289(24):3243-3253

<sup>3</sup> Chlebowski RT et al. Estrogen plus progesterin and breast cancer detection by means of mammography and breast biopsy. *Archives of Internal Medicine* 2008, 168(4):370-377.

<sup>4</sup> Chlebowski RT et al. Estrogen plus progesterin and breast cancer incidence and mortality in postmenopausal women. *Journal of the American Medical Association* 2010, 304(15):1684-92.

<sup>5</sup> Hersh AL et al. National use of postmenopausal hormone therapy: annual trends and response to recent evidence. *Journal of the American Medical Association* 2004, 291(1):47-53.

<sup>6</sup> Alexandraki I, Mooradian AD. Barriers related to mammography use for breast cancer screening among minority women. *Journal of the National Medical Association* 2010, 102(3):206-18.

<sup>7</sup> Espinosa de Los Monteros K et al. The Relevance of Fatalism in the Study of Latinas' Cancer Screening Behavior: A Systematic Review of the Literature. *International Journal of Behavioral Medicine*. 2010 Oct 17. [Epub ahead of print].

<sup>8</sup> Delort L et al. Risk factors for early age at breast cancer onset: The "COSA Program" population based study. *Anticancer Research* 2007, 27:1087-1094.

<sup>9</sup> Pasanis P et al. (2009). Oral contraceptive use and BRCA penetrance: A case-only study. *Cancer Epidemiology, Biomarkers and Prevention* 2009, 18:2107-2113.

<sup>10</sup> Gaffield ME et al. Oral contraceptives and family history of breast cancer. *Contraception*. 2009 Oct;80(4):372-80. Epub 2009 Jun 10.

<sup>11</sup> Iodice S et al. Oral contraceptive use and breast or ovarian cancer risk in BRCA1/2 carriers: a meta-analysis. *European Journal of Cancer* 2010, 46(12):2275-84.

<sup>12</sup> Hunter DJ et al. Oral contraceptive use and breast cancer: a prospective study of young women. *Cancer Epidemiology, Biomarkers and Prevention* 2010, 19(10):2496-502.

living near NL Industries as well as urine testing for uranium levels in approximately 100 residents and 100 former NL workers. (Video on DU at: <http://www.youtube.com/user/ICBUW>)

I want to share the following reports as first published in the November 2010 CCNL newsletter and written by Co-Chair Anne Rabe. CRAAB! continues to support the efforts of CCNL to investigate the possible connection between exposure to depleted uranium and the development of many forms of cancer. We join with them in the desire to seek social justice for all affected by the radioactive contamination of the NL Industries site in Colonie.

### NL Health Study Overview

CCNL's health Committee has been meeting with the DOH staff to design the health outcomes study. This committee includes Tom Ellis, Sharon Herr, Anne Rabe, Nancy Snow, Joan Sheehan and Dr. David Carpenter of the University of Albany School of Public Health. CCNL and DOH have developed a list of illnesses, time periods and geographic areas for the health study design. As we move forward on this effort, both CCNL and DOH will provide public updates to the community surrounding NL Industries.

### Illnesses and Time Periods

DOH has the following databases that can be used for the study:

1. Cancer Registry
2. Birth Defects Registry
3. Hospitalization Records (Includes autoimmune disorders and other illnesses related to uranium exposure.)

DOH has tentatively agreed to look at the following illnesses and time periods for residents and compare them with statistics on the state level as well as an unexposed Capital District community.

1. **All Cancers from 1970 to 2004.** A summary total of all cancers and a sub group total of radiation-related cancers like leukemia, bone cancer, etc. can be done.
2. **All birth defects from 1970 to 2004.** A total of birth defects grouped by methodology would need to be done as DOH changed their methodology process over the years.
3. **Targeted diseases from Hospitalization Records from 1993 to 2006.** This focuses on diseases of the autoimmune system (Lupus, Crohn's, rheumatoid arthritis, etc.); kidney diseases; lung diseases; thyroid diseases; and others.

### Geographic Area

Geographic area is a key factor. If it is too large an

area, it can include unexposed people and "wash out" any statistical significance. If it is too small an area, it can result in too small numbers with no statistical significance. Therefore, we are looking at a three ring approach based on exposure levels.

1<sup>st</sup> ring – By streets, covering the contaminated residential areas that were remediated by the federal government because they had levels of depleted uranium in excess of the cleanup standard.

2<sup>nd</sup> ring – By census tracks, covering the 1/3 mile area where uranium was found in soil which follows the wind flow contamination plume.

3<sup>rd</sup> ring – By census tracks, covering the 2/3 mile area where uranium was found in soil which follows the wind flow contamination plume.

### NL Testing Project Overview

DOH received a large federal grant for a number of bio-monitoring projects including "assessing exposure to depleted uranium (DU) in residents and workers of NL Industries." They have already purchased the highly sensitive equipment and are gearing up to start testing people in the next six months. The testing project may take up to 2-3 years to complete.

### Test 100 Residents and 100 Workers

CCNL requested that 100 former NL workers and 100 residents have their urine tested for depleted uranium, focusing on those who were most exposed. The residents would be selected based on these criteria; Lived close to NL in the remediated area and lived there for at least 10 years between 1958 and 1980. CCNL requested that everyone be tested for Total Uranium (U) and Depleted Uranium (DU). DOH is considering going with a staggered approach – if significant U excretion is found, then they will do a more detailed DU excretion level.

DOH also agreed to test teeth and bones of exposed residents or former workers. So far, CCNL has gathered 13 teeth and lone hip bone from highly exposed residents and DOH has agreed to test them as well. These tests can add to the body of scientific knowledge in terms of comparing the teeth results with urine results. It is possible that DOH may also do bone tests for some people to find out about lead exposure.

CCNL will work with DOH on the community outreach process. In 2011 DOH will hold public meetings for people interested in being tested. If you are interested in being tested and lived near and/or worked at NL Industries between 1958 and 1981 please contact Anne Rabe at 782-4358 or [annerabe@msn.com](mailto:annerabe@msn.com).

## Susan Cohen: Our Leader, Teacher, Inspiration

By Andi Gladstone,  
NYSBCN Executive Director,  
and Margaret Roberts,  
NYSBCN Board Member

Susan M. Cohen, 69, beloved co-founder and Chair of the New York State Breast Cancer Network, died on December 22, 2010, in New York City. Susan, a public service lawyer with Legal Services NYC, was a fierce advocate for low-income tenants and breast cancer survivors.

Susan co-founded NYSBCN with a small group of other New York State breast cancer survivor power-houses in 1998. For the past twelve years she has been our leader, our teacher, and our inspiration. NYSBCN is the only statewide network of free-standing, survivor-driven, community based, breast cancer organizations in the country. Our member organizations, located in different regions of the state, are represented by their chosen delegates – a group of passionate, strong-willed, opinionated community leaders. The groups serve different populations and have their individual approaches and priorities in the struggle against breast cancer, yet we all develop and promote Network activities throughout the year that advance the public policy agenda we introduce at annual Advocacy Days in Albany.

When we began in 1998, our member organizations were competing for the few, private foundation grants available for community-based breast cancer organizations. It would have been easy for us to implode into disarray and competition. Susan had another idea. She believed that our differences could become our strength. Susan knew that to be successful we had to address three areas – access to quality care, direct support services, and primary prevention or environmental links to breast cancer. However, because we are small, under-funded organizations that work hard each day just to keep our doors open, many of our groups can only focus on one priority – not all.

Susan's vision was a structure that was loosely knit enough to encompass our differences, but tight enough to be a unified, strong voice in public policy decisions. Under her direction, we agreed to support each other's priorities, without having to become experts in every aspect of the breast cancer movement. We depend on each group to inform us about their particular area of



expertise and guide us to the most relevant issues and legislation. It's a brilliant design and it works.

Susan was a tireless advocate, often interviewing legal clients after midnight hours, and composing the Network's memos of support and other Advocacy Day materials until the early morning hours. She excelled at writing, strategic thinking and negotiating with advocates and state lawmakers. Despite putting in long hours organizing Advocacy Day, and leading NYSBCN annual meetings the day before, Susan was able, with the help of multiple cups of coffee, to moderate the intense day-long events of twelve Advocacy Days and lead SHARE's legislative visits with

boundless energy, focus and grace under pressure.

Susan, together with other Network board members, spearheaded important legislation, including: establishing the Survivors Support Initiative that awards state funds through a grant application process to community-based groups that provide crucial services to breast cancer survivors, their families and caregivers; adding breast cancer survivors as voting members to the NYS Health Research Science Board (HRSB) that oversees the NYS Pesticide Registry and awards breast cancer education and research grants; banning the hazardous chemical BPA from children's products; and expanding the Breast and Cervical Cancer Treatment Program by extending Medicaid coverage for treatments. She became an advocate on the HRSB; she was an active member and volunteer of SHARE in NYC and was a member of the National Breast Cancer Coalition.

In 2010, Susan received the New York State Woman of Distinction Award from the NYS Legislature. It wasn't only her well-honed community-building and advocacy skills that Susan shared with us. She had many interests – reading, listening to chamber music, and traveling to cold climates among them. Each year we looked forward to viewing her photographs of trips taken to Alaska or Antarctica where she delighted in viewing polar bears, seals, penguins and other wildlife, especially those whose habitats were threatened.

Twelve years after its founding, NYSBCN is still a loud, opinionated, unwieldy group of advocates, but now we are also grief-stricken. Susan left us with the history and the heart to continue our mission, and that is what we will do. In Susan's memory, in Susan's honor.

# 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.

## Propelled by God's Goodness

By Pamela Harper

In April of 2007, at the age of 39, I was diagnosed with invasive ductal breast cancer in my right breast. This diagnosis was a result of a recommended follow-up to a mammogram taken seven months earlier, after I was no longer breast feeding my son. I vividly remember receiving the news by phone from my doctor.



First, I prayed; then I called my husband. Trying to be strong, I discouraged him from cancelling his scheduled meeting, but he came home right away anyway to be with me, thank God! As the wife of a Pastor and a believer in Jesus Christ, confronting breast cancer still tested my faith. The disease had struck before in my family. My paternal grandmother was diagnosed with it earlier in her life yet lived on to be 96 years old, but my mother passed away at the age of 47 (19 years before my diagnosis) from breast cancer.

As my mother had done, my first inclination was to keep this illness a private matter. However, I kept getting gentle reminders that God was trusting me with this... trusting that I would share with others how He has revealed Himself to me through this...trusting that I would have the right attitude through this...trusting that I would maintain faith that He is in control of the situation...trusted that I would believe that He has never left nor forsaken me... trusted that I would strive to be a blessing to others through it all. I also recall being reminded by a church member that everyone must go through something in order to have a testimony of God's goodness. That comment really stuck with me and served as a source of inspiration and encouragement.

At that time my son, Timothy, was three and my daughter, Brianna, was seven. While shaken by the news, my husband and I were determined to maintain our normal routines at home and church, so it meant a lot to have the support of family and friends to make that happen. My father came from Indiana right away after hearing the

news. He cared for the children while my husband Tim and I took the trip to Sloan-Kettering in New York City to get a second opinion.

My sister and nephew came from Arkansas and my brother from Indiana at the time of the initial surgery. When family members were not available because they all live out of town, my church family at New Jerusalem Home of the Saved Church stepped right in. For example, one of our church members attended doctor visits and would watch the children in the waiting area while my husband and I met with the doctor.

The 1.5 cm tumor was thankfully caught early. However, given my family history and the denseness of my breast

tissue, I opted for a bi-lateral prophylactic mastectomy with tissue expander breast reconstruction. I think the expansion of the tissue was the most painful part of all, but the massage therapy recommended by my surgeon was helpful.

Although a test for the potential recurrence of breast cancer turned out to be "borderline," I opted for the more aggressive treatment of chemotherapy with Cytoxan and Taxotere. The four weeks of chemotherapy could have been far worse. I recalled what mother had gone through with chemo treatment back in the late eighties and felt extremely grateful for the medical advances made. My husband's attendance at every one of my chemo appointments was a real source of strength. During these sessions, I felt particularly empowered to encourage others... patients, attending doctors and nurses. I was so happy to be able to bring in treats for those in the oncology practice on the last day of my treatment.

In November of 2007, genetic testing revealed that I carry the BRCA2 gene which may increase risk of ovarian and breast cancer, so I elected to have a total hysterectomy. Again, I was blessed for I had the minimally invasive da Vinci procedure. My post-op pain was nearly non-existent and recovery was quick.

Having spent six years as a stay-at-home mom following an 11-year career at GE as a manager, I was blessed to receive the long-awaited answer to my prayer of "Lord, what should I do next." My husband encouraged my consideration of pursuing a Ph.D. in Management, as he had done several years earlier. While I had entertained the

*Continued on next page.*

## Profile *continued.*

idea from time to time, I now was given an opportunity to attend a conference in Chicago sponsored by the PhD Project. It was at this conference that I truly felt that serving as a Professor was my calling for this time in my life. So, in the fall of 2008 my son entered Kindergarten and I returned to school at RPI as a Ph.D. student.

I definitely would not have chosen this bad thing to happen to me or mine; however, the diagnosis of breast cancer served as a turning point in my life. Just as the Lord Jesus Christ has blessed me through this entire journey, my desire to be a blessing has been strengthened. In addition to having the opportunity to continue to be my children's mom and my husband's wife, among other roles, I get to serve as New Jerusalem's Adult Sunday

School teacher and as the Chairperson of the Annual Community Block Party. This annual, inner-city based event takes place the second Saturday in September and provides free food, fun and info for families that might benefit from all the free health, education, financial management and safety resources available there. I am so appreciative of CRAAB's attendance and support of this community-based event.

Again, I reflect on the comment from a beloved church member who reminded me that everyone must go through something in order to have a testimony of God's goodness. Well, I have a testimony that God has and is truly, completely, propelling me.

## True Burden *continued from page 1*

president of CRAAB!, as science research consultants; and with Dr. Henry Pohl, Vice Dean of Academic Affairs, Albany Medical College; and Dr. Janet Gargiulo, of New York Oncology Hematology, P.C., as medical consultants.

Bonnie states that this project will have "a powerful effect in educating the next generation of health care

professionals who can pass this information along to their patients, as well as educating a diverse group of college students who can inform their families and friends. Until the public addresses primary factors affecting our health, we cannot hope to eliminate these diseases." The power points will also be burned to CDs that will be available in 2012 to colleges, community groups and the 25 groups of the New York State Breast Cancer Network, among other non-profit organizations.

Research into environmental links to breast cancer and other cancers has accelerated since the 1990s, when scientists published findings of large scale studies and breast cancer advocates pushed for more research on environmental connections to the breast cancer epidemic. The new National Institute of Environmental Health Sciences is one result of that scientific and political activism. Still, only a small percentage of research dollars goes to primary prevention or investigating the causes of cancer. This project, I believe, will help raise awareness about current research into primary prevention and possible ways to reduce one's risk for getting cancer, and describe the potential contributors to breast cancer that researchers are actively investigating.

In the ten years since the human genome was deciphered, scientists have learned more about gene/environment interactions that may make a person more susceptible to cancer and other diseases, partly through greater sensitivity to environmental toxins. Based on current knowledge about the genome and DNA, scientists and physicians know that only 5-15% of breast cancer

cases are due to inherited genes that carry mutations, but that percentage could rise slightly with the possible discovery of new genetic markers, and as the function of genes, gene expression and the epigenome become more clearly understood. The "True Burden" project will explore findings from the new avenue of epigenetic research and

*"Until the public addresses primary factors affecting our health, we cannot hope to eliminate these diseases."*

will examine our body burden of chemical contaminants, some carcinogenic, that potentially raise risk for cancer. "True Burden" educational materials will also illustrate the connection between a person's

lifetime exposure to estrogen and breast cancer, and the environmental and lifestyle factors that interfere with normal estrogen metabolism and increase levels of circulating estrogen in a person's body.

During the past two decades environmental connections to cancer have been investigated at academic cancer research centers, the young National Institutes of Environmental Health Sciences, the Department of Defense Breast Cancer Research Program and other national and international research laboratories. Recent research has uncovered surprising correlations between breast cancer and the early onset of puberty in US girls – a growing trend; the overuse of alcohol; obesity; lack of physical activity; smoking and 2<sup>nd</sup> hand smoke; the use of oral contraceptives and hormone replacement therapy; overexposure to artificial light; exposure to ionizing radiation; and intake of persistent organic pollutants found in air, soil and water, certain pesticides, and specific home, building and manufacturing products.

CRAAB! President Joan Sheehan states that "this information is especially important for young people who can learn that the habits they form early in life can impact their health later in life and that of their children and even grandchildren."

# Thank You!

## ***We welcome new members!***

Marilyn Frantsov                      Kathryn Nardacci  
Carolyn Meilhede                      Diane Rosen

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

### ***In memory of:***

Susan Battaglini by Alpha Sigma Beta sorority sisters  
Sophrona Battershall by Marea Reid-Roberts  
Dorothy Condon by Joan Sheehan  
Venera M. Grillo by Lenora Grillo  
Karen Helmes by Diane Levesque-Kopecki  
Alice Ann Rocke by Betty-Jean Haner  
Faye Scott by Kim Baker  
Dr. Jean Strang by Florence Conway  
Janet Walck by Sandra Zwink

### ***In honor of:***

CRAAB! by Lynn Rogers  
Victoria Cooper by Mary Ellen Nagengast  
Giselle Hicks by Suzanne Hicks  
Maria Loescher by Michelle and Jeff Lesko  
Berte Meilhede by Carolyn Meilhede  
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### ***Special Donations:***

Michael Bishop and Pauline Holmes  
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Bonnie Mitchell - Artistic Nails by Bonnie  
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Janet Cornell                      Marsha Kayser  
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Lorraine Kaifer                      Dee Wind

## **The NYS Susan M. Cohen Breast Cancer Education and Advocacy Day**

### **Convention Center Empire State Plaza Concourse March 15, 2011**

**Prepaid \$25 fee includes  
a continental breakfast and box lunch.**

**The NOVA film, "Ghost in Your Genes,"  
will be shown in AM.**

**In PM we will advocate with legislators  
for the following bills:**

#### **Restrict Bisphenol A in Thermal Store Cash Receipts**

Most New Yorkers are unaware that they are regularly exposed to high levels of BPA (250-1000 times higher than BPA in canned foods) in cash register or thermal store receipts used by major retailers, grocery stores, convenience stores, gas stations, automatic teller machines (ATM), among others. Since many retailers such as Target, Whole Foods Supermarket, Starbucks and Bank of America ATMs, are already using BPA-free thermal paper, this route of exposure can be easily eliminated. However, because of the paper recycle stream, now 90% of dollar bills contain BPA, along with some paper towels and other paper products.

#### **The Cancer Oral Chemotherapy Equity Bill**

This is an act to amend the insurance law, in relation to policy coverage of chemotherapy treatment. This bill would require health insurance plans in New York to cover orally administered chemotherapy treatment no less favorably than intravenously administered or injected chemotherapy treatments. Currently there are about 400 chemotherapy drugs in the pipeline waiting for full approval and 25% are oral. This bill is supported by a large coalition of groups, including the Leukemia & Lymphoma Society, and others.

**For more information and to register,  
call CRAAB! at (518) 435-1055.**