



CRAAB!

Capital Region Action Against Breast Cancer!

Vol. 12, No. 3 • Summer/Fall 2010

NBCC Conference

Joan Sheehan, Kim Baker, Wanda Burch, and Carol Davis represented CRAAB! at the NBCC Annual Advocacy Training Conference in Washington, DC, May 22-25. Here are two of their reports.

Joan Sheehan

I was thrilled once again to be able to attend the annual conference. What made it even more special was that three others who attended with me had never been to this event. We were all impressed with the scope of the conference and the diversity of the participants. This conference's plenary sessions and workshops have always challenged and inspired me to learn more about breast cancer. NBCC brings together the best researchers, policy makers, advocates and media specialists to help us with the work we do for our grassroots organizations.

My favorite speaker is always Dr. Susan Love. This year she was a panelist for the plenary session: *So What's New In Breast Cancer?* Dr. Love spoke about her belief that prevention is better than a cure and that we should go beyond the cure mentality to strive for prevention. She wants to find out what causes mutated cells and what conditions support them in order to change the environment in which they develop. Examples she gave were the stopping of HRT, which created a positive change in the body's environment, and how physical inactivity is setting up a negative environment for cancer to develop. Dr. Love believes that personalized targeted treatments will help to cure cancer and that screening goals should be developed to find and distinguish clinically relevant tumors. The fifth edition of her book will be out in October!

I have been following the **Carolina Breast Cancer Study** so I was happy to attend a workshop that gave an update. For over 17 years a population-based case controlled study has been conducted on both younger and older women from North Carolina. This study includes African American and white women from rural, urban and suburban geographical locations. Currently Phase III is underway with the goal of enrolling 3,000 additional cases from an expanded geographical region to better understand how the treatment chosen affects survival and quality of life for a breast cancer patient.

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Joining Congressman Paul Tonko for a "photo op" after meeting with him to discuss NBCC's legislative priorities are NYS advocates Carol Davis, J. Eisele, Wanda Burch, Suzanne Hicks, Joan Sheehan, Marie Kaplan and Kim Baker.

Save the Dates!

For more details, contact CRAAB!.

CLASSES

Resist-A-Ball

Led by Randi Jurus. Plaza Fitness Center, Stuyvesant Plaza, Albany
Mondays at 6:15 p.m.: Sept. 13, 20, 27, Oct. 4, 11, 18, 25, Nov. 1, 8, 15

Life Coaching for Breast Cancer

Survivors Linnea Pascucci, LCSW-R, CWC, CASAC. Gilda's Club, One Penny Lane, Latham
Thursdays from 6-7:30 p.m. on Sept. 16, 23, Oct. 7, 14, 21

Pilates Classes

Led by Janice Pastizzo. Colonie Community Center, 1653 Central Avenue, Albany
Fridays at noon: Sept. 17, 24, Oct. 1, 8, 22, 29, Nov. 5, 12, 19, Dec. 3

Healthy Steps™ Moving You to Better Health with the Lebed Method

Led by Diane Levesque-Kopecki, RN, MS, CLM. Gilda's Club, One Penny Lane, Latham
Thursdays from 6-7 p.m. on Sept. 23, Oct. 7, 14, 21, 28, Nov. 11, 18, Dec. 2

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CRAAB!

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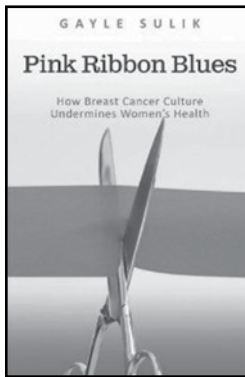
Book Review

Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health

by *Gayle Sulik, Ph.D.*

Oxford University Press, 2010

Reviewed by Joan Sheehan and Bonnie Spanier



JOAN: The title grabs you, the content consumes you and the conversational tone of this well-researched book absorbs you in introspection that leads to consciousness raising. Before the women's rights movement of the 1970s, a breast cancer diagnosis was a very private and socially isolating matter. The effects of this movement in bringing into the open an awareness of breast cancer from the viewpoints of diagnosed

women is expertly described by Gayle Sulik, Ph.D.

In the early 80s, I was young, raising my children, teaching elementary school and occasionally reading stories about survivors in magazines. I was picking up on the idea AND learning to do self-exams but not relating to the movement — until I found my own lump. When diagnosed in 1986, I personally still did not know anyone with breast cancer. Through the ACS's Reach to Recovery program I met a caring woman who helped me tremendously and I went on to become a volunteer with the program for many years, having become much more attuned to breast cancer than before.

Going into the 90s, much more was being written, and shown in the popular media that indicated breast cancer had become an epidemic, and it became a topic everyone knew about. As grassroots organizations began forming to educate, support and advocate for diagnosed women in the 90s I realized I had many reasons to be part of this growing movement. Much of what Gayle described in this book I feel I have experienced — from helping to organize a grassroots breast cancer organization that used the pink ribbon as an awareness symbol to coming to terms with its current over-extended role in breast cancer advocacy.

For me, the content of this book hits close to home and inspires me to reflect on our journey to where we are today. Particularly riveting for me were chapters six (Under the Pink: Optimism, Selfishness and Guilt) and seven (The Balancing Act) as these chapters consider the emotions of diagnosed women who balance their lives within the social expectations of the pink ribbon culture prevalent today. Optimism, selfishness and guilt are three “feeling rules” that

Gayle presents as “an overarching framework to analyze the impact of social context on women's experiences of breast cancer and sense of self.” They can either empower or constrain a woman. She contends that survivorship requires a strong sense of optimism in terms of hope, faith and transcendence, requires using selfishness as a coping strategy related to the natural inclination of a woman to nurture others, and requires understanding the stigma of guilt when there is non-conformity to expectations for a woman's role in society.

Gayle conducted many interviews with breast cancer survivors to determine their personal coping mechanisms, and to these interviews she applied her excellent analytical skills. I can easily see survivors reading through this chapter and understanding their own personal style of coping while asking: do I fit into one style or have I developed my own survivorship road which allows for personal introspection?

Reading in chapter seven that 210 million women are living with breast cancer today causes one to pause and realize that we can't all be coping in the same way, nor should we be.

There is much to learn from Gayle, based on the many interviews she conducted, on how to balance the survivorship journey through setting boundaries and accepting and asking for help. The balancing act is a process of re-socialization and also choosing a problem-focused

On October 26th, The Sister Thea Bowman Center for Women at Siena College and CRAAB! are honored to be co-sponsors of a talk by Gayle Sulik about her book.

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President's Corner

by Joan Sheehan

This June, I had the great pleasure of being a team participant at the International Dragon Boating Festival held in Peterborough, Ontario Canada with this region's only dragon boating team, Hope in the Boat. International festivals are only held once every four years, so this was a wonderful opportunity to meet and compete with teams from Canada, UK, Italy, South Africa, New Zealand, Australia and teams from various states.

Peterborough opened its arms to the international visitors. Town citizens went out of their way to be welcoming and helpful, and approximately 1,000 volunteers made all Olympic-like events run smoothly. What struck me the most was that I was one of 2,000 participants, all of whom have had breast cancer! I really believe that dragon boating provides individuals with a focus beyond the disease. For further proof of this please read the community profile by Jude Lilly in this issue.

One compelling speaker at the opening ceremony was Herb Wagner, a male breast cancer survivor, whose family physician in Cincinnati, Ohio, disregarded one of the primary signs of breast cancer – an inverted nipple – and advised Herb that he had nothing to worry about. Herb revealed that at the time he was unaware that men could develop breast cancer and so he trusted his physician's diagnosis. Five months later he was persuaded by family and friends to get a second opinion. His new physician in Florida told him that men have breast tissue too, some more than others. He further explained that less than 1% of all breast cancers occur in men, and they are found mostly in men over age 60. This doctor ordered a mammogram right away and followed up with a biopsy that indicated male breast cancer (MBC). Today Herb is five years cancer-free after treatment with Arimidex and speaks of his experience wherever and whenever he can in order to increase MBC awareness.

A local Peterborough newspaper told the story of an Australian with MBC, and how, after his diagnosis and treatment with aggressive surgery, chemotherapy and radiation, he was urged to connect with *Dragons Abreast* in Sydney. Both these male

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NBCC Conference *continued from page 1.*

Information is obtained through in-person interviews, medical records and DNA samples.

Their results to date are:

- 1. Younger African American women have a higher frequency of basal-like or triple negative (ER-PR-HER2-) breast cancer.
- 2. The higher frequency of basal-like breast cancer may be due to lower levels of breast feeding among other factors.
- 3. Survival for basal-like breast cancer is similar in African American and white women. They are not biologically different and need to be treated in the same way.

In this phase, they are looking at what factors influence survival including: breast cancer sub type, treatment, access to care, quality of life, body size and other factors identified by advocates involved in the study design. Advocates are present at every study meeting. They review study materials and procedures and help the principal investigator decide what will be studied.

A breast cancer resource directory for the state of NC, which lists support services and products, grew out of this project and has become a reference source to help all diagnosed women in NC.

The conference culminated with all attendees reaching out to their state senators and congressional representatives. New York State had the most delegates and filled a huge room where we were addressed by Senators Shumer and Gillibrand. Our CRAAB! group then met with Congressman Tonko. All three have voted favorably to support federal funding for peer reviewed breast cancer research and pledged to support this research in FY 2011.

Carol Davis

I was interested in the session on Integrative Oncology given by Donald Abrams, MD. He is Professor of Clinical Medicine at the University of California San Francisco (UCSF), and Director of Integrative Oncology Research at the UCSF Osher Center for Integrative Medicine. Dr. Abrams is also the Vice-President of the Society for Integrative Oncology and has co-edited an Oxford University Press textbook in Integrative Oncology with Andrew Weil, MD.

Dr. Abrams began his presentation, "It is more important to know what sort of patient has a disease than what disease a patient has." He emphasized "relationship centered care" and the importance of being truly present to patients. "Participants want time with providers." Integrative oncology engages the mind, body, spirit and community. This approach maintains that healing is possible even when curing is not. Providers are encouraged to model a healthy lifestyle. Treatment goals include increasing the patient's sense of control, decreasing ongoing inflammation, increasing the body's innate immunity to fight against cancer, decreasing

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Presidents' Corner *Continued.*

survivors encourage other men to visit www.malebreast-cancer.org and to also research dragon boating.

A personal highlight for me was to hear Dr. Donald McKenzie of the University of British Columbia give a keynote address at the gala dinner since he pioneered dragon boating for women with breast cancer in Canada in 1996. He wanted to dispel the myth prevalent in that era that repetitive upper body motion exercise in women treated for breast cancer encouraged lymphedema. He believed that by following a special exercise and training program women could enjoy full and active lives. He launched *Abreast in a Boat* to test his theory. Participants were carefully monitored; no new cases of lymphedema occurred and not one of the existing cases became worse. The idea of dragon boating caught on and there are now more than 150 dragon boating teams world wide.

Dr. McKenzie believes it can also help people with other types of cancer and is starting teams for these patients. He was very excited to tell about another project he is starting with his daughter, that blends cancer patients with young people who have not had cancer and will be especially focused on reducing their risks of disease through exercise. The doctor believes it is important for the younger generation to get in the habit of including exercise in their daily lives.

Many good studies are now showing the benefits of exercise, and more health professionals are recommending increased activity for cancer patients. Please refer to our recent mailing about CRAAB's exercise programs — so many survivors have benefited from these classes!

As we go to press, breast cancer survivor, Mary Ibbetson, is working to develop a group personal training program for survivors of all cancers with the Ciccotti Center in Colonie. Currently the center is hosting her "Get Up and Go with Gilda and Mary" from 5:30 to 7 p.m. every Monday using the floor and indoor track in the Center. Cancer patients can join at any time. As Mary explains, "Exercise for me is survival. There is a side effect of endorphins, which just make you feel good and allows you to feel a sense of pride in yourself." There is no charge for this program. Please contact Mary at mkibbetson@gmail.com or 518-376-6077 or CRAAB! at 518-435-1055 for more information.

In July, long time Board member Michele Keleher, MS, PT, retired from CRAAB's Board of Directors. Michele was a founding member of CRAAB! and we are most grateful for her many years of service. Her dedication to the mission of CRAAB! plus her expertise in the treatment of breast cancer survivors with lymphedema made her a valued addition to the Board. We will continue to depend on her in this regard. We wish Michele well as she balances devoting more time to exploring complementary additions to her physical therapy practice, Delmar PT, located in Slingerlands, NY. with finding time to dote on her expanding number of grandchildren. CRAAB! wishes Michele much happiness.



On May 15th the Iroquois Rod and Gun Club and NY Assemblyman, George Amedore, sponsored "Trap Shoot for the Cure." Assembly George Amedore, Schenectady Mayor Brian Stratton, Robert Paley, John McDonald, Anita Paley and Denise Sheehan were all competing at the shoot!

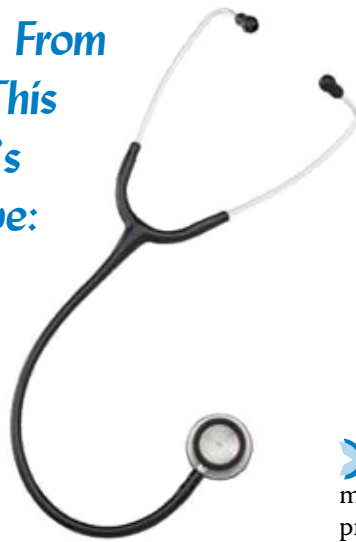


Suzanne Hoffman, Steve Morrison, Dick Moran and Lorraine Wilson enjoy winding down in the club house of the Colonie Golf Course after a first place winning round at the CRAAB! Golf Tournament on June 21st.



Volunteers for the July 11th Action Against Cancer Tennis Event sponsored by Albany Tennis Club, Ridgefield Park are (seated) Nancy Guest, Helen Tomaso and Brenda Ginardi. They are joined by players Alan Chen and Margaret Roberts, chair of the event.

From
This
Nurse's
Perspective:



Is All Prevention the Same?

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

I recently reviewed notes that I had taken while at the National Breast Cancer Coalition Annual Advocacy Training Conference and read the statement, “there are medications that should be avoided by women taking tamoxifen for the prevention of breast cancer, either primary or recurrence.”

I began to wonder how many people think of interventions aimed at the recurrence of breast cancer as a form of prevention? When I think of prevention, the first thing that comes to mind is preventing the disease from occurring, but it's important to understand that when researchers and health experts talk about prevention they are referring to a wide range of strategies or “interventions” aimed at reducing the risk of disease, preventing progression and/or reducing complications caused by disease. In general, prevention is grouped into three categories: *Primary, Secondary and Tertiary.*

Primary Prevention

Involves activities that will prevent the development of disease. Know your risk factors and identify ways to reduce their influence. Having one or many risk factors does not mean that you will get breast cancer. Some risk factors (drinking alcohol, being overweight, and lack of physical activity) can be changed through personal choices. But most risk factors (family history of breast cancer, genome changes and reproductive and menstrual history) can't be avoided. Many health advocates and medical professionals also believe that reducing one's exposure to environmental toxins and estrogenic chemicals can also reduce one's risk for disease and so play an important role in primary prevention. Until breast cancer is eradicated, primary interventions may not guarantee that you will remain disease free, but will lower your overall risk of developing the disease.

Some Interventions at the Level of Primary Prevention:

Advocate for increased access to affordable healthcare: <http://docs.house.gov/energycommerce/SUMMARY.pdf>. Obtain regular exams and screening tests to monitor risk factors for disease: possibly BRCA 1 and BRCA 2 if known to have a family history: <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>.

Demonstrate social responsibility to ensure that policy makers support programs that foster healthy behaviors and prevention. Participate in advocacy work both locally and nationally to ensure policy and environmental interventions that will lower cancer risk factors: CRAAB!*, National Breast Cancer Coalition: <http://www.stopbreastcancer.org/>, New York State Breast Cancer Network: <http://www.nysbcscen.org>.

Participate in prevention trials involving women who have not had breast cancer, but are at high risk of developing the disease. For information on breast cancer prevention trials, refer to the National Cancer Institute: <http://www.cancer.gov/cancertopics/factsheet/Prevention/breast-cancer>.

Develop healthier individual lifestyle choices, i.e. increase physical activity, stop using tobacco, make good nutritional choices, limit alcohol intake: <http://www.mayoclinic.com/health/breast-cancer-prevention/W000091>.

Advocate for discovery of a vaccine to prevent the development of breast cancer: <http://www.knowbreastcancer.org/news-research/news/a-breast-cancer-vaccine.html>.

Secondary Prevention

Involves activities that detect disease early and limits disease effects after diagnosis. Outcomes for patients with many types of breast cancer, for example, can be dramatically improved through early detection followed by appropriate treatment. Although not all types of breast cancer respond to early treatments, the goal is to find and treat disease before it has spread to areas outside of the primary site.

Some Interventions at the Level of Secondary Prevention:

Follow current recommendations for screening using film mammography and for screening using other methods, i.e., Clinical Breast Exam, digital mammography, MRI, Breast Self Exam: <http://www.ahrq.gov/clinic/uspstf09/breastcancer/brcansum.htm>.

Be aware of the NYS Cancer Services Program: Uninsured or Underinsured Women 50+ eligible for breast, cervical and colo-rectal cancer screening.

Obtain quality medical management of breast cancer to prevent further spread of disease. Advocate to obtain

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RECENT RESEARCH

CRAAB!

TIPS

Capital Region Action Against Breast Cancer



Summer/Fall 2010

From Jessica Werder, M.P.H.

This report is made possible through a grant from the Susan B. 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.

certain environmental risk factors. This study suggests that it is not the case. It also suggests that, in the case of the genes examined, genetics is not the most important factor; a woman's risk is still affected more by other factors, including environmental and behavioral ones. However, it must be noted that researchers did not include an analysis of the genes BRCA I and BRCA II. These genes are known to increase risk of cancer significantly, above and beyond other factors, and were therefore not included in the analysis.

Genes or Other Factors?

Background and Recent Evidence:

Since 1996, researchers at Oxford University have been conducting a large-scale study examining the effects of Hormone Replacement Therapy (HRT) on cancer incidence in women over 50. Between 1996 and 2001, 1.3 million women enrolled in the Million Women Study, making it the largest of its kind to date in the world.¹

Recently, researchers examined the genetic information from 7,610 of these women with breast cancer and 10,196 women without breast cancer. They identified certain gene variants in these women that may predispose them to cancer; they also looked at 10 factors labeled as "environmental risk factors": age at menarche (first period), parity (number of births), age at first birth, breastfeeding, menopausal status, age at menopause, use of HRT, body-mass index, height and alcohol consumption. They found that, in general, the environmental factors contributed more to a woman's risk of cancer than did the genetics. They also found that genetic risk and environmental risk are separate; the cancer risk for a woman with a "cancer" gene may increase when she uses HRT, but not any more than for a woman without a "cancer" gene.

Interpretations and Implications

Many studies have suggested that there is an interaction between genes and environment,² that women with certain genetic patterns increase their risk of cancer exponentially when they perform certain behaviors or are exposed to

Women Forgo Medical Care

Background and Recent Evidence

Cancer survivors have a host of special medical needs. Their medical providers must continue surveillance for potential recurrences, deal with any chronic effects resulting from the disease itself or from aggressive treatments, and provide services and preventive care for other illnesses, including mental illnesses.³ Unfortunately, it appears that many cancer survivors in the United States may be forgoing needed health care, due to its associated costs.

Recently, a group of researchers examined data from the National Health Interview Survey, a survey conducted by the National Census Bureau and monitored and evaluated by the Centers for Disease Control.⁴ Using self-reported information from 6602 cancer survivors, they project that over 2 million such individuals who were living in the United States between 2003 and 2006 forwent one or more needed medical services because they were concerned about the cost.⁵ They also found that, among people younger than 65, cancer survivors were more likely to forgo medical care because of concerns about cost than were similarly-aged individuals who had never been diagnosed with cancer.

Implications

Cancer survivors often face many barriers to receiving continuing health care. The exorbitant costs of treatment may lead to financial hardship for some or to changes in employment and loss of health insurance coverage for others.

Whatever the case, it is disturbing that these individuals, who have already faced and overcome, such an aggressive disease, would take risks with their future health simply because of its cost. It is yet another issue for the larger question of how best to reform the health care industry in our country.

Breast Cancer Vaccine in Mice

Background and Recent Evidence

Vaccines are effective public health tools, used to prevent a host of different diseases by provoking an immune system response against specific germs or viruses. For years, researchers have dreamed of creating a vaccine against cancer. Unfortunately, cancer itself presents one crucial problem: unlike many diseases, cancer rarely arises because of an infection (though there are exceptions); instead, cancer develops from a person's own cells, therefore possessing the same proteins and markers as normal cells. Therein lies the difficulty – the immune system has no way of distinguishing between cancer cells and normal cells, making it almost impossible to stimulate an effective immune response with a vaccine. However, new research may provide some clues to overcoming this crucial complication.

An article published in the June issue of *Nature Medicine* reports on a successful attempt to create a vaccine against breast cancer in mice.⁶ Scientists used a protein found in mammary cells (breast cells) to develop the vaccine. This particular protein has a unique characteristic that allowed researchers to develop a vaccine from it – after mice finish lactating, they no longer have the protein (but it is still found in breast cancer cells). Therefore, by injecting the protein into mice that were no longer lactating, the researchers triggered an immune response against the protein and possible future cancers without negative effects for the mouse. This immune

response successfully prevented cancer in 100% of mice receiving the vaccine.

Implications

Any human vaccines developed from this research are years away. While the experiment proved successful in mice, there is a large leap between the relatively simple systems of rodents and those of humans. A vaccine would need to be developed, tested and used in clinical trials before it made it to the market for the general public, a long and difficult process. And if developed as is, the vaccine would only be useful in women who were not going to breast feed anytime in the future. However, the research is exciting because it presents a novel approach for creating a cancer vaccine and has large implications for the ways in which researchers proceed with vaccine development in the future.

¹The Million Women Study: a Confidential National Study of Women's Health. 21 June, 2010. <http://www.millionwomenstudy.org/introduction/>.

²Mucci L et al. The role of gene-environment interaction in the aetiology of human cancer: examples from cancers of the large bowel, lung and breast. *Journal of Internal Medicine* 2001, 249(6): 477-493.

³Ganz P. Monitoring the Physical Health of Cancer Survivors: A Survivorship-Focused Medical History Reference for long-term medical needs of cancer survivors. *Journal of Clinical Oncology* 2006, 24(32): 5105-5111.

⁴National Health Interview Survey. 15 June 2010. <http://www.cdc.gov/nchs/nhis.htm>.

⁵Weaver K et al. *Forgoing medical care because of cost: assessing disparities in health care access among cancer survivors living in the United States.* *Cancer* 2010; DOI: <http://dx.doi.org/10.1002/cncr.25209>.

⁶Jaini R, An Autoimmune-mediated strategy for prophylactic breast cancer vaccine. *Nature Medicine* 2010, doi:10.1038/nm.2161.



Nominated by CRAAB! and Siena College, Gina Castelli accepts the Albany-Colonie Regional Chamber of Commerce 2010 "Women of Excellence" award for Excellence in the Professions on June 17.

FREE SCREENINGS

CRAAB! is an active member of four Cancer Services Program (CSP) Partnerships that work with area medical personnel to provide **free screenings for breast, cervical, and/or colorectal cancers** for men and women 50-64.

For more info., contact:

- CSP Partnership of Albany County
Kathy DiCaprio, Program Manager
454-4017, kathy.dicaprio@cancer.org
- CSP Partnership of Rensselaer County
Aimee Pachucki, Program Manager
454-4075, aimee.pachucki@cancer.org
- CSP Partnership of Schenectady County
Margaret Brodie, Program Coordinator
347-5760, brodiem@smha.org
- CSP Partnerships of Fulton and Montgomery Counties
Suzanne E. Hagadorn, Program Coordinator
841-3726, hagadorns@smha.org

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strategy. I found that this chapter added credence to the work that patient navigators do.

It was sobering to learn that my own personal feeling, about how far afield the symbol of the pink ribbon is from its initial meaning, was in accord with Gayle's insights. Marketing the pink ribbon brand seems to be no longer focused on finding the cause or the cure of breast cancer but instead profiles a specific product so as to increase its sales.

I think all readers will benefit from reading Gayle's analysis of the "Think Before You Pink" campaign as developed by **Breast Cancer Action (BCA)**, a not-for-profit grassroots organization based in California. BCA offers another model for how breast cancer fundraising should be carried out today and conforms to donors' expectations for the support they give. This is a book for all concerned about the breast cancer epidemic, how survivors might be supported on their breast cancer journeys and how responsible fundraising could support these efforts.

Disclaimer: I was one of the many women whom Gayle interviewed for her research and attended a program that CRAAB! held for Gayle to up-date those women who lived in the Capital Region. I found her preliminary work to be compelling and on target with so many of the issues she brings to light in this book.

Bonnie:

Gayle Sulik's book pulls no punches. As her title suggests, she argues that today's most visible presence in the breast cancer education and advocacy movement — dubbed 'pink culture' for its sea of feminine pink ribbons — too often has ignored biomedical evidence and thus is not in our best interests. This may not surprise many CRAAB! newsletter readers, but I suspect that Gayle's strong assertions will ruffle many feathers in our charity and advocacy arenas. Her scholarship, however, is reliable and underwritten by the prestigious Oxford University Press. Gayle's intentions for women's health are always constructive, and I have faith that the book will promote fruitful discussion among the open-minded.

As Gayle documents, the public fight against breast cancer has deep and divergent roots in several societal trends: the women's health movement of the 1970s, the rise in consumer action for public health, the growth of the American Cancer Society in health education, and the partnerships of industry with physicians and their patients for research. 'Pink culture' refers to the commercialized culture of breast cancer advocacy recognizable as almost a corporate brand of pink ribbons. Its way of funding research and education is through shopping for a cure and charities. The major problem is that these proponents have glossed over scientific controversy and minimized the public's reasonable and responsible questioning of the experts, standard medicine and high-tech advances. Medical information from this predominating 'pink culture' comes from the industries that makes large profits from cancer, including multinational pharmaceutical corporations and

their public relations organization, PhRMA; medical equipment makers such as General Electric; biomedical research and hospital complexes; and the medical professions.

In contrast, a more skeptical approach to conventional medical wisdom about breast cancer keeps asking about the validity of the evidence — about treatments, about detection, about how to prevent the problem in the first place by eliminating its causes. This alternative approach raises money for research and education through charity work, but also through political action to increase tax dollars for breast cancer research and, more broadly, for universal quality healthcare. (While *Pink Ribbon Blues'* analysis focuses on the shortcomings of the 'pink culture' approach, Gayle also has a whole chapter on this alternative approach, epitomized by the National Breast Cancer Coalition and Breast Cancer Action.)

You may remember Gayle Sulik from her CRAAB! days, starting as a volunteer in the late 1990s and then becoming Administrative Director in 2000. She earned graduate degrees in Women's Studies and Sociology at the University at Albany, and since then has engaged her students in evidence-based community education while publishing extensively in peer-reviewed journals and books.

Over the years she has interviewed hundreds of survivors, caregivers, and sister travelers in and around the recent breast cancer advocacy movement, and her writings bring their voices to the public. Although relatively young, Gayle's extensive experience with service, education, and research on breast cancer activism has produced a thoughtful and provocative book. Her compassion is evident throughout this work, even as she takes to task how cancer industries that benefit from the disease's human cost fall short of their promise to science and to humanity. She is at home with cancer statistics as much as with the complex feelings of those who have to personally engage with this disease, which she has done herself through close friends and colleagues. While *Pink Ribbon Blues* is a thoroughly documented academic work, Gayle's clear thinking and tight writing make it a stimulating and hugely educational read for anyone looking for guidance or insights on the vicissitudes of current efforts to improve our health.

With her claim that mainstream pink culture does not maximize critically important benefits for women comes another key insight. With smiles and enforced optimism, the pink culture that has come to predominate after 30 years of hard-working advocacy too often denies or suppresses real-life experiences of women who must live with their diagnosis.

Pink Ribbon Blues can help each of us make our own decisions about which sources to believe, which groups to support with our money and energy, and what future vision we choose for women's and men's health advocacy.

*Disclaimer: I have known Gayle Sulik since graduate days at the University at Albany. I was a member of her dissertation committee, as co-President of CRAAB! supervised her, and have continued to follow her career. Oxford University Press asked me to write the Foreword to *Pink Ribbon Blues*, which anyone can order online through major booksellers.*

Advocacy Works!

NYS Governor David Paterson recently signed into law a ban on the sale of baby bottles, sippy cups and other children's products containing bisphenol A (BPA). The new law takes effect on December 1, 2010.

CRAAB! has been active at the local, state and national levels to raise public awareness about the connections of BPA with cancer and other serious diseases.

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stress and increasing hope.

There is not much evidence that stress causes cancer, however, there is evidence that stress fosters the growth of cancer cells. Integrative oncology includes finding stress reduction options. Evidence shows that meditation can reduce anxiety, depression, pain and it can improve sleep. Yoga and Tai Chi are also effective. Massage and acupuncture are useful in decreasing pain and depression following surgery in cancer patients, according to a study. The findings of the randomized controlled clinical trial are reported in the March 2007 issue of the "Journal of Pain and Symptom Management." Acupuncture treatment was based on the traditional Chinese medicine standardized core set of acupuncture points and was used to treat pain, nausea and anxiety.

Support groups, guided imagery, biofeedback and hypnosis are options for improving the mind/body connection, decreasing stress, increasing hope and having a sense of healthy control; that is, there is helpful action that can be taken. Plant-based oncology is a growing interest in cancer risk reduction and in cancer treatment. The meat-sweet pattern of food consumption that is prevalent in the United States is associated with a two-fold increase in estrogen receptor breast cancer compared to a soy based diet. Alcohol is a risk factor. "If you drink wine, drink red wine ... in moderation." Dr. Abrams suggests increasing plant based food, whole grains, fruits and vegetables and Asian mushrooms. Green tea is highly recommended. Dr. Abrams noted that some antioxidants might interfere with the action of chemotherapy and radiation. Useful antioxidants are vitamins A, C and E. Antioxidant rich food is okay throughout treatment, supplements are not. Talk with your doctor.

For more information: <http://www.osher.ucsf.edu>, <http://www.integrativeonc.org>, <http://www.annieappleseedproject.org>.

Look for reports from the other two attendees in the next issue..

Prevention *continued from page 5.*

continued funding of U.S. Department Of Defense Breast Cancer Research Program: <http://cdmrp.army.mil/bcrp/>.

Tertiary Prevention

Involves activities that prevent further disability and restores a higher level of functioning in someone with disease. Like secondary prevention, tertiary prevention can involve treatment; however, it also includes rehabilitation and pain control. The goals include preventing further physical deterioration and maximizing quality of life.

Some Interventions at the Level of Tertiary Prevention:

- ▶ Participate in chronic pain management programs and/or treatment of lymphedema: CRAAB!*, National Lymphedema Network, www.lymphnet.org.
- ▶ Participate in patient support groups: CRAAB!*, Gilda's Club: <http://www.gccrny.org/>. Obtain quality medical management to prevent the disease from causing other problems or "complications."
- ▶ Obtain quality medical management to prevent the spread of cancer to areas outside of the breast. Explore complimentary and holistic medicine alternatives: CRAAB!*, Breast Cancer Options: www.breastcanceroptions.org; Annie Appleseed Project: [annieappleseedproject.org](http://www.annieappleseedproject.org), http://www.breastcancer.org/treatment/comp_med/.

Despite the evidence that prevention works, the focus in our health care system over the past century has not been on the primary prevention of chronic disease, but on the treatment of short-term, acute health problems. We as a nation have placed an emphasis on expensive treatments rather than cost-effective primary prevention thus adding to a health care system that can not afford to treat people with chronic illnesses. As noted in a fact sheet prepared by the Committee on Energy and Commerce, true reform requires an increased emphasis on primary prevention to reduce the strain that disease and poor health exert on our health care system (1). The new healthcare legislation provides \$15 billion in mandatory spending to support prevention and wellness activities and offers a comprehensive policy designed to ensure that all Americans receive state of the art clinical and community preventive services. CRAAB!* offers many exercise programs, nutrition programs and Risk Reduction workshops that focus on primary prevention. Stay involved, remain active and optimize your health!

References

1. Committee on Energy and Commerce Health Care Reform Publications Sunday, 21 March 2010 07:25 http://docs.house.gov/energycommerce/PREVENTION_WELLNESS.pdf

CRAAB!* indicates a topic where more information can be obtained from CRAAB!: 518-435-1055 or <http://www.craab.org/>.

Community Profile

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

A Celebration of Life

by Jude Lilly

This past June 11, I spent the most outrageous birthday with 2000 breast cancer survivors from around the world at the International Dragon Boat Festival in Peterborough, Ontario, Canada. Survivors from 70 teams chanted, sang and danced along in the Parade of Nations, many dressed in costumes such as our team's

Statue of Liberty headgear, or others' crazy hot-pink outfits, pirate regalia or flashy bras worn on top of their shirts.

For three days, I freely shared my cancer experience with others as we laughed and cried and whooped it up. I echoed the sentiments of Mary Alice Edmonds, a member of the *Dragon Heart Vermont* team and a 19-year breast cancer survivor when she said: *I considered us all ambassadors for breast cancer survivors everywhere and we wanted people to know that life did not end because of a diagnosis.* The energy and

spirit I absorbed from the women around me made me feel empowered in dealing with this dreaded disease. For the first time in my two-year journey I felt in control of my fears.

Saved by a Bra

Boats seem to play a significant role in my cancer story. In February 2008, the day after *my* NY Giants had won the Super Bowl, I took a group of learning-disabled adults on a Caribbean cruise. I have been the Assistant Director of Recreation Programs for 23 years at Wildwood Programs, a non-profit agency serving people with learning disabilities, neurological impairments, or autism. On the cruise I was wearing my new Oprah Winfrey recommended Le-Mystere Bra and for some unknown reason was feeling an itch in my left nipple whenever I wore it.

When I got back home, my doctor sent me for a mammogram, which proved negative. I persisted, however, and further testing, a sonogram and an MRI, revealed "hot spots." A needle biopsy pinpointed a specific three-layer cancer. The third layer was acting very aggressively. I guess I could say a bra saved my life. I subsequently learned that I have the BRCA 1 gene. I am the first known carrier in the family.

My Reaction

I was angry. I was in denial. One of my best friends, Judy, had died from cancer three years earlier. I decided to tell few people about my diagnosis. My husband, my son, my future daughter-in-law, my daughter, and her boyfriend were given the news. I told no one else except immediate family and core staff at work. I isolated myself from my close circle of friends in the community by refraining from telling them what was going on in my life. I feared cancer and did not want to talk about it with anyone.

I wanted my life to go back to normal – daily workouts in the gym, the work, which I loved, and socializing with friends on weekends. I had my faith, K-Love, (a contemporary Christian radio station) and Bella Boo (my Jack Russell Terrier) at my side. But as Theresa Harman, *Survivors Abreast*, said in memory of her former Dragon Boat team member: *"We have no choice except to get on with our lives as best we can."*



Treatment

During each phase of my surgery and treatment (double mastectomy, reconstructive surgery, removal of ovaries and five sessions of chemotherapy) I found joy and support in the life and people around me. My husband Dan was at my side at every medical appointment and hospital stay. He meant well, but his sense of humor sometimes led him to make strange comments. For example, when I was being wheeled in for surgery, he quipped, "I'll see you on the other side." This came on the heels of my friend Sara saying "don't go toward the light!"

Loads of Support

My family members live far from us so it was difficult for them to show the depth of their concern and support, which made their efforts even more appreciated. My Siena alum Godson Kevin drew me a St. Jude and Batman picture, which accompanied me to the hospital. He also transported my favorite lemon ice cream 300 miles just so I could have some. My son and daughter-in-law got me into the White House to see MY Super Bowl Champions NY Giants being honored by President Bush. My daughter Erin sent me "The Blue Box" filled with funny and heartfelt gifts. My niece Lisa made sure she visited my mother at her Nursing Home in my stead while I was recovering. My sister-in-law Barbara and brother-in-law Michael sent me gifts by mail for every chemo session I had. My sister Jane called daily and was always there when I needed her.

My son got engaged the month after I was diagnosed and got married one year later. A few weeks after he was married, another dear friend Nancy, who attended the wedding, was diagnosed with cancer. I decided it was time to share my experiences with her in an effort to help her cope with her ordeal. Nancy was very upset with me when she learned the secret I had been keeping. She wanted to have

been there for me. Nancy lost her battle with cancer one year ago on June 30, 2009. I promised her that I would share my cancer experience with our other friends.

In July, my Oncologist realized I was quite depressed at Nancy's passing, and he strongly suggested I get involved with a support group. I attended a conference in August 2009 where, seeing me crying in the parking lot, a woman gave me CRAAB! President Joan Sheehan's name. After contacting Joan, who told me about the dragon boat team, I set my course with *Hope In The Boat* (HITB).

Another Boat

My incredible journey in a boat continued as I worked out with my welcoming survivor sisters from HITB and found my way to the International Festival one year later. After keeping my story to myself for two years and being fearful of joining a group in which I could potentially lose another friend, here I was at the Festival listening to the stories of others and openly sharing my own. I was marching in the International Festival parade dressed as the Statue of Liberty representing the Capitol District of New York. I danced at a Gala with newfound friends from around the world celebrating life and survivorship. I participated in a flower ceremony remembering those who had passed. I threw two pink carnations into Little Lake in remembrance of Judy and Nancy who did not survive their battles. And in my mind I heard these lyrics as their flowers bobbed on the small waves:

*"This is where the healing begins
This is where the healing starts
When you come to where you're broken within
The light meets the dark,
The light meets the dark."*
Tenth Avenue North

Celebrate & Support CRAAB!

*BUY AT BORDERS –
BENEFIT CRAAB!*

Borders Benefits Days

September 25-26. Use the voucher, which you'll get in a mailing from CRAAB!, at the time of purchase and a portion of sales will go to CRAAB!. Vouchers can be used at these Borders stores: Albany at Crossgates Mall, Clifton Park at 3 Southside Dr., Saratoga Springs at 395 Broadway, and can also be used when you shop at www.Borders.com.

*JANICE PASTIZZO
SUPPORTS CRAAB! –
HOW ABOUT YOU?*

Luncheon for the Cure

Friday, October 15, 1 p.m.,
Outback Steakhouse,
610 Old Route 146,
Clifton Park.
Dine in or Carry-out.
\$20 per person.
Sponsored by Fit for Life
Wellness Center and
Outback Steakhouse.

*PATTERSON DENTAL IS READY TO ROCK
AND BOWL FOR CRAAB!. ARE YOU?*

"Strike Out Cancer and Help Spare Lives"

Rock and Bowl Halloween Bash,
Saturday, October 30, 2-5 p.m.
at Boulevard Bowl, Erie Blvd., Schenectady,
to benefit CRAAB! Sponsored by Patterson
Dental. \$25 per bowler (includes shoes
and food). \$10
per non-bowler
(includes food).
Call 452-0307
to register.



Thank You!

We welcome new members!

Elizabeth Flynn	Proskin Law Firm
Patty Franco	Mary Robinson
Nickie Herold	Samaritan Cancer Center
Glenda Hess	Assemblyman Jim Tedisco
Kitty Murphy	Lucille Thomas
Candace Person	Ann Wall

We are grateful for your donations!

In Memory Of:

Constance Christo by Helen Tomaso	Jane Lamb by Brenda Ginardi
Carl and Frances Clarke by Janet Hotis	Agatha Maloy by Mary Maloy
Phyllis Dagner by Susan Charbonneau	Gertie McKain by Carolyn McKain
Loretta Dalia by Nancy Guest	Frances Newton by Shirley Phillips
Patricia Dufek by Barbara Flass	Karen Petrillo by Linda Vaccaro
Rita Gillis by Sheila Platt	Robin, Sybil and Shirley by Kitty Foyle
Jean Marie Klevanosky by Lucy Klevanosky	Susan Roberts by Mary E. Roberts
	Alcyne Severson by Pat Wager
	My sisters by Jean Insley

In Honor Of:

Bernice Bytner by Karen Weir	Margaret Long by Susan Goin
Kristine Edwards by Karen P. Layman	Maureen and Betty by Sue Kelly
Francine Frank & Ruth Schmidt by Bonnie Spanier	Beverly Moquin by Jean Bambury
Christine Gottwald by Joan and Douglas Gottwald	Regina Mooney by Gina Mooney
Barbara Gross Cantwell by Sharon Patrick	Joan Sheehan by Carole Condon
Lynda Johnson by Priscilla P. Johnson	Joan Sheehan by Pat Mitchell
	Mary Sloan by Luba Ricket
	Mary Sloan by Sandy Zwink
	Lynda Van Alstyne and Sandy Ford by Ichabod Crane Primary School
	Virginia Wilson by Lorraine Wilson

Special Donations:

Boscov's Department Store
Congregation Beth Emeth, REYUT Committee
Ichabod Crane Primary School
Doris French in honor of the 50th anniversary of
Mr. and Mrs. Nicholas D'Agostino
Ann Gifford
Holmes - Bishop Charitable Fund
Morgan Stanley Investments
Rotary Club of Latham
The Zonta Club of Albany

Save the Dates!

Continued from page 1.

Yoga Classes

Albany - Led by Mary Sloan, LCSW, LMT, RYT, The Yoga Loft, 540 Delaware Avenue. Wednesdays from noon-1:15 p.m. on Sept. 22, 29, Oct. 6, 13, 20, 27, Nov. 3, 10

Niskayuna - Led by Vicki Braunstein, Upstate Hematology/Oncology, 2125 River Road. Wednesdays from 5:30-6:30 p.m. on Sept. 22, 29, Oct. 6, 13, 20, 27, Nov. 3, 10

Amsterdam - Led by James Meehan, United Methodist Church, Golf Course Road. Thursdays from 5:45-6:45 p.m. on Sept. 16, 23, 30, Oct. 7, 14, 21, 28, Nov. 4, 11, 18

Update on Breast Cancer and Exercise

Discussion led by Linda Miller, Clinical Director of the Breast Cancer Physical Therapy Center, Philadelphia. Tuesday, Oct. 5, at 5:30 p.m., Mercy Auditorium, St. Peter's, 315 S. Manning Blvd., Albany

Luncheon for the Cure, Fri., Oct. 15, 1 p.m., Outback Steakhouse, 610 Old Route 146, Clifton Park. Dine in or Carry-out. \$20 per person. Sponsored by Fit for Life Wellness Center and Outback Steakhouse

Pink Ribbon Blues

A discussion with author Gayle Sulik, Ph.D. Tuesday, Oct. 26, at 5 p.m., Sarazen Student Union, Room 243, Siena College, Loudonville

A Woman's Journey - Traveling with Your Breast Friends

Minority women's health forum. Wed., Oct. 27, 4 p.m. exhibits by regional breast health services providers, 6-8 p.m. free dinner. Sponsored by the Women's Center of Northeast Health at Samaritan Hospital, Komen for the Cure Foundation and CRAAB! Hilton Garden Inn, 235 Hoosick St., Troy. Register at 435-1055, CRAAB!

Strike Out Cancer and Help Spare Lives!

Rock and Bowl Halloween Bash
Saturday, Oct. 30, 2-5 p.m.
Boulevard Bowl, Erie Blvd., Schenectady
\$25/bowler (includes shoes & food) \$10/non-bowler (includes food) Sponsored by Patterson Dental. Call 452-0307 to register.

Medical Massage

By Mary Beth Halayko. Performed in the privacy of your own home, at your convenience! Call CRAAB!