

The CRAAB! Breast Cancer Resource Guide



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(CRAAB!)
Albany, New York

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Have you come to the Red Sea place in your life,
Where, in spite of all you can do
There is no way out, there is no way back,
There is no other way but through?

Annie Johnson Flint



This Resource Guide was created to help women and men make better informed decisions about diagnosis, treatment, care and prevention of breast cancer. It is the first comprehensive compilation of breast cancer resources available in the Capital Region of New York State. CRAAB! has compiled these resources for your convenience. CRAAB! does not necessarily endorse the products, services and organizations listed herein.

Primary care physicians and medical specialists, such as oncologists, surgeons and radiologists are not included in this guide because that information is readily available from regional medical centers, HMO's (health maintenance organizations) and the American Medical Association.

This Resource Guide was produced with a grant from the Susan G. Komen Breast Cancer Foundation *Albany Race for the Cure*, presented locally by the Junior League of Albany; with additional support from the New York State Legislature, and a Harvey Grant from Siena College.

We Want to Hear From You

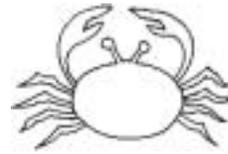
Resources on breast cancer are changing rapidly, so please let us know about any additional information that has been helpful to you. We would appreciate any corrections, updates or additional information that you may find.

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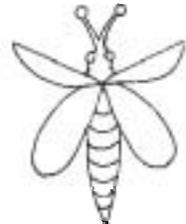
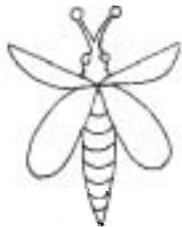
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***know of no exemplary way to be ill.
We all have to find our own way,
but we do not necessarily have to be
alone.***

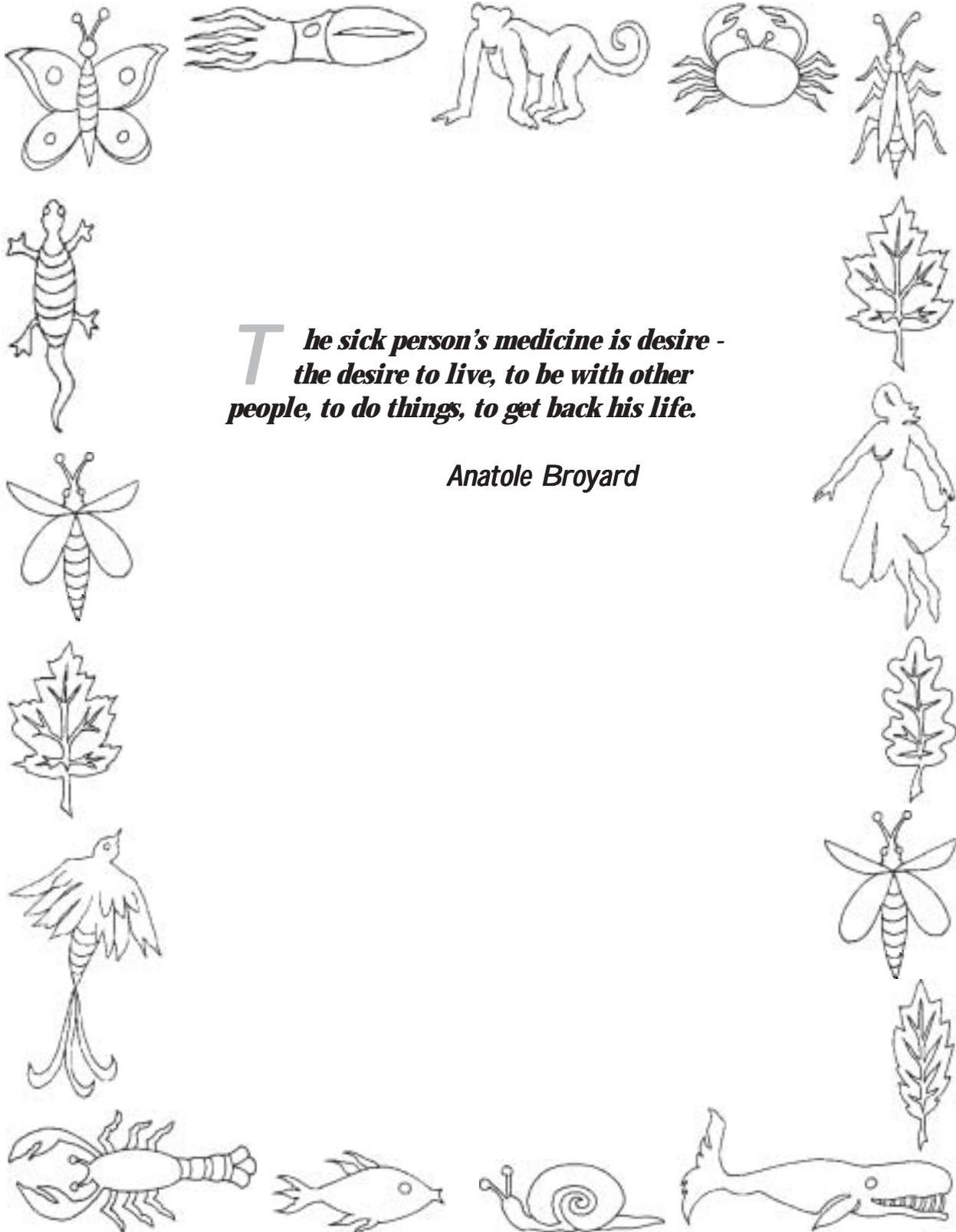
Arthur Frank



CRAAB! Mission

The mission of CRAAB! is to make the eradication of breast cancer a priority through education and advocacy, to empower women and men to participate fully in decisions relating to breast cancer, and to promote and focus research into the causes, prevention, treatment, and cure of breast cancer.

-  Capital Region Action Against Breast Cancer (CRAAB!) was founded in October, 1997 and is a 501(c)(3) not-for-profit corporation in Albany, New York.
-  We are a diverse group of survivors and advocates, including professors, nurses, scientists, librarians, lawyers, environmentalists, students, artists, and health-care providers. We are mothers, sisters, daughters, husbands, fathers, sons and other citizens concerned about breast cancer.
-  Our individual members 1) organize breast cancer support groups, 2) teach art courses for women with cancer, 3) facilitate a lymphedema support group, 4) teach undergraduate courses on breast cancer and women's health, 5) coordinate state-wide advocacy and awareness programs, 6) provide lymphedema treatment, 7) facilitate monthly educational discussions on books and medical articles on breast cancer, 8) work with local, state, and federal agencies to develop policies to improve the environment and 9) act as community contacts to newly diagnosed individuals.
-  Our members review state and federal breast cancer research grants under the New York State Health Science Research Board, the University of California Breast Cancer Research Program, and the U.S. Department of Defense Breast Cancer Research Program.
-  In addition, we work with a number of national and local organizations in efforts to prevent breast cancer and improve treatment for this disease. These groups include: the National Breast Cancer Coalition (NBCC), NBCC's Project LEAD, the National Action Plan on Breast Cancer, the New York State Breast Cancer Network (NYSBCN), New York State Health Research Science Board, Susan G. Komen Foundation, the Junior League of Albany, NY Public Interest Research Group (NYPIRG), and Environmental Advocates.



***The sick person's medicine is desire -
the desire to live, to be with other
people, to do things, to get back his life.***

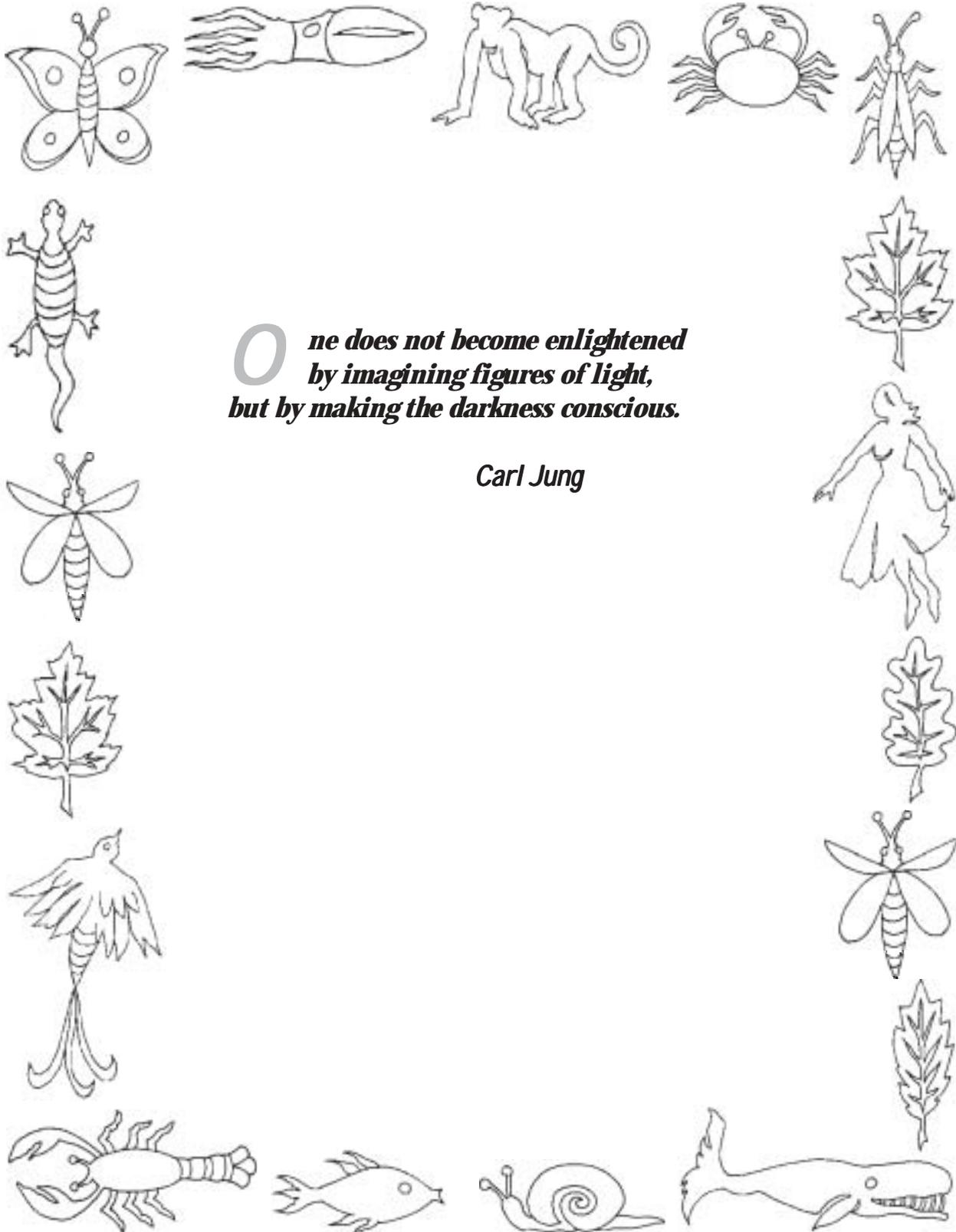
Anatole Broyard

Many people have asked why our organization is called CRAAB! — Capital Region Action Against Breast Cancer. Aside from the fact that the name includes our location and emphasizes our call for *action*, its acronym has both historical and symbolic significance. Historically, the term *cancer* means “crab” in Latin, and the word *karkinoma* means “crab” in ancient Greek.

Hippocrates (460–377 BC), a Greek physician and author of the Hippocratic oath that includes the phrase, “*First Do No Harm*,” first compared the swollen blood vessels radiating from some breast tumors to the limbs of a crab, and referred to the disease as *karkinoma*. The word *cancer* was later used by Pliny (AD 23–79) in his scientific treatise, *Natural History*, to mean a malignant tumor. In addition, *Cancer* has long been used for the Zodiac constellation of the Crab, located between Gemini and Leo.

In its natural habitat, a crab is a fast, resilient decapod crustacean that springs to action, moves in multiple directions, and is sensitive to its surroundings. Like a crab, our CRAAB! members and volunteers move quickly and in several directions to respond to the many issues that relate to breast cancer. We look to the past to understand what shaped current policies and procedures, and we look to the future to find possible solutions. We are active at the local, state and national levels in developing a wide range of programs and services. We are a diverse group who share the common interest in education and the need to stay informed. The concerns of one of us become the common cause of many.

In addition, we feel that the facts about breast cancer give us good reason to be dissatisfied (or even “crabby”). No one can be happy that cancer has become epidemic in our society, that many types of cancer are increasing annually, that few cures are in sight. Clearly something has to be done. The voices of cancer survivors and other concerned citizens must be heard. CRAAB! is dedicated to working to ensure that positive changes are made quickly — for us and for future generations.



***One does not become enlightened
by imagining figures of light,
but by making the darkness conscious.***

Carl Jung

This Resource Guide was created by members of the Capital Region Action Against Breast Cancer! to help you make connections, find and assess information, and get the support you need.

Since breast cancer and many other kinds of cancer are so prevalent in the United States, **everyone** should be informed about risks, diagnosis, treatment, follow-up health issues and prevention. Our increased awareness, however, sometimes breeds overall anxiety and fear. In fact, recent studies suggest that many women, particularly young women, tend to over-estimate their risk for breast cancer.

While we can't help but feel concerned, and even anxious, about the increased attention to the breast cancer epidemic in our country, we believe that we can channel that concern into a constructive and farsighted response. We believe that knowledge — as imperfect and incomplete as it may be at times — is a powerful tool in our struggle to cope with the disease and to eliminate breast cancer and other cancers from our society.

Breast cancer is not a single disease with clearly identified causes. Detection, treatment options and long-term consequences are not currently understood well enough to give sure answers that work for everyone.

When any one of us is diagnosed with this disease, we deserve the best treatment and support to live as full and as long a life as possible. There is no one "best" answer for everyone about assessment, treatment, support and follow-up care. **You, as a wise consumer must find what is right for you.** This guide is intended to help you make more truly informed decisions throughout your healing journey.

use not only all the brains I have, but all I can borrow.

T. Woodrow Wilson

have always believed that intelligent people...not only wish to know as much as possible about any ailment they have, but also that such people are entitled to know everything that is known about such ailments.

Rachel Carson

Staying informed, however, is an on-going process. Acquiring up-to-date information is a challenge because of the proliferation of information sources (some reliable, some not) and the developments in research, medicine and healthcare policy which are continually changing. Hundreds of research centers around the world are investigating possible causes of cancer and ways to prevent it. Current state and federal legislation is changing the quality of our medical care. New cancer treatments are continually being developed, studied, and marketed to the general population, sometimes before there is clear evidence that they are effective. Clinical trials, that are testing the newest and most promising drugs and therapies, are available for cancer

patients at various medical centers around the country. Some complementary and alternative therapies are increasingly being used and accepted as supplemental forms of care or as viable treatment options.

CRAAB! members try to stay informed about these developments. We read books, find up-to-date information on the Internet, and acquire the latest information from national organizations such as the National Cancer Institute, the National Institute of Environmental Health Sciences, the American Cancer Society, the National Breast Cancer Coalition, and the National Alliance of Breast Cancer Organizations. We attend and sponsor various educational seminars, healing programs, and conferences on breast cancer. We participate in breast cancer research review programs and we coordinate local support groups. And most importantly, we continue to have conversations with cancer survivors who often are the best source of knowledge, advice and encouragement.

For this guide we have selected a variety of resources that we have found helpful in our continuing journeys. We hope you find them as useful as we did as you begin to navigate the healthcare system. Perhaps the most important message we can offer is that **even though you may often feel that you are alone, you do not have to be isolated, or feel alienated. There are multiple sources of information and support available. Many women and men who have been diagnosed with breast cancer and who have already been through treatments are here to help.**

It's true that hearing a diagnosis may be shocking and overwhelming to you and your family. You may feel pressure to make crucial decisions quickly. Collective wisdom suggests:

-  *Slow down. Take a deep breath. You have time to make decisions.*
-  *To make important decisions, arm yourself with knowledge.*
-  *To increase your knowledge in the first few weeks, you can connect with a variety of resources.*
-  *To start, we have found the following **Key Information Sources** and materials to be particularly useful: **

Breast Cancer Treatment Guidelines for Patients, American Cancer Society and the National Comprehensive Cancer Network. A 24-page pamphlet for newly diagnosed individuals that explains types of breast cancer with clear illustrations and diagrams of treatment options. For a free copy, call 888-909-NCCN, or 800-ACS-2345. Also available on websites: www.nccn.org and www.cancer.org.

Understanding Breast Cancer Treatment: A Guide for Patients, National Institutes of Health, National Cancer Institute, Publication NIH 98-4251. An easy to read 72 page booklet with glossary that includes explanations of breast cancer types and terms; making decisions about treatments;

** These and other resources are available at the CRAAB! office. Please call (518) 462-4472.*

questions to ask your doctor after a biopsy, after surgery, and during treatments; breast reconstruction; emotional health. Available by calling (800)-4-CANCER (442-6237).

Dr. Susan Love's Breast Book, by Susan M. Love, MD, with Karen Lindsey. (Third Edition, October 2000) Often called "the bible for women with breast cancer," this book provides detailed information about breast biology, new diagnostic techniques, recent research breakthroughs, treatment options, HMO's and insurance issues. It gives sound advice on alternative self-care and top-notch medical treatment. "After a breast cancer diagnosis, most women call a specialist. Then, to understand it all, they consult Dr. Susan Love's Breast Book." (Chicago Tribune) Available in paperback at most bookstores.

Breast Cancer: What You Should Know (But May Not Be Told) About Prevention, Diagnosis, and Treatment, by Steve Austin, ND, and Cathy Hitchcock, MSW. Prima Health Publishing, 1994. A book for women who choose to actively participate in their diagnosis and treatment, and that deals openly with negative side effects. A skillful blend of "intense personal experience and a searching analysis and evaluation of all types of breast cancer therapy." Includes chapters on diagnostic and treatment choices, tamoxifen, alternative options, diet, developing a prevention lifestyle, dealing with change, and getting on with life.

Choices in Healing, Integrating the Best of Conventional and Complementary Approaches to Cancer, by Michael Lerner, MD. A comprehensive overview of both orthodox and alternative therapies, with detailed explanations and evaluations of each; including spiritual and psychological approaches, nutrition, support groups, massage, yoga, acupuncture, Chinese herbal medicines, and traditional medicines from around the world. Explores the art of living fully with the possibility of recurrence. Available in paperback at any bookstore.

Advanced Breast Cancer: A guide to Living with Metastatic Disease, by Musa Mayer. An in-depth guide to making treatment decisions, managing side effects, finding support, dealing with family issues, and coping with emotions. A 45-minute video by the author is also available, by calling 800-998-9938.

NABCO Breast Cancer Resource List (National Alliance of Breast Cancer Organizations) 80 page publication listing comprehensive resources including chapters on helping families, partners, and children cope with the disease; lists regional support organizations by state. Copies are \$5.00 each and available by calling (888) 80-NABCO (806-2226); or e mail: NABCOinfo@aol.com

The Cancer Survival Toolbox: Building Skills that Work for You (1999), the National Coalition for Cancer Survivorship, the Oncology Nursing Society and the Association of Oncology Social Work created this set of six audio programs to help cancer survivors develop the vital skills of: Communicating; Finding Information; Making Decisions; Solving Problems; Negotiating; and Standing Up for

Your Rights. Newly diagnosed persons are the focus, but three tapes address special needs: Topics for Older Persons; Finding Ways to Pay for Care; and Caring for the Caregiver. Available in English and Spanish, free of charge by calling NCCS at 877-TOOLS-4-U (877-866-5748)

In addition, we suggest that you:

- *Consider getting a second opinion about any of your treatments, if you feel the need for more options.*
- *Talk with friends and other breast cancer survivors. They can provide helpful information by sharing their experiences and offering emotional support.*
- *Read what survivors have written about their experiences. Many offer perspective and personal insights. (see Reading List)*
- *Consider finding a support group - there are many types of support groups, so find one that is right for you. (see Support Group list)*
- *Make time for yourself, to care for yourself. Now is the time to add rest and relaxation to your daily routine, and to enjoy activities that increase your sense of well-being. Illness can be an opportunity to re-evaluate your priorities, to find your reasons for living, to choose the life you will lead. It can be a time for growth - a personal retreat to explore your emotions and regain wellness.*

And, **please remember that some treatments may cause long-term health problems.** Before you make your final decisions about treatments, be sure you understand that some treatments increase the risk of secondary long-term health problems. For example, lymph node removal (also called axillary node dissection), mastectomy and radiation, alone or in combination, may cause **lymphedema** — a chronic, painful, and potentially disabling condition of fluid accumulation usually in the limbs. (see section on **Lymphedema Resources** for treatment options).

Other secondary health problems may include skin, heart or lung damage from radiation and phantom pain from mastectomy. Chemotherapy can cause vascular and digestive tract problems, mental impairment, early menopause and in some cases, secondary cancers. Endometrial cancer and pulmonary embolisms are possible effects of tamoxifen. Be sure to ask your medical team about any of these health problems **before you begin treatment**. Certain therapies may alleviate some of the harmful side effects, and reduce the pain and discomfort.

It's clear that cancer patients need education and training in order to understand their options and make appropriate choices. Some cancer patients find themselves with a medical team that offers too little information, while others find themselves with too much information but not enough guidance

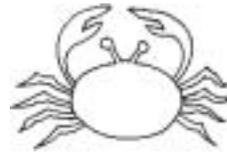
about how to make the best decision. We have heard many stories from cancer patients who feel “lost” or anxious because they have been given different treatment recommendations by each of their physicians. They are simply told the final decision is up to them. Consequently, they need help in assessing the information they have been given. They need reliable resources and connections to people and programs that can offer knowledge and support.

CRAAB! offers this Resource Guide as a list of guideposts, like markers on a map, to help cancer survivors navigate the maze of healthcare choices and challenges, and to perhaps make their journeys with cancer richer and more interesting experiences. There’s no question that getting cancer is certainly a stressful time, one of emotional upheaval, disbelief and uncertainty...but it can also be a time for growth, for discovering one’s own inner strength, and for reconnecting with one’s deepest values.

T *here are no right or wrong decisions here; there is only your need, and your right to have the most accurate information possible, and to decide based on who you are, what choices make the most sense for you.*

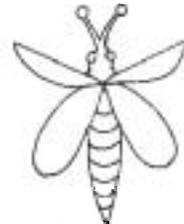
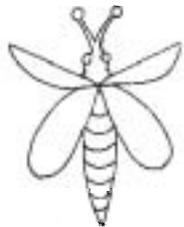
Dr. Susan Love

Notes



This is an experience
to learn about our-
selves.

Bernadette Ambrose
CRAAB! Member



Facts About Breast Cancer in the United States and New York State: Year 2000

The following statistics have been compiled by the National Breast Cancer Coalition (NBCC) and by CRAAB! from the references listed. As members of CRAAB! and NBCC, we are committed to eradicating breast cancer through education, action and advocacy. The statistics speak for themselves about the importance of ending this disease.

-  Breast cancer is the most common form of cancer in America, excluding skin cancers. An estimated 3 million women in the US are living with breast cancer.
-  In 2000, an estimated 225,400 new cases of breast cancer will be diagnosed among women in the US: 182,800 invasive breast cancers and 42,600 *in situ* cases.
-  One out of eight women in the US will develop breast cancer in her lifetime a risk that was one out of 14 in 1960. This year, a new case will be diagnosed every three minutes, and a woman will die from breast cancer every 12 minutes.
-  Approximately 40,000 women in the US die from breast cancer each year. Approximately 400 men in the US will die from the disease. It is the second leading cause of cancer death for women in the US and the leading cause of cancer death for women worldwide.
-  It is currently estimated that of the 182,000 women diagnosed with breast cancer this year, 48% will die from it within 20 years. In other words, almost half of all women diagnosed with breast cancer will eventually die from the disease within 20 years.
-  African-American women have a higher breast cancer mortality rate at every age than Caucasian women. Nearly half of all African-American women diagnosed with breast cancer (47%) will die from the disease within 10 years.
-  Mammography does not prevent or cure breast cancer; it can only detect it "early." Early detection followed by treatment increases five-year survival rates. However, because tumors can exist six to ten years or longer before they grow large enough to be detected by mammography, there is no method of detection that is **truly** early.
-  Breast cancer is an epidemic. Invasive breast cancer incidence in New York state increased from 1976 to 1995. The five year averages per 100,000 during this period were 84.7 (76-80), 90.1 (81-85), 98.9 (86-90), and 101.1 (91-95). This is an increase of 19.5% in 20 years.

- ☛ Mortality rates for breast cancer have been consistently high in northeastern US compared to other areas of the country for the past 50 years. The average breast cancer mortality in the US from 1975 to 1996 varied from a low of 24.3/100,000 (1996) to a high of 27.5 (1985,88, 89). During this time the five year averages for New York State remained well above the national average (31.9, 31.3, 31.1, 28.6, respectively).
- ☛ New York State's five year average mortality rate from 1992-1996 was 28.4/100,000. **This rate is among the five highest in the country.** Other high areas include New Jersey, Rhode Island and Massachusetts. The average for the entire country during this period was 25.4. **New York's breast cancer mortality is 11% higher than the US average during this period.**
- ☛ In the US, there has been a slight decline in breast cancer mortality of white women under 50 (6.8 in 1973 to 5.0 in 1995) and over 50 (89.7 in 1973 to 85.8 in 1995). There has been no similar decline in black women under 50 (8.9 in 1973 and 8.8 in 1995) and there has been a significant increase in black women over 50 (79.8 in 1973 and 103.2 in 1995).
- ☛ It is estimated that the average years of life lost for each person who died of breast cancer is 19.2. By contrast, the average years of life lost from testicular cancer is 35.2, for prostate cancer 9.1, and colo-rectal 13.3. Because so many women die of breast cancer, it is estimated that 826,000 years of life are lost to breast cancer each year. The only cancer that claims more person-years of life is lung cancer.
- ☛ Recent data from a study of 44,788 pairs of twins from Sweden, Denmark and Finland concluded that inherited genetic factors make a minor contribution to the development of cancer. Instead, the environment has the principal role in causing cancer.
- ☛ ***We do not know how to cure or how to prevent breast cancer.***

References

American Cancer Society. *Breast Cancer Facts and Figures 1999-2000*. Atlanta, GA, 2000.

Lichtenstein P, Holm NV, Verkasalo, PK et al. Environmental and heritable factors in the causation of cancer; Analyses of cohorts of twins from Sweden, Denmark, and Finland. *N Engl J Med* 2000;343:78-85.

New York State Department of Health. *Cancer Incidence and Mortality in New York State. Vol. 1. Cancer Incidence and Mortality by County, 1993-1997; Vol. 2 Detailed data for New York State, New York City and New York State excluding New York City, 1983-1997; Vol. 3. Trends in Cancer Incidence and Mortality by County, 1976-1995*, Albany, NY. 2000, 2000, 1998.

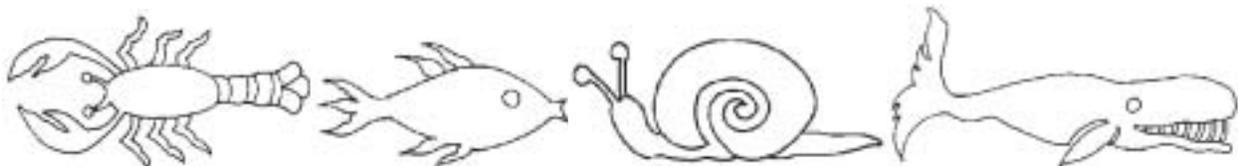
Pisani P, Parkin DM, Bray F, Ferley J. Estimates of the worldwide mortality from 25 cancers in 1990. *Int. J Cancer* 1999;83:18-29.

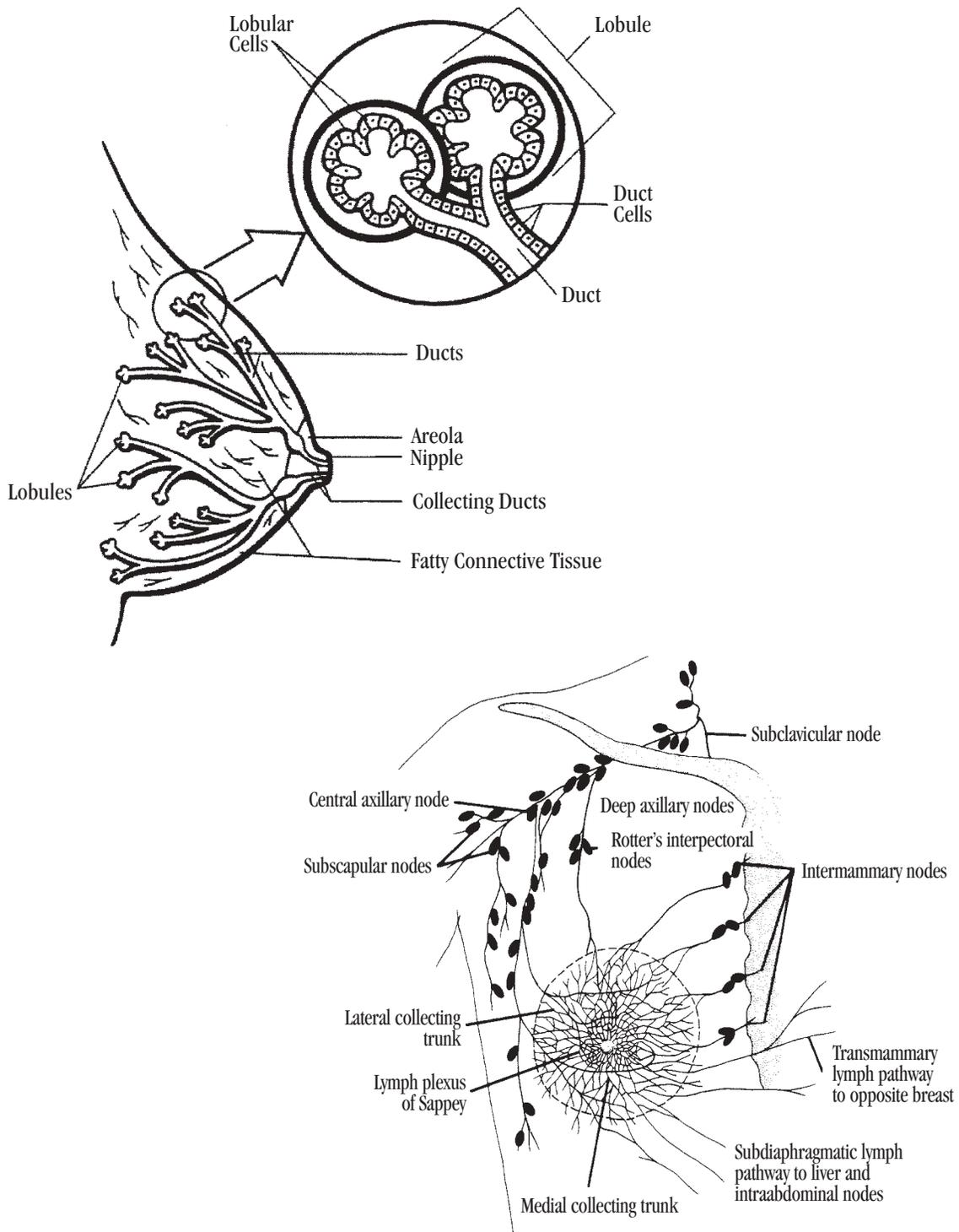
Ries LA, Kosary CL, Hankey BF, Miller BA, Edwards BK (eds). *SEER Cancer Statistics Review, 1973-1996*. National Cancer Institute, Bethesda, MD. 1999

Rockhill B, Weinberg CR, Newman B. Population attributable fraction estimation for established breast cancer risk factors: considering the issues of high prevalence and unmodifiability. *Am J Epidemiol* 1998;147:836-833.

Wingo PA, Ries LA, Parker SL, Heath CW Jr. Long-term cancer patient survival in the United States. *Cancer Epidemiol Biomarkers Prev* 1998; 7(4):271-282.

Wingo, PA, Ries LA, Giovino GA, et al. Annual report to the nation on the status of cancer, 1973-1996, with a special section on lung cancer and tobacco smoking. *J Natl Cancer Inst* 1999;91:675-690.





Lymphatic drainage of mammary gland. Major drainage is toward axilla.

The following information was adapted by Patricia S. Brown, Ph.D., from the American Cancer Society's Community Information Database, the **Iowa Breast Cancer Resource Guide**, and Albert's et al **The Molecular Biology of the Cell**.

Cancer, in general, is a group of many related diseases involving abnormal cell growth. Cancer occurs in some organs in the body, but not others, and different types of cancer grow at different rates and may spread to various locations in the body.

A **tumor** or a neoplasm is a relentlessly growing mass of abnormal cells. As long as the neoplastic cells remain clustered together in a single mass, the tumor is said to be **benign**, and a complete cure can usually be achieved by removing the mass surgically. A tumor is technically counted as cancer only if it is **malignant**, that is, only if its cells have the ability to invade surrounding tissue. Invasiveness usually implies an ability to break loose, enter the bloodstream or lymphatic vessels, and form secondary tumors, or **metastases**, at other sites in the body.

It is the combination of these two features - abnormal cell division and malignancy - that makes cancers dangerous. Because it's not clear which localized tumors may become malignant, there is much controversy and confusion in standard cancer terminology. (Please see Cancer Terminology chapter).

Cancers are classified according to the tissue and cell type from which they arise. Cancers arising from epithelial cells (cells that cover or line organs or form glands) are termed **carcinomas**. In contrast, those arising from connective tissue or muscle cells are termed **sarcomas**. Most breast cancers are carcinomas because they arise from the cells that line the milk producing glands or **lobules**, or else from cells that line the **ducts** that transport the milk to the nipple. (Since they arise from glands they are sometimes referred to as **adenocarcinomas**.) Cancers that arise from connective tissue in the breast are exceptionally rare.

Breast Anatomy

The main parts of the human female breast are **lobules** (milk-producing glands), **ducts** (passages that connect the lobules to the nipple), and **stroma**. Stroma consists of connective tissue that supports the glands and includes adipose (fat) tissue, fibrous tissue, blood vessels and lymphatic vessels. **Lymph vessels** are similar to veins and form a network of vessels throughout the body. They function in returning the fluid and protein that leaks out of your capillaries to the circulatory system. Fluid inside lymph vessels is called **lymph**. Along the lymph vessels are **lymph nodes** (lymph glands). These are small structures that are part of your **immune system**. They produce white blood cells that increase when you are fighting an infection. Lymph flows through the lymph nodes, picking up white blood cells and transporting them into your circulatory system. It is the interruption of this complex lymphatic system of vessels and glands from surgery and radiation that can lead to **lymphedema**, that is the accumulation of lymph fluid in your arm or other region.

Breast Cancer Terminology

Types of Breast Cancer and Related Terms

One of the major challenges of producing a single guide about diagnosis, treatment and follow-up care —indeed, of being truly informed about crucial decisions — is that standard terms and treatments are being questioned within the biomedical research community and the activist survivorship communities. In the definitions below we have included some of these questions regarding the exact classification of breast cancer terms, and how they might influence treatment options or considerations.

A more comprehensive **glossary** of breast cancer and related terms can be found in **Dr. Susan Love's Breast Book** (Third edition) and **Breast Cancer Treatment Guidelines for Patients**, (ACS and NCCN publication). Please see this Guide's Introduction for more information about these two books.

I. In situ: This term is used to indicate an early stage of cancer in which a tumor is confined to the immediate area where it began. Specifically in breast cancer, *in situ* means in place — the cancer remains confined to the ducts or lobules, and it has neither invaded surrounding fatty tissues in the breast nor spread to other organs in the body. Because it is not clear which localized tumors may become malignant there is much controversy and confusion about whether in situ tumors should be classified as potentially malignant cancer.

Lobular carcinoma in situ (LCIS): Categorizing LCIS as cancer is controversial because it begins in the milk-producing glands but does **not** penetrate through the walls of the lobules. However, LCIS is sometimes classified as a type of non-invasive breast cancer, called lobular neoplasia. Although it is thought that LCIS does not develop into invasive breast cancer, women with LCIS are at a somewhat increased risk for developing invasive breast cancer over the long term. For this reason, it is important for women with LCIS to be carefully followed by having examinations and mammograms.

Ductal carcinoma in situ (DCIS): A non-invasive breast cancer. Cancer cells fill the ducts but do not spread through the walls of the ducts into the stromal tissue of the breast. Nearly 100% of women diagnosed at this early stage of breast cancer may be cured. Almost all of DCIS is detected by mammograms and only rarely is it detected by breast self-examination or clinical breast examination. With more women getting mammograms each year, the diagnosis of DCIS is becoming more common — increasing from 1-2% of all breast cancers 20 years ago to 17% in 1997. There are a number of controversial issues associated with treating DCIS. Because it is non-invasive and so lacks the capacity to metastasize, one can question if this is really breast cancer. Some physicians treat DCIS by lumpectomy only or by lumpectomy plus radiation. (For more information see the Consensus Conference on the Classification of Ductal Carcinoma in situ, in *Cancer*, Vol. 8, No. 9, 1997, pp 1798-1802 and an article by M.J. Silverstein, Ductal Carcinoma in situ of the Breast: Controversial Issues, in *The Oncologist*, 1998, 3: 94-103).

II. Invasive/Infiltrating: Cells that line the mammary gland invade or infiltrate the stroma or connective tissue below and can invade blood vessels and lymph vessels.

Infiltrating (or invasive) ductal carcinoma (IDC): Starting in a milk passage or duct of the breast, this cancer breaks through the wall of the duct and invades the fatty tissue of the breast. At this point, it has the potential to metastasize or spread to other parts of the body through the bloodstream or lymphatic system. Infiltrating ductal carcinoma is the most common type of breast cancer, accounting for about 80% of breast malignancies.

Infiltrating (or invasive) lobular carcinoma (ILC): ILC has arisen in the milk-producing glands and is invasive in the breast's fatty tissue. This cancer has the potential to spread elsewhere in the body. About 10–15% of invasive breast cancers are invasive lobular carcinomas. ILC is often difficult to detect by physical examination or even by mammography.

Inflammatory breast cancer: This rare type of invasive cancer accounts for about 1% of all breast cancers. It is an aggressive cancer that usually spreads rapidly to other parts of the body. Characteristically, it makes the skin over the breast look red and feel warm, and causes it to thicken to the texture of an orange peel. Sometimes the breast develops ridges and small bumps that look like hives. These symptoms are caused by cancer cells blocking lymph vessels or channels in the skin over the breast.

Medullary carcinoma: This special type of infiltrating breast cancer has a relatively well-defined, obvious boundary between the tumor tissue and normal tissue. It accounts for about 5% of breast cancers. The outlook, or prognosis, for this kind of cancer is considered to be better than that of other types of infiltrating breast cancer.

Paget's disease of the nipple: This type of breast cancer starts in the milk passages or ducts and involves the skin of the nipple. It can spread to the areola, the dark circle around the nipple. It is a rare type of cancer, occurring in only 1% of all cases. With Paget's disease, there is usually a long history of crusting, scaly, red, inflamed tissue on the nipple and itching, oozing, burning or bleeding. Using the fingertips, a lump may be detected within the breast. If no lump can be felt, the cancer generally has a good outcome, or prognosis. Paget's disease may be associated with in situ carcinoma or with infiltrating breast carcinoma (see above).

Mucinous carcinoma: This type is formed by mucus-producing cancer cells. The prognosis for mucinous carcinoma is considered to be better than for the usual types of infiltrating breast cancer.

Phyllodes tumor: This very rare type forms from the connective tissue of the breast, in contrast to carcinomas that arise in the ducts or lobules. Phyllodes tumors are usually benign but rarely may be malignant. Benign phyllodes tumors are treated by removal, while malignant ones may metastasize and become life-threatening.

Metastases: These are satellite tumors that indicate a cancer has spread from the site where it began (referred to as **primary cancer**) to a lymph node or distant organ such as the lung or brain. In **micrometastasis**, the metastases are so small that they can be seen only under a microscope.

Microcalcifications: These are calcium deposits, often found in clusters by a mammogram. These deposits, sometimes called *calcifications* **are neither cancer nor tumors**. But they **are** signs of changes within the breast, often merely due to aging, and they are very common. Because certain patterns of calcifications can be associated with cancer or benign breast disease, your medical team will want to monitor these changes. Follow-up may be either by periodic mammography or by **biopsy**, a procedure in which a sample of the breast tissue containing the calcium deposit is removed to test for cancer cells.

Node-positive (or negative) breast cancer: *Node-positive* means that the cancer has spread (metastasized) to the lymph nodes under the arm on the same side, which are called axillary nodes. *Node-negative* means that the biopsied lymph nodes are free of cancer. This is an indication that the cancer is less likely to recur.



[Portions adapted from the *NABCO Breast Cancer Resource List, 2000/01 Edition*, available by calling 888-80-NABCO (806- 2226) or see www.nabco.org]

At this time, the vast majority of women who get breast cancer did not inherit the disease. Only about 5-15% of all breast cancer is thought to be hereditary.

The 1995 discovery of the BRCA1 and BRCA2 breast cancer susceptibility genes has added an important dimension to counseling women who may be at high risk of developing breast cancer, as well as other diseases. Currently, a limited number of trained genetic counselors have expertise in cancer susceptibility, and professionals are still investigating the types of information and interventions most helpful to women considering being tested for genetic mutations. Some questions for consideration are: Does knowing if you have a "susceptibility gene" affect your treatment options? Is the information useful to your children? Might the information affect your access to insurance coverage or employment opportunities?

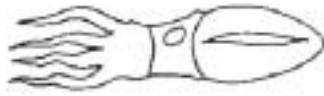
Women have raised a number of concerns about the potential misuse of this information by insurers and the possible invasion of privacy. Despite reassurances, we currently do not have sufficient legal protections against the misuse of genetic information (see NBCC's Legislative Priorities 2000 in *Political Action*).

Here, technology tends to move faster than legal and ethical safeguards. In addition, hasty conclusions from early research can be seriously misleading. For example, because some of the early research on inherited factors in breast cancer focused on families whose heritage was Ashkenazi Jewish, the risk to women of that heritage was vastly over-estimated.

It is important to remember that much is still being learned about the influence of genetic factors on cancer. For example, in Iceland, a particular breast cancer-promoting mutation has a significantly lesser effect compared to the same defective gene in women in the U.S. Thus, the actual results from having a particular defect (called the "penetrance" of a gene) vary greatly and may well be modified by environmental factors as well as other genetic factors.

The Massachusetts Breast Cancer Coalition (800-649-6222) suggests women consider the following before making a decision about being tested for breast cancer susceptibility genes:

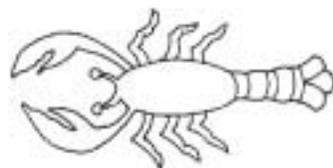
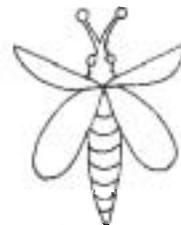
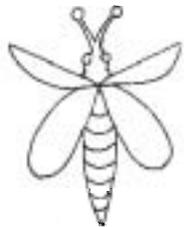
- The tests only indicate susceptibility, or increased risk, not whether you will get breast cancer or not.
- If you test positive, there is no therapy that is certain to prevent the disease. Even preventive mastectomy may not remove all breast tissue.
- Not enough is known about the psychological impact of genetic testing on individuals and their families.
- Current state and federal laws do not adequately protect your confidentiality, should you have the tests done.



Surgery and chemotherapy would irrevocably break my body's continuity with its past.

I did not dread what I would become, but I needed to mourn the end of what I had been.

Anatole Broyard



The National Cancer Institute has given recognition to certain cancer centers based on peer review of their research programs. The three categories are:

-  **CANCER CENTERS** (formerly called Basic Science Cancer Centers) that focus on basic research or cancer control research but do not have clinical programs and usually do not provide patient care;

-  **CLINICAL CANCER CENTERS** that conduct programs in clinical research and may also have other research programs;

-  **COMPREHENSIVE CANCER CENTERS** that conduct programs in all of the areas of research (basic, clinical, and prevention and control) as well as programs in community outreach and education. There are now more than 30 cancer centers that meet the NCI criteria for comprehensive status and more than 50 altogether, engaged in multidisciplinary research to reduce cancer incidence, morbidity, and mortality.

A list of NCI-designated cancer centers is available from CRAAB! or from the NCI (800-4-CANCER). NCI publications providing information about cancer can be obtained for free by calling 301-330-7968.

Notes

[This information has been adapted from the National Breast Cancer Coalition, 1999.]

What are clinical trials?

- 1) Clinical trials are scientific studies of new interventions in prevention, early detection, treatment, and quality of life. Prior to using a treatment with patients, laboratory studies are conducted to identify new methods most likely to succeed with the greatest safety and effectiveness.

- 2) Clinical trials are absolutely necessary. They provide the best evidence of whether an intervention will work. Without trials we will never learn how to prevent breast cancer, how to best treat it, or how to cure it, and our demands for "quality care" will have no meaning.

- 3) As an example of the importance of clinical trial participation, mortality in childhood cancers has dropped 57% since the early 1970s. In fact, 70% of cancer patients under 19 participate in clinical trials. Clinical trial participation, however, falls drastically with respect to age. According to the American Cancer Society's "Facts and Figures" (1998), only 4% of cancer patients aged 20-49 and a mere 1.5% of patients aged 50 or older participate in clinical trials. ***Clinical trial accrual in the adult population is dangerously low. In order to discover better means of detecting, preventing, treating and curing cancer, more adults must participate in clinical trials.***

- 4) The National Breast Cancer Coalition believes that a "quality" trial should be reviewed and approved by each participating institution's institutional review board (IRB); have its study progress monitored by a data and safety monitoring committee at regular intervals; and include a collaborative team of individuals which integrates trained clinicians and consumers. In addition, the protocol should be well-documented, well-designed, and carried out in an ethical fashion.

There is a great need for more scientific information on the usefulness of cancer treatments. However, you should only participate in a clinical trial when it will be helpful to your own healing. To determine whether the clinical trial is appropriate for you, it's necessary and wise to get as much information as possible to make a truly informed decision about participating in any trial. With the recent increase in funding for clinical trials in relation to breast cancer treatments, factors such as drug company interests or publication concerns may affect how physicians and other healthcare workers encourage or discourage women from enlisting in certain trials.

Questioning Breast Cancer Treatment

No one likes to hear bad news. As many breast cancer advocacy groups point out, in spite of our aggressive medical treatment, the mortality from breast cancer in the United States is among the highest in the world. New York State's mortality rate is one of the five highest in the country. Because of these high mortality rates in the US, it is clear that none of the current breast cancer treatments are working well enough to consistently save lives from this disease. **What can we do?**

For people who choose to question the standard medical treatments for breast cancer, it is especially important to be well-informed. All medical treatments have risks as well as benefits. A common complaint from patients who experience serious side effects from surgery, radiation, chemotherapy or hormone therapy is that they were not made aware of the potential side effects and that the "cost:benefit ratio" was not presented in a manner that made clear all the issues. Often detrimental side effects are "down-played," presented as occurring rarely or classified as very unlikely to be a serious problem for the patient. Frequently, few serious studies have been done of side effects and so they may be estimated to occur at a lower rate than really happens. A common consequence is that as patients, we seldom seriously consider these side effects until they become a problem to us personally. **The earlier we raise questions, however, the better informed we will be when facing difficult decisions.**

You may choose to explore breast cancer in the medical literature in order to understand the effectiveness of the current methods of detection and treatment. A close and careful look at some of the medical literature makes it clear that there are many controversies surrounding breast cancer. Some of the questions that have been asked or are being asked by cancer survivors and activists involve current detection and treatment. They include:

-  Does mammogram screening of healthy women save lives? Of women under 40? Under 50? Over 50? Over 70?
-  Do women who do breast self-exams have fewer deaths from breast cancer than women who do not do breast self-exams regularly?
-  Is lumpectomy associated with higher mortality than mastectomy?
-  Is there any difference in survival in DCIS between lumpectomy and mastectomy?
-  Is sentinel node biopsy as effective as axillary lymph node dissection in determining the spread of the disease?
-  Is it necessary to biopsy lymph nodes by any method if the outcome will not alter treatment plans?

- 🕷 When do the side effects of radiation outweigh its benefits for DCIS? for invasive cancer?
- 🕷 Is ovary removal in premenopausal women a more effective treatment than chemotherapy?
- 🕷 Is tamoxifen equally effective in pre- and postmenopausal women? In women with ER+ or ER- breast cancer?
- 🕷 When do the negative side effects of tamoxifen outweigh the benefits? How long should women be on tamoxifen?
- 🕷 Why were so many high dose chemotherapy and stem cell transplants done in women before there was evidence of its effectiveness?
- 🕷 What evidence is there that taxol and its derivatives increase survival in either metastatic or primary breast cancer?
- 🕷 What percentage of women benefit with an increase in survival from standard chemotherapy? What is the average benefit in terms of months or years?
- 🕷 What alternative treatment methods have been studied and found to be viable options?

These are questions that challenge many of the assumptions behind current treatment. Even though they are often not received favorably by surgeons, oncologists and radiotherapists, breast cancer activists are bringing them to light to ensure that cancer survivors receive the best care possible. Many of the risks and benefits of standard breast cancer treatments are explored in *Dr. Susan Love's Breast Book* and in *Breast Cancer: What You Should Know (But May Not be Told) About Prevention, Diagnosis, and Treatment*, by Steve Austin and Cathy Hitchcock (see *Introduction*).

Free Mammograms and Cervical Exams

Healthy Women Partnerships of the Capital District

The Healthy Women Partnerships are groups of individual healthcare providers and organizations such as county health departments, community centers, human service agencies and medical facilities. They work together to offer women a way to get no cost or low cost mammograms and cervical exams. Funded by New York State and the federal government, these partnerships have been formed in every county in New York State..

Who is eligible for services?

If you are a woman:

- age 50 or older (women 40 years and older **may** be eligible) **and**
- you are uninsured **or**
- you have limited health insurance **and**
- you meet program income guidelines.

Whom do I call to receive a free exam or mammogram?

In **Albany and Rensselaer Counties**, call the American Cancer Society at (518) 438-7841 or (800) 725-3185

In **Rensselaer County** you may also call Northeast Women's Health/Samaritan Hospital at 518-271-3288 or Seton Health for Women at 518-268-5991

In **Schenectady County**, call *ENCOREplus Program*, YWCA of Schenectady at 374-3394, ext. 122
For information on Bellevue Woman's Hospital Mobile Mammography Van, call 888-423-3366.

Transportation and Lodging Information

Air Transportation

A few not-for-profit corporations arrange free or reduced cost air transportation for cancer survivors going to and from cancer treatment centers. Financial need is not always a requirement. To find out about these programs, talk with a medical social worker or contact:

Corporate Angel Network: *Westchester County Airport, 1 Loop Road, White Plains NY 10604 (914) 328-1313*

A free service that flies qualified patients to recognized treatment centers. No financial need requirement.

National Patient Travel Center Helplines: (800) 296-1217 or (800) 325-8908,

Email: mercymedical@erols.com; Websites: www.patienttravel.org, or www.patientticket.org

No cost or low cost, long distance air travel for specialized medical evaluation, diagnosis or treatment. Part of the Angel Flight America System.

Airlifeline, Sacramento, CA: A free nationwide service that flies qualified patients to treatment centers within a 700 mile radius: (800) 446-1231 or (877) AIR-LIFE (247-5433).

Ground Transportation

American Cancer Society: (800)ACS-2345, or (518) 438-7841. Your local ACS office may offer reimbursement for travel expenses related to cancer treatment.

Albany County Dept. of Social Services: (*Medical Transportation 447-7492*) works with *Access Transit Authority* to provide free transportation for Medicaid recipients in Albany, Schenectady and Rensselaer Counties. Call 518-459-8747 for more information.

Veterans Administration Medical Center (Albany Stratton) 113 Holland Avenue, Albany, NY 12208
For free transportation for veterans to the VA Hospital, call 518-462-3311, x2266 or x2317.

Senior Services of Albany - Medical Transportation : *Senior Medical Express* provides transportation for Albany city residents, 60 years and older, to doctors' offices, clinics, or any medically related appointments within the city. M-F, 8:30AM-4:30PM. Also offers *Enhanced Assistance* for individuals using wheelchairs or who require special assistance. *Hilltowns Express* offers transportation for Seniors going to Albany from Berne, Knox, Westerlo, Rensselaerville, and Coeymans. Suggested contribution requested. Call 518-465-3322 for more information.

Lodging

For lodging during medical care away from home, contact your treatment center or the services listed below:

National Association of Hospital Hospitality Houses, Inc. (800) 542-9730; Website: nahhhcom.com.

Albany Medical Center, Albany - Wolaner House: Available to Albany Med cancer patients who live outside a 60 mile radius from Albany Medical Center. Call David Walker at Patient Relations: 518-262-3499 for more information.

St. Peter's Hospital - Becky's Lodge (Rebecca Sloan Tyrrell Mercy Lodge)

296 Hackett Blvd.

Albany, NY 12208

518-438-1212

Financial Assistance and Insurance Information

Health Insurance

The Cancer Survival Toolbox: A free audio program (tape cassettes) on "Finding Ways to Pay for Care." Available from the National Coalition for Cancer Survivorship (877) TOOLS-4-U (866-5748)

Cancer Treatments Your Insurance Should Cover: A publication available from the Association of Community Cancer Centers (ACCC), 11600 Nebel Street, Suite 201, Rockville, Maryland 20852, (301) 984-9496, FAX: (301) 770-1949; Website: www.accc-cancer.org. Describes standard and investigational treatments that should be covered and what to do if reimbursements are denied.

Patient Advocate Foundation (PAF), 780 Pilot Drive, Suite 100-C, Newport News, VA 23606
(800) 532-5274, FAX (757) 873-8999; Email: Patient@pinn.net; Website: www.patientadvocate.org
Provides information on insurance issues.

Health Insurance Association of America (202) 824-1600

Offers brochures and information about many insurance issues. Brochures include:

1. Consumer's Guide to Disability Insurance
2. Consumer's Guide to Long-term Care Insurance
3. Consumer's Guide to Medicare Supplement Insurance

New York State Insurance Department *Empire State Plaza, Agency Building 1, Albany, NY 12257*
Website: www.ins.state.ny.us

Consumer Services: (800) 342-3736 or (518) 474-6600, Email: consumers@ins.state.ny.us
Processes consumer complaints against insurance companies, HMO's, brokers and adjusters. Order Insurance Dept. publications on Medicare, Medigap, long-term care, or the Consumer's Guide for HMO's. Licensing information about insurance companies, brokers or adjusters.

Health Bureau: (518) 474-6272, Email: health@ins.state.ny.us. Caller usually must leave a message and wait for a reply. Responsible for product regulation for all accident and health insurance companies, HMO's, integrated delivery systems (IDS), and health insurance products. Responsible for regulating the financial condition, corporate conduct, and administration of the Insurance Law for health insurers, nonprofit health services, and HMO's. Performs certain investigative activities.

Health Insurance External Appeal Questions: (800) 400-8882, Answers questions about the external review process. Website has applications for review process for providers and consumers:
www.ins.state.ny.us

Financial Assistance

Cancer survivors, their families and caregivers should discuss any concerns they may have about costs of care with their physicians, medical social worker, or the business office of their hospital or treatment center.

The services and programs listed below may provide information or offer supplemental financial assistance to those who qualify.

The Cancer Survival Toolbox, a free audio program (tape cassettes) on "Finding Ways to Pay for Care." Available from the National Coalition for Cancer Survivorship, (877) TOOLS-4-U (866-5748)

Federal Insurance and Financial Assistance Programs

Medicaid: Medicaid provides health insurance for low-income and indigent people who are elderly, blind or disabled as well as for certain groups of children. **Services are coordinated by local or county government** through the Dept. of Social Services or the Social Security Administration.

To apply for medicaid: Call your local Dept. of Social Services and make an appointment. Also ask for an application and list of documents to be sent to you, which you can fill out and bring with you to the interview. **You can have someone else apply for you;** however, it's a very lengthy process that requires information in many specific categories. It normally takes 2-8 weeks for your application to be reviewed, and for you to be notified if you are eligible for medicaid assistance.

Albany County Department of Social Services

162 Washington Avenue
Albany, NY 12210
Medicaid: (518) 447-7400

Rensselaer County Department of Social Services

1801 6th Avenue
Troy, NY 12180
(518) 270-3928

Saratoga County Department of Social Services

152 W. High Street
Ballston Spa, NY 12020
(518) 884-4148

Schenectady County Department of Social Services

487 Nott Street
Schenectady, NY 12306
(518) 338-4470

Medicare: Eligible individuals include those 65 or older who receive social security payments, people of any age with permanent kidney failure, and disabled people under 65 who have received social security payments for at least 2 years. Call SSA at (800) SSA-1213 (772-1213), English and Spanish.

Supplemental Security Income (SSI): Supplements social security for individuals who have certain income and asset levels. Call (800) SSA-1213 for more information on eligibility, explanations of coverage and applications.

Veteran's Benefits: Eligible veterans and their dependents may receive cancer treatments at a VA medical center. Call the New York Regional Office of the Department of Veteran's Affairs at (800) 827-1000 for more information.

Life Insurance: You may be able to obtain "accelerated benefits" directly from your life insurance company, which can be 50-100% of whatever portion of the policy applies. You may also want to consider a "viatical settlement" under which a terminally ill person sells his or her life insurance policy for about 40-80% of the face value of the policy. Call your Life Insurance company for more information.

The Medical Escrow Society: Since 1989 this society has helped people with life-threatening illnesses become the beneficiary of their life insurance policies. Call 800-422-1314 or FAX 352-343-3004 for more information.

Income Tax Deductions: In New York State medical and hospital costs that are not covered or reimbursed by insurance policies can sometimes be deducted from annual income before taxes. Medical expenses are deductible, however, only if you itemize deductions and only if they do not exceed a certain percentage of your adjusted gross income. Examples of tax-deductible expenses might include mileage for trips to and from medical appointments, some out-of-pocket costs for treatment, prescription drugs, certain equipment, and lodging up to \$50 per night if you are away from home.

Telephone Hotlines and Information

Telephone hotlines and telephone information services are often a quick way to get basic information, and to connect with other survivors who may have similar diagnoses and treatment protocols. Connecting with breast cancer survivors who have been through similar experiences can ease your fears, be mutually supportive as well as increase your knowledge of treatment options. Telephone hotlines that are starred (*) offer "patient-to-survivor," or "veteran-to-rookie" connections. Literature on most of these other hotlines is available at the CRAAB! office. Please call 518-462-4472 to read more about any of these hotline services.

New York Statewide Breast Cancer Support Hotline * (Adelphi University)

800-877-8077 or 516-877-4444, 9 AM-9 PM, 7 days.

Staffed by trained and professionally supervised volunteers, most of whom are breast cancer survivors who provide information, referrals and emotional support. Phone counseling with social workers is available for individuals. Relevant literature, from many sources, is mailed at no charge.

ElderSource Line (Albany, NY)

518-465-1903

Hotline offered by *Senior Services of Albany* to provide access to a professional Information Specialist of eldercare issues, including insurance, caregiving, community resources, communication skills.

Cancer Hope Network *

877-HOPENET (467-3638)

This service matches cancer patients with survivors (out of treatment at least one year) who have had similar diagnoses and treatments, for one-on-one support via telephone. Callers usually receive a survivor's call back within 24 hours.

National Cancer Institute Cancer Information Services (CIS)

800-4-CANCER (422-6237), 9 AM - 4:30 PM, M-F, English and Spanish

A nationwide network of cancer information specialists who provide information about treatments, clinical trials, financial and travel assistance, emotional support, among other topics. Pre-recorded information is available 24 hours a day.

Cancerfax

301-402-5874

Cancerfax is an automated fax service that provides up-to-date cancer information from the National Cancer Institute. Direct mail materials are also available free of charge as an option for those without a fax machine by calling 800-422-6237.

CancerCare, Inc.

800-813-HOPE (4673), English and Spanish

9 AM - 7 PM (ET), M-Th, and 9 AM - 5 PM, Fridays

Social workers provide education, information and community referrals. Brief telephone counseling and teleconferencing services are available. Will mail literature at no charge.

National Cancer Hotline *

800-433-0464, 9 AM-4 PM, M-F.

Richard Bloch's Foundation provides this "patient to survivor" telephone service. Caller is matched with survivor who has a similar diagnosis. Also offers general information, including regional organizations and support groups. Messages left on voice mail are promptly returned.

American Cancer Society Resource Center

800-ACS-2345, 24 Hours, 7 days, English and Spanish

Provides information and directs caller to ACS and other community services in one's local area.

I'm Aware Helpline (Susan G. Komen Foundation, LA Chapter)*

800-IM-AWARE (462-9273), 9 AM - 4:30 PM (CST), M-F.

Recorded message in English and Spanish. Staffed by volunteers, most of whom are breast cancer survivors, who provide information on breast health and cancer, and short-term moral support.

SHARE Hotline (Information line) *

212-382-2111 (English) or 212-719-4454 (Spanish)

Provides peer support by immediate sharing or matching callers with women who have had similar breast or ovarian cancer experiences. Volunteers can discuss options, help with information research, and provide emotional support.

Stony Brook Cancer Helpline

800-UMC-2215 (862-2215), 8:30 AM - 5:00 PM, M-F

Staffed by oncology nurses who provide information on cancer and treatment options. Will send information on current clinical trials, and give referrals to support groups.

Y-Me Hotline*

800-221-2141 (English) or 800-986-9505 (Spanish), 24 Hours, 7 Days

Staffed by trained counselors and volunteers who have had breast cancer (male counselors available for men). Access to wig and prosthesis bank for people who can't afford these products or whose insurance will not cover them.

Bone Marrow Transplant Link*

800-546-5268 (LINK-BMT), 24 Hours, 7 Days, Fax 248-932-8483

Patient to survivor telephone link. Caller leaves message on voice mail.

Medwatch

888-463-6332, 1-800-FDA-1088 (to get a recording), 301-827-7250 (a real person)

Receives voluntary reports from patients and professionals regarding problems with products and drugs.

National Center for Complementary and Alternative Medicine Clearinghouse

888-644-6226 8:30 AM - 5:00 PM, M-F (EST), 301-495-4957 FAX; 800-531-1794 (fax back system)

Provides information and printed materials on research in complementary and alternative medicine, websites and Internet resources. Does not list practitioners or give referrals. Funded by the National Institutes of Health.

Online Resources

Introduction to the Internet or the World Wide Web

The Internet, or World Wide Web, can be a useful tool and a great source of information specific to your problem or need related to the issue of breast cancer. To connect to the internet or web, you will need a personal computer and internet "browsing" software such as Netscape Navigator or Microsoft Internet Explorer, which is usually furnished with your account by the Internet Service Provider (ISP). The ISP can be one of the national online services or a local service provider.

Please note: Many public libraries provide computers with Internet connections for public use.

National service providers like America Online (AOL), Compuserve, Microsoft Network, Earthlink, and Road Runner, are large private information systems that require user accounts and monthly fees for access. To help you in your search of the ISP that is right for you, check out the following web sites:

WebNovice ISP Help www.webnovice.com/isp_help.htm

ISPs.com www.isps.com

Searching the Web

The Web is made up of millions of individual websites. Each website has a specific address, called a **URL**. The Susan G. Komen Breast Cancer Foundation website is <http://www.komen.org>.

A few of the websites are actually **search engines** which can search for information contained in other websites. You perform a search by inserting a **key word** and the search engine will give you a list of all websites that contain the word that you selected. You can then click on whichever websites look interesting.

Popular search engines include Yahoo, Lycos and Alta Vista. The URL for Yahoo is <http://www.yahoo.com>; for Lycos, the URL is <http://www.lycos.com>; and for Alta Vista, the URL is <http://www.altavista.com>.

Unfortunately, a search by a common word may produce an unmanageably large list of websites. You can **narrow your search by using more than one word**. For example, most search engines allow you to search for two or more words in a row by using quotation marks around the words, for example, *"breast cancer treatments."* You can also search for two or more words that are contained within a website that are not in a row by typing the first word, then AND followed by the next word. For example, *breast cancer AND metastatic AND psychosocial support*. You can get additional search tips from the homepage of a search engine's website.

One interesting search technique is to **search for words in the website address**, that is, the URL itself. For example, if you want a list of URLs that contain the words *metastatic* and *breast*, use the Alta Vista search engine and search for: `url: metastatic AND breast`.

Internet Quick Reference Dictionary

http Means *Hypertext Transfer Protocol*, and is one way that information from web pages is transmitted on the net.

www Means *World Wide Web*. These are pages of information that can be viewed by Internet browsers.

URLs Means *Uniform Resource Locators*. These are Internet or Web addresses. They never contain any spaces or parentheses and never end in periods. Web addresses must be typed exactly as written, including all slashes (/) or dots or tilde (~).

Selected Online Resources Related to Breast Cancer

The following websites will help you in your information search. This list is by no means exhaustive. We have included just some of the breast cancer-related websites that we have found both useful and comprehensive, and most will link you to many other breast cancer-related sites. Although the Web can be a reliable source of information, it is important to be aware that not all the information you find has equal quality, integrity or purpose. You must protect yourself by checking out the source of any information you obtain. Capital Region Action Against Breast Cancer! neither endorses nor recommends any products, processes, services or views and opinions expressed on these websites.

American Cancer Society, <http://www.cancer.org>

This general site provides information on treatment, early detection and prevention of all types of cancer, as well as support services available to survivors and their families. Included are news stories, research information, statistics, alternative approaches, and tips for living with cancer. The *Campaign Against Cancer* section can help citizens voice their opinions to elected officials about funding cancer research, providing quality care, and more. Other sections advise how to tell children about a parent's cancer diagnosis, and describes ACS' prominent *Reach for Recovery* program. You can order videos and materials, including those for the men as caregivers. The *Breast Cancer Resource Center* has information about causes and risk factors, prevention, new diagnostic techniques, and the latest treatment options.

Association of Cancer Online Resources, <http://www.acor.org>

ACOR manages a large number of online support services for patients, practitioners and researchers. The website serves as a resource for people with cancer who wish to find others with their same diagnosis. You can add your name to its Oncology Support Mailing Lists Center at no charge to receive e-mail messages on breaking news, treatment protocols and the psychosocial effects of specific types of cancer. The site also provides links to other related web sites.

Avon Breast Cancer Awareness Crusade, <http://www.avoncrusade.com>

Provides women, particularly those who are medically underserved, with information about breast cancer, and with direct access to early detection services. Programs include community-based breast health programs; the Avon Worldwide Fund for Women's Health; Make the Promise (for early detec-

tion); AVON Kids Care Essay Contest; funding contributed to Project LEAD; and educational videos. *Breast Health Resources* include a list of support groups around the country, detailed information about mammograms, FAQ's, and a detailed glossary.

Breast Cancer Answers, <http://www.medsch.wisc.edu/bca>

A patient-oriented service of the University of Wisconsin Comprehensive Cancer Center (UWCCC) provides accurate and up-to-date information from reliable sources on breast cancer research, risk factors, prevention, screening/detection, diagnosis, stage and treatment. Included are news headlines, information on clinical trials, questions to ask your doctor, and a comprehensive resource guide and list of internet links. You can also email questions to Ask a Breast Cancer Question to be answered by the Cancer Center.

Cancer Care, Inc., <http://www.cancercareinc.org>

This comprehensive website is a good starting point for accessing a wide range of cancer information, from current medical news to coping with cancer. It describes Cancer Care's free programs, and offers information on specific diagnoses, treatments, access to support groups, financial assistance, cancer resources for minorities, and more. The site also contains a special section on breast cancer and sexuality, and suggested links to other cancer-related sites.

CancerGuide: Steve Dunn's Cancer Information Page, <http://www.cancerguide.org>

Maintained through the efforts of a cancer survivor, this site provides links to a variety of cancer information resources to help you find the questions you need to ask. Written in a conversational tone, the website serves as a basic primer on specific diagnoses, clinical trials, alternative therapies, rare cancers, and other issues from the patient perspective. The research has been conducted by Mr. Dunn, who is not a medical professional. He recommends you share any information you gather with your physician.

Cancer News on the Net®/ CancerNews.com, <http://www.cancernews.com/>

A site dedicated to bringing patients and their families the latest information on cancer diagnosis, treatment and prevention. This site continuously searches for the best cancer information on the internet. This includes numerous articles on a variety of cancer related subjects, links to other cancer related web sites, recent cancer news, cancer support groups, clinical trials, cancer and medical books, and events calendar, and a whole section dedicated to just breast cancer, including research, news, treatment, drugs, resources, support, Q&A, networking and medical articles.

Department of Defense Breast Cancer Decision Guide, <http://www.bcdg.org>

The Decision Guide was developed by the U.S. Department of Defense to provide reliable breast cancer information so that patients can make informed decisions about their breast cancer treatment. The site, for both military personnel and civilians, features an interactive consultation in which you respond to prompts for medical and non-medical information that are specific to your diagnosis and personal situation. While the site states that it does not provide medical advice, it can be helpful in helping you make an informed decision about your treatment.

Intercultural Cancer Council, <http://icc.bcm.tmc.edu>

The ICC serves minority and medically underserved communities by providing cancer-related information and programs specific to various ethnic groups. Its website has information on coping and survivorship issues, research news, a calendar of events, and links to resources for minorities at the National Cancer Institute, Centers for Disease Control and Prevention, and others. The site includes detailed listings of health organizations for Hispanic/Latino Americans, African Americans, Asian and Pacific Island Americans and other ethnic groups.

Living Beyond Breast Cancer, <http://www.lbbc.org>

A non-profit, educational organization committed to empowering all women affected by breast cancer to live as long as possible with the best quality of life. This site helps women and families take an active role in their ongoing recovery from the disease, regardless of educational background, social support or financial resources. It addresses the physical, social, emotional, legal and financial issues women face after they have completed their primary treatment for breast cancer. Highlights include information on educational conferences, newsletters, outreach, a Young Survivors group, links to related web sites, and educational materials.

The Mautner Project for Lesbians with Cancer, <http://www.mautnerproject.org>

This site directs services to lesbians with cancer, their partners and caregivers. Services include education and information for the lesbian community and health care providers about special concerns of lesbians with cancer and their families. The site also contains updates on the project's advocacy efforts on lesbian health issues in national and local arenas, in English and Spanish.

National Alliance of Breast Cancer Organizations, <http://www.nabco.org>

NABCO is a leading non-profit breast cancer organization and a network of more than 400 organizations providing breast cancer detection, treatment and care. Its website provides a breadth of information on breast cancer detection, prevention and treatment, as well as the latest news and developments on breast cancer clinical trials. To get immediate assistance close to home, the site offers links to local breast cancer support groups, organized by state.

National Asian American Women's Health Organization, <http://www.nawho.org>

Provides information and statistics to dispel the myth that Asian Americans are the "model minority" group whose women do not get breast and cervical cancer. Includes information on overcoming cultural barriers to prevention, detection and treatment, and updates on its Asian American Women's Breast and Cervical Cancer Project in English, Laotian, Korean, Vietnamese, and Cantonese.

National Black Leadership Initiative on Cancer, <http://www.nblic.org>

Established by the National Cancer Advisory Board in 1989, NBLIC is the first minority outreach initiative of the National Cancer Institute (NCI), to increase awareness among African Americans about cancer prevention, early detection, and to promote utilization of available preventive and detection services. This site is currently under construction, but offers a substantial amount of infor-

mation about cancers disproportionately impacting African Americans (such as breast, cervical, colorectal, lung and prostate). Also offers detailed information on NBLIC's Network Project, NBLIC II, an education/ outreach and research program within minority and medically underserved communities, funded by the NCI, that operates in 33 states and the District of Columbia. This all reflects their motto, "knowledge is the key to the cure."

The National Breast Cancer Coalition, <http://www.natlbcc.org>

NBCC is a grassroots advocacy effort committed to increasing breast cancer research funding, ensuring access to high quality care and clinical trials, and teaching women with breast cancer how to influence the policy decision-making process. On its website you can find out how to become involved in the fight against breast cancer, review updates on NBCC's legislative agenda, and learn how to take part in advocacy training programs, Project LEAD, and other initiatives.

National Cancer Institute CancerNet, <http://cancernet.nci.nih.gov>

CancerNet is the National Cancer Institute's website for patients and the public that contains the latest cancer research, treatment options, detection, prevention, genetics, supportive care, cancer information for different ethnic groups, and clinical trials information. Within CancerNet you can link to CANCERLIT, NCI's research database, and to *CancerTrials*, where you can search the Physician Data Query (PDQ), NCI's comprehensive list of clinical trials, to find a clinical trial that might be appropriate for your type and stage of cancer.

National Center for Complementary and Alternative Medicine, <http://nccam.nih.gov>

This center within the National Institutes of Health conducts and supports research and disseminates information on complementary and alternative medicine for the public and practitioners. This site explains the role that alternative medicine can play in cancer treatment and provides news, events, and resources for additional information on the subject.

National Coalition for Cancer Survivorship (NCCS), <http://www.cansearch.org>

Founded in 1986 of, by, and for cancer survivors, NCCS has grown into a leading national advocacy organization. NCCS is the only patient-led organization working on behalf of people with all types of cancer and those who care for them. NCCS leadership frequently provides testimony before Congress, the Administration or other governmental and non-governmental agencies. Moreover, NCCS leadership plays key roles on a variety of boards and committees involved with issues of quality care for people with cancer. This website includes information on survivorship programs, public health policy issues, a page to order publications, and other issues of interest to cancer survivors. A major feature of the site is *Cansearch: A Guide to Cancer Resources on the Internet*, which is a well-researched, step-by-step guide to the many cancer resources found on the Web.

National Lymphedema Network, <http://www.lymphnet.org>

NLN provides education and guidance to patients with lymphedema, a condition that can develop when lymph nodes are removed, and which results in fluid accumulation and swelling in the arms

and legs. This website provides information on the prevention and management of primary and secondary lymphedema, plus resources for support groups, article reprints and videos, prevention information and links to other websites.

OBGYN.net Latina, <http://latina.obgyn.net/espanol/>

This Spanish-language site provides information on women's health issues, including breast cancer. The site contains statistics on cancer in Latina women, as well as links to resources and treatment centers.

Or try <http://www.obgyn.net> to locate information on women's health issues anywhere, by selecting languages or countries throughout the world.

OncoLink, <http://oncolink.upenn.edu> or <http://cancer.med.upenn.edu>

This site has been referred to as "one-stop shopping" for all your cancer research needs. Sponsored by the University of Pennsylvania Cancer Center, OncoLink offers a comprehensive, well-organized source of the latest and most newsworthy developments in cancer research and treatment, as well as information on clinical trials, dealing with pain, financial assistance, access to support services, a showcase of art by cancer survivors, and a host of other useful information. The site contains a search index at the bottom of the first page to make searching easier.

Sisters Network®, Inc., <http://www.sistersnetworkinc.org>

A national African-American breast cancer survivors support organization committed to increasing attention to the devastating impact that breast cancer has in the African-American community. This site offers information on the organization's national conference and other special events, and how to contact the group for medical information, emotional and psychological support, cancer prevention programs in local communities, and its family home caregiver program.

Susan G. Komen Breast Cancer Foundation,

<http://www.komen.org> or <http://www.breastcancerinfo.com>

The Komen Foundation supports breast cancer research, education, screening and treatment through its national *Race for the Cure®* series, research grants, and other programs. Its website provides extensive information on a wide variety of topics related to breast cancer, and offers analyses of recent breast cancer news, information on breast health, a calendar of events, and announcements of research initiatives. You can take the Komen NetQuiz to test your knowledge of cancer-related risks and myths.

Y-ME National Breast Cancer Organization, <http://www.y-me.org>

Y-ME provides information and support to people with breast cancer, their friends and families through its prominent hotline staffed by breast cancer survivors and through the dissemination of useful cancer information. A user-friendly website includes facts about breast cancer, frequently asked questions, a kid's corner, articles from its newsletter, publication ordering information, breast cancer information for men, and survivor stories, all in English and Spanish.

Education and Advocacy Programs

Knowledge can be “the best physical and psychic nourishment.” Knowledge is power, knowledge creates opportunity, knowledge widens our horizons.

Information, however, or too much information can sometimes be overwhelming and confusing. After hearing a diagnosis of cancer, we often become overwhelmed with new information and disoriented by the sudden need to accept unwelcomed change. We become immersed in new scientific terms and medical knowledge, and we must learn quickly to navigate the complex worlds of medicine and managed care. In a way, we become instant medical students! At the same time, we have to adjust to unsettling routines of debilitating medical procedures.

To help us meet these challenges we need to be educated in ways that are respectful, thoughtful and thorough. We need clear and honest answers to our inevitable questions. As research studies have shown, understanding our experience with cancer is a key to managing our healing process.

For many of us, our experience with cancer has fostered a deep sense of comraderie and connection to the larger community of survivors. We seek to understand how our individual experiences “fit into the larger tapestry” of women’s healthcare issues. In recognizing that this disease is so widespread, we realize the need for changes in our society to ensure that the eradication of breast cancer, already epidemic, becomes a public health priority in every community in the country. This sense of community and the dire need for change are at the heart of advocacy efforts by many groups in New York State and across the country.

The Capital Region and New York State are fortunate in having a variety of organizations that offer educational programs on many topics related to breast cancer. This list also includes national groups that, in many cases, have been sources of inspiration and knowledge for these state and regional organizations.

The lessons have been many: How do I provide myself with the best physical and psychic nourishment to repair past and minimize future damage to my body? How do I give voice to my quests so that other women can take what they need from my experiences? How do my experiences with cancer fit into the larger tapestry of my work as a Black woman, into the history of all women? And most of all, how do I fight the despair born of fear and anger and powerlessness which is my greatest internal enemy?

Audre Lorde, *The Cancer Journals*

Capital Region

Capital Region Action Against Breast Cancer (CRAAB!)

Women's Building, 79 Central Avenue, Albany, NY 12206

518-462-4472; FAX 518-462-0776; www.CRAAB.org (starting in Spring 2001)

Grassroots advocacy group of breast cancer survivors, their family and friends who have open meetings the 4th Tuesday of each month for program development, business planning, and personal support. CRAAB!'s ***Conversations About Breast Cancer*** educational series has monthly meetings (2nd Tuesday) to discuss books and scientific journal articles on a wide range of topics with speakers, panel discussions, and healing workshops. CRAAB! organizes annual Advocacy Days at the NY State Capitol with other members of the New York State Breast Cancer Network (see Political Action and NYSBCN page). CRAAB! promotes research and awareness of the environmental links to breast cancer, and works with local groups to increase education and outreach to medically underserved communities.

New York State Breast Cancer Network (NYSBCN)

Capital Region Contact: CRAAB! at 518-462-4472; FAX 518-462-0776

Statewide coalition of 26 grassroots organizations who joined forces to share information and to advocate for comprehensive legislation to improve all aspects of cancer care, working towards the eventual eradication of breast cancer. (please Political Action and page on NYSBCN).

Albany Medical Center

Marjorie Doyle Rockwell Cancer Resource Center; 8:30 AM- 5:00 PM, M-F

47 New Scotland Avenue, Rm. A-136, MC 173, Albany, NY 12208

518-262-4673 (AMC-HOPE)

Monthly educational forums, resource library and reading room, computers and video library open to the public. For more information, contact Cathryn Corlew at 518-262-4673. (See also **Support Programs**).

American Cancer Society

200 Osborne Road, Loudonville, NY 12211

(518) 438-7841; 800-ACS-2345 (24 Hour Information, with oncology nurse on duty)

380A Glen Street, Glens Falls, NY 12801

(518) 792-5358; www.cancer.org

Breast Self-examination Training: Classes held upon request, are available on an ongoing basis.

Speaker's Bureau: Composed of leaders in the medical field and breast cancer survivors; available in all counties.

ACS programs also include ***Reach for Recovery; Look Good, Feel Better; Road to Recovery; The Loan Closet; Wig Bank; and Image Center.*** (Please see **Support Programs** for more detailed information).

American Cancer Society Advocacy

200 Osborne Road, Loudonville, NY 12211

518-438-9327; mbopp@cancer.org

Michael Bopp, Director

ACS works to secure funding for uninsured and underinsured screening for breast and cervical cancer, and advocates for patient rights and participation in clinical trials.

Ellis Hospital

1101 Nott Street, Schenectady, NY

888-355-4746 or 518-243-4000

Director of Women's Health: Kathie Wunderlich, NP at 518-243-4415; email: wunderlich@shine.org

Periodic educational programs on ovarian and breast cancer.

Honest Weight Food Co-op

484 Central Avenue, Albany, NY 12206

518-482-2667

Offers several educational programs each month, some of which address issues related to cancer and nutrition, diet, healthy cooking and food as our best medicine. All classes are free of charge in the Co-op Community Room, 7-9 PM.

Northeast Health and Samaritan Hospital Treatment Center

Includes Albany Memorial Hospital, Samaritan Hospital, and The Eddy

2212 Burdett Ave. (Samaritan Hospital at 2215 Burdett Avenue), Troy, New York 12180

Cancer Treatment Center: 518-271-3220 ext. 3534; www.NortheastHealth.com

Monthly educational programs and quarterly newsletter, *HealthTalk*. Part of the National Cancer Information System (NCIS) that provides information at 800-4-CANCER.

St. Peter's Hospital Cancer Care Center

315 So. Manning Blvd., Albany, NY 12208

518-525-1547 (Cancer Care Center and Info-line)

Resource Library for anyone with cancer; **Community Lecture Series** (monthly except July and August); **Women and Children's Services Lecture Series** from March- May, plus September and October. Lectures usually held in Cusack Auditorium, 632 New Scotland Avenue, Albany, NY.

Senior Services of Albany

25 Delaware Avenue, Albany, NY 12210

518-465-3322, FAX 518-465-6188; www.seniorservicesofalbany.com

ElderSource Line: 518-465-1903, information on community resources, personal and practical counseling about health insurance, medical problems, among other issues. Offers Wellness programs, Health Expos, Health Insurance Counseling, and other enrichment programs.

To Life!

278 Delaware Ave., Delmar, NY 12054

518-439-5975; (Fax) 518-439-8643; info@tolife.org, www.tolife.org

M-F, by appointment. Education forums; breast self-exam instruction; newsletters; services for women, partners and family during and after treatment; mentoring program, plus image enhancement products.

New York State**Benedictine Hospital Oncology Support Program**

Fern Feldman Anolick Breast Center, 105 Mary's Ave., Kingston, New York 12401

845-338-2500 ext.4453

Barbara Sarah, Coordinator, Oncology Support Program; E-mail: bsarah@benedictine.org

Regular speakers; bi-monthly newsletter; **Nurturing Neighborhood Network** for education and support; **Complementary Medicine Discussion Group** with networking opportunities meets monthly.

Breast Cancer and Environmental Risk Factors (BCERF)

112 Rice Hall, Cornell University, Ithaca, New York 14853-5601

607-254-2893; fax: 607-255-8207; www.cfe.cornell.edu/bcerf/

Offers research and education to identify environmental risk factors; newsletter with research updates.

Breast Cancer Coalition of Rochester (BCCR)

200 Park Avenue, Rochester, NY 14607-2614

716-234-3337, FAX 716-264-1442; www.breastcancercoalition.org; E-mail: bccr@frontiernet.net

BCCR advocates for increased funding for breast cancer research, promotes legislative issues beneficial to all women, seeks to improve access to quality care, and is dedicated to finding a cause and cure. Has a resource library, and offers the *Hope Booklet*, a free resource workbook that helps newly diagnosed women be in control of their treatment and recovery.

Cancer Awareness Coalition, Inc.

PO Box 533, New Paltz, NY 12561

845-255-0836; FAX 845-255-5101; www.cacinfo.org; E-mail: jwill527309@aol.com

Huntington Breast Cancer Action Coalition (HBCAC)

900 Walt Whitman Road, Melville, NY 11747

(Mailing address: PO Box 564, Huntington, NY 11743-0564)

Excellent HBCAC Newsletter, and comprehensive Long Island breast cancer resource list.

Ithaca Breast Cancer Alliance (IBCA)

Women's Community Building, 100 W. Seneca Street, Ithaca, New York 14850

Phone 607-277-0960, FAX 607-275-0632; Hotline: 607-277-9410, website: www.ibca.net

Information network that links newly diagnosed women and men with breast cancer; offers professionally facilitated support groups, referral service, resource center library, *Choices* newsletter, community education series, among other services.

Mid Hudson Options Project, Inc.

c/o Ulster County Community Action, 70 Lindsley Avenue, Kingston, NY 12401

(845) 657-8221

Hope Nemiroff, Chairperson

Offers current information and education, supports political action and investigations into environmental issues related to breast cancer, advocates for quality healthcare, works with health care professionals to train volunteers to educate newly diagnosed women, among other projects.

1 in 9: Long Island Breast Cancer Action Coalition

Nassau County Medical Center, 2201 Hempstead Turnpike, East Meadow, NY 11554

PH: 516-357-9622, FAX: 516-357-9658; Email: OneinNine@worldnet.att.net

Statewide workshops, conferences and forums on causes, prevention, treatments, new technologies, and the latest research. Informative newsletter and a *Guide to Political Action* brochure. Has a strong presence in the political arena and has advocated for legislation that provides better healthcare, a cleaner environment, and more research into the causes and cures of breast cancer.

SHARE - Self-Help for Women with Breast and Ovarian Cancer

Central Office: 1501 Broadway, Suite 1720, New York, NY 10109-0331

212-719-0364, FAX 212-869-3431, Spanish: 212-719-4454

Offers a variety of support groups facilitated by survivors, free of charge to diverse communities in NYC. Through active advocacy, SHARE has developed strong alliances and a strong voice for survivors. Offers an excellent quarterly newsletter, and an *Alternative/Whole Health Study Group*, among other projects.

Young Survival Coalition

c/o Levy, 77 Fulton Street, Suite 19K, New York, New York 10038

212-577-6259; www.youngsurvival.org

As a national network for young women surviving breast cancer, YSC is a central point of contact. YSC provides forums for information exchange, advocates for research on young women with breast cancer, and educates young women and their health care professionals.

Massachusetts and Vermont

Massachusetts Breast Cancer Coalition (MBCC)

51 Diauto Drive, Suite B, Randolph, MA 02368

800-649-6222 or 781-961-7460; E-mail: 1in8mbcc.org

Women's Community Cancer Project (WCCP)

c/o The Women's Center, 46 Pleasant Street, Cambridge, MA 02139
617-354-9888; www.wccp-cancer-project.org

A grassroots, volunteer organization created to make changes in social, medical and political approaches to breast cancer. Offers publications on many relevant topics, a newsletter, environmental information.

Breast Cancer Network, VT

40 Wright Court, South Burlington, VT 05403
802-864-3494, FAX: 802-656-2191

National**American Institute for Cancer Research (AICR)**

1759 R Street, NW, Washington, DC 20009
(800) 843-8114 or (202) 328-7744; www.aicr.org; email: aicrweb@aicr.org

A national organization focusing on the relationship between nutrition and cancer.

Breast Cancer Action (BCA)

55 New Montgomery, Suite 323, San Francisco, CA 94105
(800) 2STOP BC (278-6722) or (415) 243-9301; FAX (415) 243-3996
www.bcaaction.org; email: info@bcaaction.org

A grassroots member-based organization of breast cancer activists who are not afraid to examine all sides of all issues. BCA serves individuals while reaching the broader population, and recognizes that structural changes in society are needed to eradicate breast cancer. As part of the Bay Area Toxics Link Coalition, BCA developed the *Stop Cancer Where it Starts* initiative that focuses attention on environmental causes of cancer and promotes the Precautionary Principle. Has perhaps the best newsletter on current issues and controversies surrounding breast cancer, with up-to-date information on promising research and new therapies.

Breast Cancer Fund (BCF)

282 Second Street, San Francisco, CA 94105
(415) 543-2979; FAX (415) 543-2975; www.breastcancerfund.org

A national non-profit organization to innovate and accelerate the response to the breast cancer epidemic through research, action, and policy. Seeks to research non-toxic treatments, safer and more effective detection methods, environmental links to breast cancer, and promotes holistic wellness and healing programs. Sponsors national fund-raising activities, such as mountain climbing expeditions and bike tours; and provides community service grants to breast cancer programs.

Cancer Care, Inc.

275 Seventh Avenue, New York, NY 10001
(800) 813-HOPE (813-4673); (212) 302-2400

Educational programs, workshops, teleconferences, one-to-one counseling (see Hotlines), support groups. Provides restricted financial assistance in New York City, Long Island, New Jersey and Connecticut.

Cancervive

6500 Wilshire Blvd., Suite 500, Los Angeles, CA 90048
(310) 203-9232; www.cancervive.org; Email: cancervivr@aol.com;

Assists cancer survivors to face and overcome the challenges of life after cancer; assists with insurance issues and offers support groups.

Cancer Liaison Program

Food and Drug Administration, 5600 Fishers Lane, Rockville, MD 20857
(301) 827-4462

Provides information on the FDA drug approval process, cancer clinical trials, and access to investigational therapies.

The Dream Foundation

621 Chapala Street, Suite D, Santa Barbara, CA 93101-7011
(805) 564-2131; www.dreamfoundation.org; Email: dreamkr@aol.com;

The Dream Foundation tries to fulfill last wishes of adults (18-65) when life expectancy is less than one year.

Encore Plus: YWCA of the USA

624 9th Street, NW, 3rd Floor, Washington, DC 20001-5394
(202) 628-3636; www.ywca.org

A service for women over 50 in need of early cancer detection information, breast and cervical cancer screening, or support services.

Mautner Project for Lesbians with Cancer

1707 L Street NW, Suite 500, Washington, DC 20036
(202) 332-5536, FAX: (202) 332-0662;
www.mautnerproject.org; Email: mautner@mautnerproject.org

Provides free services to lesbians with cancer and assists their partners and caregivers; education and advocacy on lesbian health issues in national and local arenas; also provides a comprehensive resource library.

Men's Crusade Against Breast Cancer

4502 Fidelity Court, Annandale, VA 22003-4525
703-978-3336; FAX 703-931-9572

Committed to the prevention and cure through education and focused research. Promotes grassroots action by men, women and families. Publishes *A Family Guide to Fighting Breast Cancer*.

Mothers Supporting Daughters with Breast Cancer (MSDBC)

21710 Bayshore Road, Chestertown, MD 21620-4401

410-778-1982, FAX 410-778-1411

Helps clients to cope with breast cancer by providing a support network enabling mothers and daughters to communicate more effectively with each other.

National Alliance of Breast Cancer Organizations (NABCO)

9 East 37th Street, 10th Floor, New York, NY 10016

888-80-NABCO (806-2226), FAX: 212-689-1213; www.nabco.org; Email: NABCOinfo@aol.com

NABCO is a leading non-profit breast cancer organization and a network of more than 400 organizations providing information on breast cancer detection, treatment and care. Also provides assistance and referral.

National Breast Cancer Coalition (NBCC)

1707 L Street, NW, Suite 1060, Washington, DC 20036

202-296-7477, FAX 202-265-6854; www.stopbreastcancer.org

NBCC is a grassroots advocacy effort committed to increasing breast cancer research funding, ensuring access to high quality care and clinical trials, and teaching women with breast cancer how to influence the political decision-making process and to shape national policy. Political Advocacy training and education available through Project LEAD.

National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Avenue, 5th Floor, Silver Spring, MD 20910

877-NCCS-YES (877-622-7937), FAX: 301-565-9670; www.cansearch.org; E-mail: info@cansearch.org

A patient-led advocacy and information organization using educational programs, publications, and public policy expertise to lead and empower cancer survivors.

National Latina Health Organization (NLHO)

PO Box 7567, Oakland, CA 94601

510-534-1362, FAX 510-534-1364; Email: Latinahlth@aol.com

Supports bilingual access to quality health care and the self-empowerment of Latinas through education, outreach, research, and public policy.

National Lymphedema Network (NLN)

2211 Post Street, Suite 404, San Francisco, CA 94115-3427

800-541-3259, 24 Hour/Day Info. Line; 415-921-1306; FAX 415-921-4284

www.lymphnet.org; Email: nln@lymphnet.org;

Information and education about lymphedema, a referral service to medical and therapeutic treatment centers, information on locating or establishing support groups, a computer data bank, and conferences.

National Women's Health Network

514 Tenth Street, NW, Suite 400, Washington, DC 20004

202-347-1140, FAX 202-347-1168; www.womenshealthnetwork.org

Advocates for better health policies for women, maintains a library, and offers an informative newsletter.

Patient Advocate Foundation (PAF)

780 Pilot Drive, Suite 100-C, Newport News, VA 23606

(800) 532-5274, FAX (757) 873-8999; www.patientadvocate.org; Email: Patient@pinn.net

Provides information and help dealing with insurance and managed care issues. Offers publication, *The Managed Care Answer Guide*, and legal counseling.

Sisters Network

National Headquarters, 8787 Woodway Drive, Suite 4207, Houston, TX 77063

(713) 781-0255; www.sistersnetworkinc.org; Email: sisternet@aol.com

A national African-American breast cancer survivors support organization committed to increasing attention to the devastating impact that breast cancer has in the African-American community. Provides community education and awareness, person-to-person emotional and psychological support, cancer prevention programs in local communities, and offers a family home caregiver program.

Susan G. Komen Foundation

5005 LBJ Freeway, Suite 370, Dallas, TX 75244

(800) IM-AWARE (462-9273)

National volunteer organization with local chapter affiliates that sponsor *Race for the Cure* events across the country, to raise funds for research and community-based support and treatment programs.

Y-Me Advocacy Program

212 West Van Buren Street, 5th Floor, Chicago, IL 60607-3908

312-986-8338, FAX 312-294-8598; www.y-me.org

Provides hotline peer counseling by breast cancer survivors, educational programs, and information on public policy and legislative issues. Offers workshops for healthcare professionals, technical assistance, a resource library, and newsletter.

Capital Region Support Groups and Healing Programs

A support group can be an integral part of a patient's journey with cancer. It is a unique situation where patients, and sometimes families, can share their stories with others. It is a time to learn from each other, share ideas about what has helped, and sometimes just acknowledge the pain or hard transitions. It is often a chance to speak to someone who understands from experience. In some instances, patients find it easier to talk to strangers than those close to their heart.

In our Capital Region area there are a variety of support groups to help people with different needs and ways of coping. There are open-ended discussion groups, where people come together to verbally share thoughts, concerns, and sometimes solve specific problems. There are speaker groups where a variety of relevant topics, such as nutrition or spirituality, are addressed by outside speakers. There are also groups that have developed around the creative arts and involve writing, painting, quilting, collage, photography, among other artistic projects. To find the support group that best fits your needs and interests, you can contact the facilitator of the group before attending. Ask questions about the group, how it is currently operating, how many people usually attend, what kinds of projects are worked on, and any other related questions.

Kristen Ross, MSW, CSW, Oncology Social Worker, Albany Medical Center

In this list of programs, some are specific to breast cancer and are designated **BC**. Others are available to people with any type of cancer and are designated **AC** to indicate "all cancer". Meeting times and contact people change frequently and so may not be accurate.

Albany County

Albany Medical Center (AC)

Marjorie Doyle Rockwell Cancer Resource Center: Monday-Friday 8:30 AM - 5:00 PM

47 New Scotland Avenue, Room A-136, MC 173, Albany, NY 12208

Contact: Cathryn Corlew at 518-262-4673 (AMC-HOPE)

This center sponsors a wide variety of support groups and educational programs (see below), including short-term support groups on **Stress Management, Pre-surgery Support, Caring for the Caregiver, Emotional Wellness, and Story Telling for cancer patients' children.**

Living with Cancer Support Group (AC)

Marjorie Doyle Rockwell Cancer Resource Center, A-136: Wednesdays, 3:30 PM - 5:00 PM;

Albany Medical Center, Albany, NY 12208, Call 262-4673.

An open discussion group for people who have just been diagnosed or are in beginning stages of treatment, facilitated by oncology social workers, pastoral care staff, and oncology staff.

Marrow Support Group (BC)

Marjorie Doyle Rockwell Cancer Resource Center, A-136: 4th Monday each month, 5:30-7:30 PM

Albany Medical Center, Albany, NY 12208

Contact: Barbara Maloy, RN, OCN at 262-5806.

American Cancer Society (AC)

Eastern Regional Office of the Capital Region, 200 Osborne Rd., Loudonville, NY 12211

518-438-7841; 800-ACS-2345

Reach to Recovery - One-on-one mentor program, survivors will meet with patients at home, in the hospital or a neutral place. Call 800-ACS-2345.

Look Good, Feel Better - For those in chemotherapy, monthly workshops with cosmetologist present, to gain control over side effects such as hair loss, and dry skin and nails. Programs offered in Albany, Columbia, Montgomery, Schenectady and Warren Counties. Call 800-ACS-2345 for more information.

Road to Recovery - Provides cost-free transportation to and from treatment on an availability basis.

The Loan Closet - Loans hospital beds, wheelchairs, commodes free of charge, based on availability.

Image Center and Wig Bank - Breast cancer patients can examine various hairpieces, prostheses, bras, and obtain product information before they shop.

Capital District Lymphedema Support Group (AC) For those with primary or secondary lymphedema.

Second Wed of Sept., Nov., March and May, 7-8:30 PM

Woman's Healthcare Plus, 24 Computer Dr. West, Albany, NY 12205

Contact: Joan Sheehan at 459-5086 or 452-3455

Coping Through Creativity (AC)

Pen & Palette, 29 Ver Planck Street, Albany, New York 12206

2nd and 4th Thursdays, 5:30-7:30 PM, Special Saturday "healing workshops" throughout the year.

Contact: Margaret Roberts at 482-1314

Arts and crafts as self-expression and emotional support for cancer survivors.

Life Story and Poetry Writing Workshop for Cancer Survivors (AC)

Albany Medical Center Alumni Lounge, K-117

Wednesday, 7-9:00 PM

Contact: Susan Riback, RN at 475-0151

St. Peter's Can Do (AC)

St. Peter's Hospital Lobby or Suite 100, 317 S. Manning Blvd., Albany, NY 12208

First Mon. every month, 6-7:30 PM

Contact: Dee DeLollo at 525-1547

Opportunity for patients living with a diagnosis of cancer to share concerns.

To Life! (BC)

278 Delaware Avenue, Delmar, NY 12054

Contact: Mara Ginsburg at 439-5975.

M-F, by appointment. Breast self-exam instruction, mentoring program, services for women and families.

Wellness/Support Group: Working With Life Changing Illness (AC)

Albany Health Management Association, 582 New Loudon Rd., Latham, NY 12110

Director: Patricia A. Fennell, CSW-R, at 782-0551

Clinically guided group and individual therapy for cancer patients, families and couples. Bereavement counseling is offered on an individual basis.

Wellness Group (AC)

The Consultation Center, 970 Lancaster, Albany, NY 12203

Fr. John Malecki at 489-4431; Monday 3:30-5:00 PM

Coping with life-threatening illness; other counseling services available.

Columbia/Green Counties

American Cancer Society's Caring and Sharing (BC)

Green Medical Arts Center, Room D003, 159 Jefferson Heights, Catskill, NY

Contact: Nancy Lomax at 518-943-4244

Second Wed of each month (except July and August), 10 AM - noon

Fulton/Montgomery Counties

Breast Cancer Support Groups (BC)

Amsterdam Memorial Hospital with Ellis Hospital

Call 518-842-3100

Breast Cancer Support Group (BC)

Wellness Institute, St. Mary's Hospital, 427 Guy Park Avenue, Amsterdam, NY 12010

Contact: Susan Everett at 518-841-7145

For women and men with breast cancer.

Rensselaer County

Northeast Women's Health Services (AC)

Albany Memorial Hospital and Samaritan Hospital, 2215 Burdett Avenue, Troy, NY 12180

Contact: Ann Lanoue, BSN, RN at 518-271-3288

Case management and support services including stress management, therapeutic massage, hypnotherapy.

Women's View (2 locations) (BC)

Mary McClellan Family Health Center, 16 Danforth Street, Hoosick Falls, NY 12090

518-252-2600

Mary McClellan Hospital, 1 Myrtle Avenue, 3rd Floor, Cambridge, NY 12816

Breast cancer education, support, complementary therapies, emotional health resources and referrals.

Saratoga County

American Cancer Society's Reach to Recovery Cancer Support Group (BC)

Saratoga Hospital Board Room

Third Mon. of each month, 7 PM

Contact: ACS at 800-ACS-2345, or Sheila O'Connell at 584-3648

Living With Cancer (AC)

Riverview Medical Association, Rexford, NY

Second Tues. of each month except June, 7 PM

Contact: Kathy Wroblewski at 399-4600

Schenectady County

American Cancer Society Reach for Recovery Support Group (BC)

Faith United Methodist Church, Corner of Eastern and Brandywine,

Second Wed. of each month, 7 PM

Contact: Chris Brindle at 438-7841, x 306

Healing Through Sharing (AC)

Bellevue Woman's Hospital, Mansion Building, 2nd Floor, Dr. Jorgensen's waiting room,

2210 Troy Rd., Niskayuna, NY

4th Tues. of each month, 7-8:30 PM

Kelly Sil, BS, RN at 347-3369

Bellevue Woman's Hospital (AC)

To find out details about Bellevue's many support programs, please call 518-346-9438 or Community Education at 346-9410. Their Women's Health Matters newsletter contains health and community program information.

Cancer Support Group for Patients and Caregivers (AC)

Ellis Hospital - McDonald Oncology Unit, 1101 Nott St., Schenectady, NY 12308

4th Tues of every month, 7-8:30 PM

Contact: Amy Brule at 243-4114

Women's Health Program

Ellis Hospital, 1101 Nott Street, Schenectady, NY 12308

Contact: Kathie Wunderlich, NP 518-243-4415

Breast and ovarian cancer support groups.

Haven Grief Counseling Center (AC)

703 Union St., Schenectady, NY 12305

518-370-1666 FAX 370-1917

Haven is a not-for-profit organization whose mission is to provide support for people experiencing grief and life-threatening illness. Children and teen programs are also available.

Schoharie County

Cancer Support Group (AC)

Bassett Hospital of Schoharie County, 41 Grandview Drive, Cobleskill, NY 12043

2nd Tues of each month, 10 AM to noon

Contact: Susan Cimino-Carey at 254-3271

Offers an "early intervention" program that matches newly diagnosed persons with others who have been through treatments.

Warren/Washington Counties

After Breast Cancer Support Group (BC)

Glens Falls Hospital, Resource Center Library

4th Mon of every month, 7 PM

Contact: Linda Lansburg, RN, OCN at 518-926-6639

Cancer Support Group (AC)

Glens Falls Hospital, Cancer Center Library

Every Monday, 7 PM

Contact: Lois Wiegert, RN at 518-792-3233

For individuals, families and friends diagnosed with cancer.

Cancer Support Group (AC)

Glens Falls Hospital, Cancer Center Library

2nd Tues of each month, 12 noon (only patients can attend)

Contact: Cathy Howland, RN, OCN at 518-926-6589

Grief Education and Support (AC)

296 Glen St., Glens Falls, NY 12801

3rd Tues of every month, 5-6:30 PM

Sponsored by Hospice of Warren County Church of the Messiah Parish House

Contact: Susan Landry at 518-743-1672

Healing Programs

Omega Institute for Holistic Studies

150 Lake Drive, Rhinebeck, NY 12572-3212

800-944-1001; Website: www.omega.org

Offers workshops and retreats for women with cancer that focus on how creativity, humor and spirituality can support healing and well-being. Also offers workshops in art, dance, movement therapy, yoga, and a wide variety of other programs.

Commonweal Cancer Help Program (CCHP)

PO Box 316, Bolinas, CA 94924

415-868-0970; Website: www.commonweal.org

A 25-year old health and environmental research institute and healing center, dedicated to helping people seeking physical, emotional and spiritual healing in the face of cancer. A wide variety of week-long workshops are offered, including yoga, progressive deep relaxation, meditation, imagery, massage, art therapy. Located at Point Reyes National Seashore, with other affiliated programs around the country.

Hospice Care

Hospice is a philosophy of care for the dying patient and his or her family, with the emphasis on supporting the life that is left. This care can be taken into the home, nursing home, hospital or hospice unit. It may best be summarized by Dame Cicely Saunders, founder of the modern hospice movement, in this quote:

You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but to live until you die."

Community Hospice, in various areas of the Capital Region

315 S. Manning Blvd.

Albany, NY 12208

518-525-1686

40 Guy Park Ave.

Amsterdam, NY 12010

518-843-5412

47 Liberty

Catskill, NY 12414

518-943-5402

295 Valley View Road

Rensselaer, NY 12144

518-285-8100

179 Lawrence

Saratoga Spring, NY 12866

518-581-0800

1411 Union Street

Schenectady, NY 12308

518-377-8846

New York State Hospice Association

21 Aviation Road, Suite 9, Albany, NY 12205

518-446-1483

Non-profit patient information organization representing hospice palliative care programs, allied organizations and individuals who are interested in the development and growth of comprehensive end of life care services. Referrals can be made to all programs in NYS.

HOSPICELINK

Hospice Education Institute Suite 3-B, PO Box 7135, Essex Square, Essex, CT 06426-0713

800-331-1620

HOSPICELINK maintains a computerized directory of hospice programs in the US and refers callers to local hospice programs.

National Hospice Organization

1901 North Moore Street, Suite 901, Arlington, VA 22209

800-658-8898; Website: www.nho.org

Information, free publications and referrals regarding hospice care.

Choices in Dying, Inc.

200 Varick St., New York, NY

212-366-5540, Website: www.choices.org

Dedicated to fostering communication about complex end-of-life decisions. Provides advance directive, counsels patients and families, trains professionals, advocates for improved laws and offers a range of publications and services. Free information and forms on living wills, advance directives and health care proxies, as applicable in each state.

Books, Audiotapes and Websites

Lattanzi-Licht, Marcia with J.J. Mahoney and G.W. Miller. 1998. *The Hospice Choice: In Pursuit of a Peaceful Death*. Fireside.

Levine, Stephen. *A Year To Live: How to Live This Year As If It Were Your Last*.

2 cassette audiotape available from Sounds True, PO Box 8010, Boulder, CO 80306-8010, 1-800-333-9185. *Brings the dying process into the full light of awareness.*

Hospice Hands

<http://hospice-cares.com/hlinds.html>

Hospice Web

www.teleport.com/~hospice/links.htm

Lymphedema Resources

Lymphedema is a chronic swelling condition caused by an accumulation of lymph fluid. In breast cancer patients, it can occur in an arm following lymph node dissection and/or radiation of the chest wall. Normally, any extra fluid in your tissues moves into lymph vessels, passes through lymph nodes and eventually is returned to the bloodstream. Once lymph nodes and lymph vessels are cut, the lymph vessels may not regenerate and the passage of extra fluid into the bloodstream is interrupted. Approximately 15 to 50% of women will develop lymphedema after breast cancer treatment.

Lymphedema can be so slight that you scarcely notice it or so severe that your arm is huge. It can be temporary or permanent and can happen either immediately after surgery or many years later. It can start out as an acute condition with minor or severe swelling. Without early intervention it can become a chronic condition and more difficult to treat.

Both the awareness and the treatment of lymphedema has changed dramatically. A Federal law (Women's Health and Cancer Rights Act of 1998) requires that insurance companies provide coverage for "*physical complication of all stages of a mastectomy including lymphedemas.*"

Because lymphedema can be very serious and because the recognition of the prevalence has changed recently, every woman must be educated about this condition. She must be able to advocate for her individual needs with insurance providers regarding treatment, necessary bandage supplies, compression garments and follow-up care.

To insure that lymphedema is adequately recognized and treated, it is recommended that before any breast surgery (lumpectomy, mastectomy, lymph node surgery), radiation or chemotherapy treatments, you see a physical therapist who can calculate a baseline volumetric measurement of both arms. These measurements, made prior to any treatment process, will aid your physician and physical therapist in diagnosis and treatment of lymphedema.

Delmar Physical Therapy and Lymphedema Center

8 Booth Road, Delmar, NY 12054

Contact: Michele N. Keleher, MS, PT at 518-439-1485

E-mail: michele@delmarpt.com; Website: www.delmarpt.com

Comprehensive treatment services include: Vodder Manual Lymph Drainage and Complete Decongestive Therapy, Chikly lymphatic mapping, custom fitting of all brands of compression garments; authorized dealer of Medi-USA, Juzo, Beiersdorf-Jobst, Sigvaris, Reid Sleeve, Legacy and Circ-Aid.

Under a newly established program, Delmar Physical Therapy and Lymphedema Treatment Center will provide, at no charge, pre-treatment limb volume measurements. The data collected, in table and graph format, will also be forwarded to the appropriate physicians. Early diagnosis of lymphedema means easier management of the condition by the patient. It is hoped that this program will significantly increase early detection by providing the patient and physician with relevant pre-treatment data.

To schedule your free measurement, please call 518-439-1485.

Lymphedema Management Program at St. Peter's Hospital

Physical Therapy Department, 315 South Manning Blvd., Albany, NY 12208

Contact: Heather Smith, PT at 518-525-1372

Capital District Lymphedema Support Group

Women's Health Care Plus, 24 Computer Drive West, Albany, NY 12205

Contact: Joan Sheehan at 459-5086 or 452-3455

2nd Weds. in Sept., Nov., March and May. Members learn about treatment options, skin care, exercise, nutrition and preventive/precautionary measures, and receive emotional support and education.

Philmont Lymphedema Support Group

Contact: Dorothy Bowes at 518-672-7981

National Lymphedema Network (NLN)

2211 Post Street, Suite 404, San Francisco, CA 94115-3427

800-541-3259, or 415-921-1306

NLN is a non-profit organization providing information about the prevention and treatment of lymphedema to patients and health care professionals as well as support groups.

Books

Burt, Jeannie and Gwen White, PT. 1999. *Lymphedema*. Hunter House, Alamada, CA.

This book has especially helpful diagrams and exercises.

Swirsky, Joan, RN and Diane Sackett Nannery. 1998. *Coping with Lymphedema*. Avery Publishing Group, Garden City Park, NY.

Product Suppliers**Albany and Schenectady Counties****Albany Medical Center - New Image Room**

Marjorie Doyle Cancer Resource Center, Albany Medical Center, A Bldg., Albany, NY 12208

Contact: Cathryn Corlew at 518-262-4673. Mon-Friday, 9AM-4PM, by appointment.

Appointments can take 1.5 hours with personal, caring service to help select a variety of wigs, scarves, and turbans.

American Cancer Society

200 Osborne Road, Loudonville, NY 12211

800-850-9445 or 518-438-7841

Look Good, Feel Better Program; Loan Closet, Wig Bank and Image Center.

BJ Helping Hands

370 Partridge Street, Albany, NY 12208

Contact: Betty Bruni at 518-489-1366

Complete line of hairpieces, turbans and hats for adults and children; Affiliated with St. Peter's Cancer Program and ACS Look Good, Feel Better Program.

Caring Creations

144 Adams Street, Delmar, NY 12054

Contact: Helen Carroll at 518-439-1427

Hair stylist and wig supplier with a background in oncology, specializes in tlc.

Complexions Spa

8 Metro Park Road, Albany, NY 12205

Contact: Denise Dubois at 518-489-5231

Compression Dynamics Co.

8 Booth Road, Delmar, NY 12054

518-439-6801 or 518-439-1485; Website: www.delmar.com

Lymphedema garments and graduated compression hosiery; compression bandage supplies and instruction; authorized dealer of Medi-USA, Juzo, Beiersdorf-Jobst, Sigvaris, Reid Sleeve, Legacy and Circ-Aid.

Continuous Care (3 locations)

98 Wolf Road in Hannaford Plaza, Albany, NY: 518-435-9774

70A Congress Plaza, Saratoga, NY : Contact Jeanne Stoy at 518-581-8503

Northway Plaza, Queensbury, NY: 518-926-7050

Prostheses and fitted bras; hairpieces and head wraps; skin care products; bathing suits.

Integrative Care (Holistic Healthcare)

4 Executive Park Drive, Albany, NY 12203

Contact: Georgia Decker at 518-459-2252

Offers a wide range of services including prostheses and bra fittings, therapeutic massage, Reiki, QiGong, acupuncture, counseling, stress management, and nutritional counseling.

Jean Paul Spa de Beaute

Stuyvesant Plaza, Albany, NY 12203

518-482-2121

Full day spa offering massage, skin care products, with a wide variety of wigs.

Pen & Palette

29 Ver Planck Street, Albany, NY 12206

Contact: Margaret Roberts at 518-482-1314

Offers silk scarves with verses by cancer patients, and inspirational posters with verses by cancer patients that provide emotional support. Since Pen & Palette is a volunteer organization, all proceeds from their sale go to cancer research and awareness programs.

Johanna at To Life!

278 Delaware Avenue, 2nd Floor, Delmar, NY 12054

518-439-5975

Contact: Joanna Lombardo, RN, OCN

Personalized service for prostheses and fitted bras.

Joyce's Beauty Salon

10 Mildred Lane, Latham, NY 12110

Contact: Joyce Hempstead at 518-785-7902

Hair stylist and wig products.

Le Beau Chapeau

35 Margaret Drive, Loudonville, NY 12211

Contact: Nancy Matt at 518-458-7693

Unique, comfy, soft-lined, crushable hats for persons with hair loss due to chemotherapy.

Mme. Pirie's Famous Corset & Lingerie Shop, Inc.

1660 Western Avenue, Albany, NY 12206

518-869-0400

Mastectomy products, swimwear and lingerie, with in-house alterations.

White's Home Care (2 locations)

1703 Union Street, Schenectady, NY 12309

518-372-4401

New style prostheses, fitted bras and fashionable swimwear in stock and to order.

Gale Wierzbicki

Middleburgh, NY, Schoharie Cty. 518-827-5556

Individual and group instruction for breast self-exam,; free in-home service for prostheses, bras and swimwear. Accepts Medicare, Medicaid and most major insurances.

Fulton and Montgomery Counties

Classic Image

8 East Main Street, Johnstown, NY 12095

Contact: Karen Coppola at 518-762-6444

Hair stylist, wig supplier, massage, make-up services; offers home delivery, wheelchair accessibility, and will ship products.

Cristine's

9 West Main Street, Johnstown, NY 12095

518-762-8282

Hair stylist, wig supplier (cranial prostheses), turbans, hairpieces (human hair and synthetics); advice regarding insurance.

Del Negro Pharmacy

47 South Main Street, Gloversville, NY 12078

518-773-5800

Prostheses and fitted bras, swimsuits, and catalog available for clothing.

White's Home Care (2 locations)

5010 State Highway, Rte. 30, Amsterdam, NY 12010

518-843-4451

New style prostheses, fitted bras and fashionable swimwear in stock and to order.

Saratoga and Warren Counties

Menges & Curtis

472 Broadway, Saratoga Springs, NY 12866

518-584-2046

Prostheses and fitted bras available.

Continuous Care (3 locations)

70A Congress Plaza, Saratoga, NY : Contact Jeanne Stoy at 518-581-8503

Northway Plaza, Queensbury, NY: 518-926-7050

98 Wolf Road in Hannaford Plaza, Albany, NY: 518-435-9774

Prostheses and fitted bras; hairpieces and head wraps; skin care products; bathing suits.

Columbia and Greene Counties**Step II Body Fashions Boutique**

238 Mansion Street, Coxsackie, NY 12051

518-731-6842

Personalized service for 27 years offering prostheses, fitted bras, and can order swimwear.

Clarke Respiratory & Medical Supply (3 locations)

Plaza and Healy Blvd., Hudson, NY

518-828-4000

168 Jefferson Heights, Catskill, NY 12414

518-943-3456

Appointments on site or mail order for prostheses and fitted bras; accepts most insurances including Medicaid and Medicare.

Dutchess County**Clarke Supply**

Violet Avenue, Poughkeepsie, NY 12601

845-485-4800

Specialty Fittings by Christa

127 Boice Lane, Kingston, NY 12401

Contact: Christa Conlin at 914-336-5402

Private, confidential mastectomy fittings and lymphedema products in a beautiful setting.

Mail Order and Other Services**Becoming, Inc.**

416 West 13th Street, Suite 312, New York, NY 10014

800-980-9085; Website: www.becoming.com

Catalog available for mail order; lingerie, swimsuits, nightwear, breast forms.

Chemo Savvy

PO Box 62760, Colorado Springs, CO 80962

719-599-3560

Unique hats, scarves, turbans, earrings.

Magic Vanity

447 North Wells, Chicago, IL 60610

888-392-0092; Website: www.magicvanity.com

Headwear, swim suits, bras, prostheses, catalog available.

NuTech

800-698-2192

Lymphedema equipment and patient education.

"tlc" Tender Loving Care

800-850-9445 American Cancer Society

A magazine/catalog published by ACS that provides helpful and often essential products for women coping with breast cancer.

Y-Me Prosthesis and Wig Bank

Y-Me National Breast Cancer Organization maintains this bank for women in financial need. Call the 24 hour Hotline at 800-221-2141.

Notes

Alternative therapy, which is sometimes called complementary or unconventional medicine, includes a range of approaches to health. CRAAB! does not necessarily endorse alternative therapies and recommends that you research the therapy and its background.

Alternative therapy can have many different meanings to different people. The term "alternative" implies an approach to health that is different from conventional (called "allopathic") medicine as taught in U.S. medical schools. More recently, the term "complementary" is used to indicate these approaches to health that may be useful to complement allopathic medicine.

Dr. Susan Love divides complementary and alternative treatments into three groups:

I. Mind-body techniques—group or individual psychotherapy, prayer, meditation, visualization and imagery, laughter, massage, movement, dance, and music. These methods do not involve putting any physical substance into the body.

II. Diet, vitamins, herbs, and acupuncture. These methods involve ingesting different substances or the use of acupuncture needles but generally are regarded as relatively harmless when used appropriately.

III. Specific treatment (often by injection) of substances that may be hormones, other proteins, mistletoe, enzymes or other material. These treatments are regarded as "stronger" and more potentially harmful.

Medical treatment and consumer involvement is changing rapidly and many of the techniques in categories I and II that were dismissed only a short while ago are now being embraced by mainstream allopathic medicine - if they are used as a complement and not a replacement of standard Western medical treatments. Although some medical centers have started complementary (or alternative or integrative) units, nursing and medical schools do not generally train nurses and physicians in this field. As a consequence, you will need to become informed about what alternative medicine can and cannot do. See *Tips on Selecting Alternative Therapies* and note the resource, Office of Alternative Medicine at the National Institutes of Health.

Acupressure and Acupuncture

Acupressure and acupuncture are derived from traditional Chinese medicine and the discovery that pressing, puncturing, or heating certain parts of the body produces healing effects, pain relief, and improved organ function. In Chinese tradition, basic healing with breathing exercises, nutritional therapy, or herbalism are used first. If more treatment is needed, acupuncture and more complex methods can be used. Acupuncturists often use other traditional healing methods like herbs, heat therapy, diet modification, and lifestyle changes.

Acupressure Institute

1533 Shattuck Avenue, Berkeley, California 94709
(510) 845-1059; Website: www.acupressure.com

American Association of Oriental Medicine

433 Front Street, Catasauqua, Pennsylvania 18032
(610) 433-2448; Website: www.aaom.org

National Certification Commission for Acupuncture & Oriental Medicine

11 Canal Center Plaza, Suite 300, Alexandria, Virginia 22314
(703) 548-9004; Website: www.nccaom.org

Aromatherapy

Aromatherapy is the therapeutic use of essential oils extracted from plants.

Ayurveda

Ayurveda means “science of life” in Sanskrit. It is the original mind/body medicine dating back 5,000 years. It examines the causes of mind/body imbalances that lead to illness. Methods used to restore balance are diet, meditation, body typing, body purification, aromatherapy, healing sounds, music, exercise, yoga postures and herbs.

The Ayurvedic Institute

11311 Menaul Northeast, Albuquerque, New Mexico 87112
505-291-9698; Website: www.ayurveda.com

Himalayan Institute/Center for Health and Healing

Rural Route 1, Box 400, Honesdale, PA 18431
800-822-4547 or 570-253-5551; Website: www.himalayaninstitute.org

The Raj Maharishi Ayurveda Health Center

1734 Jasmine Avenue, Fairfield, Iowa 52556
800-248-9050

Biofeedback

Biofeedback is a training technique in which people are taught to improve their health and performance by using signals from their own body. One commonly used device picks up electrical signals from the muscles and translates those signals into a flashing light or a beeper when the muscles become more tense. A person can relax tense muscles by trying to slow down the beeper or flashing light. One learns to associate sensations from the muscles with actual levels of tension, so

that after treatment, a person is able to repeat this response at will without being attached to the sensors.

Association for Applied Psychophysiology and Biofeedback

10200 West 44th Avenue, Suite 304, Wheat Ridge, CO 80033
800-477-8892 or 303-422-8436; Website: www.aapb.org

Chiropractic Medicine

Chiropractic medicine is based on the premise that the spinal column and its relationship to the nervous system influences the health of the entire body. Treatment uses spinal manipulation and alignment. For more information, look in the telephone directory under chiropractors or contact the association below:

American Chiropractic Association

1701 Clarendon Boulevard, Arlington, VA 22209
800-986-4636 or 703-276-8800; Website: www.acatoday.com

Exercise and Yoga

Exercise is important after breast surgery and/or lymph node removal. It is not uncommon for women to develop a stiff or "frozen" shoulder after mastectomy. Specific exercises can be done for the prevention or treatment of this condition. In addition to dealing with the specific problems associated with breast surgery, many women choose to modify their life after a diagnosis of cancer and change their diet or engage in more exercise as a way of taking better care of themselves and their bodies. There are many possibilities in terms of types of exercise, specific programs, personal trainers, yoga teachers, physical therapists, and Feldenkrais Movement classes and therapists. For videotapes on exercise and movement after breast surgery, see *Dr. Susan Love's Breast Book (2000)*.

Herbal Medicine

Historically and cross-culturally, herbal medicine has probably been used longer and more widely than any other form of medicine. Some herbs contain antioxidant nutrients, including flavonoids, carotenoids, and vitamins as well as various chemicals that function as drugs. For more information:

American Herbalists Guild

1931 Gaddis Road, Canton, GA 30115
770-751-6021; Website: www.healthy.net/herbalists

American Botanical Council

PO Box 144345, Austin, Texas 78714
800-373-7105(automated) or 512-926-4900; www.herbalgram.org; E-mail: abc@herbalgram.org;

Holistic Health

Holistic health is actually an approach to life. Rather than focusing on illness or specific parts of the body, this ancient approach to health considers the whole person and how he or she interacts with his or her environment. It emphasizes the connection of mind, body and spirit. With holistic health, people accept responsibility for their own level of well-being. The AHHA is a volunteer organization providing free information.

American Holistic Health Association

PO Box 17400, Anaheim, CA 92817-7400

714-779-6152; E mail: ahha@healthy.net; Website: www.ahha.org

Homeopathic Medicine

In homeopathy, remedies from natural substances are used to restore or activate the body's own healing powers. Immunizations and allergy treatments are based on this same concept of introducing small doses of a natural but toxic substance into the body that triggers an immune system response. Homeopathic medicines are recognized as drugs by the FDA, and most remedies can be bought in grocery stores, health food stores, or drug stores. Homeopathy is practiced by licensed health care providers regulated by the state. In contrast, the term for Western mainstream medicine is "allopathic." For more information, contact:

National Center for Homeopathy

801 North Fairfax, Suite 306, Alexandria, VA 22314

888-624-0613 or 703-548-7790; Website: www.homeopathic.org

Massage Therapy

Massage therapists use touch in ways to relax muscles, improve circulation, and promote the body's production of endorphins. Other types of bodywork include acupressure, the Alexander technique, Hellerwork, Polarity Therapy, Reflexology, Reiki, Rolfing, Shiatsu and QiGong. For more information and help locating a massage therapist, contact:

American Massage Therapy Association

820 Davis Street, Suite 100, Evanston, IL 60201

847-864-0123; Website: www.amtamassage.org

Meditation

Meditation can be a way of reducing stress, developing a more positive attitude and an inner sense of calmness, strength and fulfillment. Studies show that meditation can revitalize the body, enhance the

quality of life, and increase mental alertness and longevity. Research of the many different forms of meditation can help you decide which is best for you.

Naturopathic Medicine

Naturopathic physicians treat disease by using a variety of noninvasive natural remedies such as clinical nutrition, herbal medicine, homeopathy, acupuncture, and stress-reduction techniques. Naturopaths are general practitioners educated in both conventional and natural medical sciences. For a national directory of licensed naturopaths and a brochure on naturopathy or for more information:

American Association of Naturopathic Physicians

601 Valley Street, Suite 105, Seattle, WA 98109
206-298-0125; Website: www.naturopathic.org

Nutritional and Alternative Medicine

For referrals to MD's or DO's with training in nutrition as well as many alternative medical specialties, please contact:

American College for Advancement in Medicine

800-532-3688; Website: ACAM.org

Orthomolecular Medicine

Orthomolecular medicine, defined in 1968 by Linus Pauling, strives to provide optimal levels of vitamins, minerals, and other nutrients normally found in the body. Most good orthomolecular physicians (MDs or other types of doctors) make a careful diagnosis, often based on laboratory tests, before recommending specific supplements or other treatments. For more information, contact:

International Society for Orthomolecular Medicine

16 Florence Avenue, North York, Ontario, Canada M2N 1E9
416-733-2117; E-mail: centre@orthomed.org; Website: www.orthomed.org

Pain Management

American Academy of Pain Management

13947 Mono Way, #A, Sonoma, CA 95370
209-533-9744; E-mail: aapm@aapainmanage.org; Website: www.aapainmanage.org

Website supplies names of physicians certified in pain management.

Tips on Selecting Alternative Therapies

Use the same criteria you would use in choosing any healthcare professional.

Your success depends on your being an informed patient choosing a knowledgeable practitioner.

Educate yourself about the general principles of alternative health care.

Even after you have selected a practitioner, continue to educate yourself.

Choose a practitioner with whom you communicate well and who is sensitive to your needs.

Choose an alternative approach in which you have confidence.

Another Resource

The National Center for Complementary and Alternative Medicine Clearinghouse National Institutes of Health

PO Box 8218, Silver Spring, MD 20907-8218

888-644-6226; E mail: NCCAMC@altmedinfo.gov; Website: NCCAM.NIH.gov

NCCAMC offers information packages, and also funds biomedical research that tests alternative treatments, just as other parts of the National Institutes of Health test allopathic medical treatments.

For local practitioners with whom CRAAB! members have experience, please call the CRAAB! office at 518-462-4472.

Environmental Resources

Once people have been diagnosed with cancer, after coping with medical decisions and treatments, they often begin to wonder what caused their cancer specifically, or what causes cancer in general. The current emphasis in the media seems to focus on only two issues - breakthroughs in genetic research and its promise; and women's lifestyle factors, such as diet, exercise, alcohol consumption, smoking, reproductive issues, age of menstruation and number of children. The environment has been left out of the picture.

Women with breast cancer however, in New York State and across the US, are aware of a growing body of research that has linked our environment with cancer incidence. * We have begun to educate ourselves and others about ionizing radiation, hazardous waste sites, pollution of the rivers, environmental endocrine disruptors (such as certain pesticides, herbicides and PCB's), and occupational exposures.

In New York State, breast cancer advocates have been instrumental in encouraging New York State to provide accurate state, county, and zip code cancer maps, and in getting New York's 1996 Pesticide Reporting Law enacted. In these efforts, we have worked with many organizations that have provided information and expertise on environmental issues. We have listed below a variety of government agencies and environmental groups that provide updated and in-depth information about the environment and health.

** A recent Scandinavian research study, reported in July 2000, tracked 44,788 pairs of twins and found that environmental and lifestyle factors play more of a part in cancer than genetic inheritance. According to this study, 73% of breast cancer cases were caused by environmental factors.*

Environmental Groups

Center for Health, Environment and Justice (previously Citizens Clearinghouse for Hazardous Wastes)

PO Box 6806, Falls Church, VA 22040

703-237-CCHW(2249) Fax: 703-237-8389; www.chej.org

Information on toxics and community organizing; organized by Lois Gibbs in response to Love Canal.

Center for Environmental Health

528 61st Street Suite A, Oakland, CA 94609

510-594-9864; Fax: 510-594-9863; Email: ceh@cehca.org

The Center for Environmental Health protects the public from environmental and consumer health hazards through direct interaction with corporations. We are committed to reducing corporate use of toxic chemicals, environmental justice, and supporting communities in their quest for a safer environment.

Citizens Environmental Coalition

33 Central Avenue, Albany, NY 12210

518-462-5527; Fax: 518-465-8349; ceanne@igc.apc.org

Anne Rabe, Executive Director

They have available a 1995 NYS map showing state superfund hazardous waste sites and other hazardous substance dumps as well as a list of these sites by county. They expect to have county maps available by December 2000.

Environmental Advocates

353 Hamilton Street, Albany, NY 12210

518-462-5526; Fax: 518-427-0381; www.envadvocates.org, E-mail: athier@envadvocates.org

Audrey Thier, Pesticide Project Director

For information on pesticide risks, state and federal pesticide policy, and other toxics issues. Env. Adv. is an Albany-based, statewide environmental lobbying organization. Along with NYPIRG, they publish the NYS Pesticide Use and Sales Report, *The Toxic Treadmill* (October 2000).

The Environmental Association for Great Lakes Education

394 Lake Avenue South, #308, Duluth MN 55802

218-726-1828 (telephone & fax); lakes@cpinternet.com

Jan Conley: Director; Craig Minowa: Projects Coordinator

An environmental non-profit organization, they work on a variety of projects, including the Great Lakes Women's Leadership Network and the Green Thumb Project - a zero discharge pesticide-free lawn care project.

Environmental Defense Fund

257 Park Ave. South, New York, NY 10010

212-505-2100; www.scorecard.org

This web site, Scorecard, allows you to type in your zip code and get a list of all the known industrial chemicals released in your area and information about their risks.

Greenpeace

702 H Street NW, Washington, DC 20001

1-800-326-0959; www.greenpeace.org

Greenpeace's new Toxics web section contains extensive data on PVC, Toxic Trade, Dioxins, Human Health, Clean Production, etc.

Greenpeace International Toxics Page

www.greenpeace.org/~toxics/index.html

This Greenpeace International site contains extensive information on the health and environmental effects of persistent organic pollutants (POPs), products containing chlorine (including PVC plastic); and information about "clean production technologies" — i.e., methods that create less waste and waste which is less toxic.

Health Care Without Harm

*c/o CCHW Center for Health, Environment and Justice, P.O. Box 6806, Falls Church, VA 22040
703-237-2249; Fax: 703-237-8389; www.noharm.org, E-mail: noharm@iatp.org*

This website has the HCWH Internet Hot List - a comprehensive list of environmental organizations around the globe. HCWH is a collaborative campaign for environmentally responsible health care made up of more than 250 organizations. Their mission is to transform the health care industry so it is no longer a source of environmental harm by eliminating pollution without compromising safety or care. It supports the development and use of environmentally safe materials, technology and products.

Hudson River Sloop Clearwater

*112 Little Market St., Poughkeepsie, NY 12601
914-454-7673
Manna Jo Greene, Environmental Director*

Mothers and Others for a Livable Planet

*40 W. 20th Street, 9th floor, New York, NY 10011
212-242-0010, ext. 305; Fax: 212-242-0545*

Organic consumer issues, with resources for non-toxic home products and organic food.

Natural Resources Defense Council

*40 West 20th St., New York, NY 10011
212-727-2700; www.nrdc.org*

NYCAP (NY Coalition for Alternatives to Pesticides)

*353 Hamilton Street, Albany, NY 12210
518-426-8246; FAX 518-426-3052; nycap@crisny.org
Pamela Hadad-Hurst, Executive Director*

For information about non-toxic pest management and pesticide risks.

NYPIRG

*107 Washington Ave., Albany, NY 12210
518-436-0876; Fax: 518-432-6178; www.NYPIRG.org; E-mail: LHaight@NYPIRG.org
Laura Haight, Senior Environmental Associate*

NYPIRG is a statewide public interest group that addresses, among many issues, pesticide and toxic exposure. They do both lobbying and direct community work.

Physicians for Social Responsibility

*1101 14th Street Northwest, Suite 700, Washington, D.C. 20005
202-898-0150; Fax: 202-898-0172; www.psr.org, E-mail: psrnatl@psr.org*

PSR (received the Nobel Prize in 1995) is committed to eliminating weapons of mass destruction, preserving a sustainable environment and reducing violence and its causes. The active conscience of

American medicine, PSR uses its members' expertise and professional leadership, influence within the medical community and strong links to policy makers to address this century's greatest threats to human welfare and survival.

Scenic Hudson (for information about PCBs)

9 Vassar St., Poughkeepsie, NY 12601

Contact: Cara Lee at 914-473-4440

Sierra Club

353 Hamilton St., Albany, NY 12210

John Stouffer, Legislative Director Atlantic Chapter at 518-426-9144

The Albany office of this national group is a resource for legislative and toxics issues.

Sierra Club - Hudson Mohawk Group

32 Buckingham Dr., Albany, NY 12208

Contact: Pete Sheehan, Chair at 518-489-5803

The Nightingale Institute for Health and the Environment

www.nihe.org, E-mail: tni@together.net

The Nightingale Institute for Health and the Environment works to further a greater understanding that human and environmental health are inextricably linked. The Nightingale Institute works with health care professionals to actualize their role in promoting human health through attention to the impact of human activity on the environment.

Toxics Targeting, Inc.

www.toxicstargeting.com, E-mail: toxtarg@toxicstargeting.com

Since 1990, Toxics Targeting, Inc. has specialized in providing Computerized Environmental Reports to many of New York's most respected engineering and environmental consultants as well as government agencies, lenders, attorneys, real estate professionals and citizens. Visit our website to learn more and to order your Computerized Environmental Report on-line.

WEDO—Women's Environment and Development Organization

355 Lexington Ave., 3rd floor, New York, NY 10017-6603

212-973-0325; Fax: 212-973-0335; www.wedo.org, E-mail: wedo@wedo.org

For direct breast cancer information: Pamela@wedo.org

This group makes the connection between the contamination of the environment and the increasing incidence of breast cancer. WEDO is an accredited non-governmental organization with consultative status at the United Nations, thus in a position to push for women's health policy worldwide.

World Wildlife Fund Global Initiative

For more information or to order documents, email the WWF Global Toxic Chemicals Initiative, or write to the following address:

World Wildlife Fund, 1250 24th Street, NW, Washington, DC 20037-1175

Fax: 202/530-0743; www.worldwildlife.org/toxics/

WWF recognizes that controlling pollution is important to conserving biodiversity. Their efforts to increase scientific understanding of toxic chemicals and to restrict or ban harmful chemicals stems from evidence of their ability to undermine the basic functions of entire ecosystems, as well as their impact on wildlife and human health.

Government

NYS Attorney General Eliot Spitzer

Health Care Bureau and Environmental Protection Bureau

State Capitol, Albany, NY 12224

1-800-771-7755; www.oag.state.ny.us

Judith Enck, Policy Advisor, Environmental Protection Bureau

518-473-9037; judith.enck@oag.state.ny.us

Jeff Gold, Special Counsel, Health Care Bureau

518-486-6557; jeffery.gold@oag.state.ny.us

NYS Health Research Science Board

New York State Department of Health

Wadsworth Center, Empire State Plaza, PO Box 509, Albany, NY 12201-0509

Dr. Trish Lowney; E-mail: lowney@wadsworth.org; 518-473-6961

The NYS HRSB oversees the use of the NYS Pesticide Registry Data and also the spending of funds from the NYS Income Tax Checkoff for the Breast Cancer Research and Education Fund.

BCERF

(Cornell University Program on Breast Cancer and Environmental Risk Factors in NY State)

110 Rice Hall, Ithaca, NY 14853-5601

607-254-2893, FAX 607-255-8207;

<http://www.cfe.cornell.edu/bcerf/>; email: breastcancer@cornell.edu

BCERF has published a number of educational articles on breast cancer as well as reviews on pesticides. It also has NYS breast cancer incidence and mortality maps available on their web site.

The New York State Cancer Surveillance Improvement Initiative

800-458-1158; Website: www.health.state.ny.us

This project is concerned with NYS cancer maps and the NYS Cancer Registry. Breast cancer maps by county and zip code became available in Spring 2000 by accessing the web site. So far, no hard copies of these maps are being distributed. Because comparisons are made only between different areas of NYS and no absolute values are given, it is not obvious from these maps that NYS has some of the highest incidence and mortality from breast cancer in the US and indeed the world.

Pesticide Reporting Section

Bureau of Pesticide Management, Robert Haggerty

Department of Environmental Conservation, 50 Wolf Road, Albany, NY 12233

888-457-0110; Website: www.dec.state.ny.us/website/dshm/prl

Final Annual Report of 1997 NYS Pesticide Sales and Application is available on their web site. The Final Annual Report of 1998 is scheduled to be available on the web site in late July 2000. This data makes possible for the first time in the State's history an annual estimate of the amount of herbicides, fungicides, insecticides, and other chemicals used that are intended to kill or repel living things. Anyone can get specific information on pesticides used in their own community by calling or visiting the website below.

Books, Films, Newsletters

Devesa, Susan S., D.J. Grauman, W.J. Blot, G.A. Pennello, R.N. Hoover, and J.F. Fraumeni. 1999. *Atlas of Cancer Mortality in the United States*. National Institutes of Health. NIH Publication No. 99-4564. This book is free by calling (1-800-4-CANCER) or faxing (301-330-7968) the National Cancer Institute. It summarizes many types of cancers in maps of the US and clearly demonstrates over a 45 year period the high breast cancer mortality in the Northeast. It also describes the power of maps in generating ideas about the environmental links to cancer.

Rachel's Environment & Health Weekly

(free on-line newsletter, also available by subscription on paper)

rachel@rachel.org

Rachel's weekly is produced by:

Environmental Research Foundation, PO Box 5036, Annapolis, MD 21403

405-263-1584; FAX 410-263-8944; E-Mail: erf@rachel.org

Carson, Rachel. 1962. *Silent Spring*. Houghton Mifflin, New York. Rachel Carson was the first person to point out the devastating effect of our use of pesticides and other toxic chemicals to humans and wildlife. She died of breast cancer shortly after the publication of *Silent Spring*. The film *Rachel's Daughters* and online newsletter are named for her.

Steingraber, Sandra. 1997. *Living Downstream: An Ecologist Looks at Cancer and the Environment*. Addison Wesley, New York, NY. Thoughtfully researched, carefully analyzed, beautifully written by one of the most articulate spokespersons for environmental links to cancer.

Sherman, Janette D. 2000. *Life's Delicate Balance: Causes and Prevention of Breast Cancer*. Taylor & Francis, New York, NY. Sherman, a medical doctor, addresses environmental chemicals as well as radiation as they relate to breast cancer. One chapter is on breast cancer incidence on Long Island. Her resource guide at the back of the book is excellent.

Gofman, John W. 1996. *Preventing Breast Cancer: The Story of a Major, Proven, Preventable Cause of this Disease*. Committee for Nuclear Responsibility, Inc. San Francisco, CA. Gofman, MD and PhD, has compiled data on the medical use of radiation as well as on radiation from the bombs used in Japan during World War II. He makes a compelling case for taking radiation seriously as a cause of breast cancer.

Williams, Terry Tempest. 1991. *Refuge: An Unnatural History of Family and Place*. Vintage Books, Division of Random House, Inc., New York, NY. A beautifully written book connecting family history, the history of the land, cancer and nuclear testing in Utah.

Colborn, Theo, Dianne Dumanoski and John Peterson Myers. 1996. *Our Stolen Future*. Dutton, Penguin Books USA Inc., New York, NY. Documentation of the relationships between environmental endocrine disruptors and abnormalities in wildlife. An important book bringing together many stories.

Anderson, Luke. 1999 *Genetic Engineering Food, and Our Environment*. Chelsea Green Publishing Company, White River Junction, VT. A short primer on what genetic engineering is, implications for our food supply, the environment, and the many unknowns that accompany this new technology.

Fagin, Dan; Lavelle, Marianne and the Center for Public Integrity. *Toxic Deception: How the Chemical Industry Manipulates Science, Bends the Law and Endangers Your Health*. Common Courage Press, Monroe, Maine, 1999. Reports how four toxic chemicals — alachlor, atrazine, formaldehyde and perchloroethylene — pose significant health risks that are routinely ignored by government regulators. An eye-opener that details the influence of special interests over government decision making.

Rachel's Daughters — Searching for the Causes of Breast Cancer (film)

Light-Saraf Films, 264 Arbor Street, San Francisco, CA 94131
415-469-0139

This excellent film interviews breast cancer advocates and scientists, as women with breast cancer search for answers to the causes of this disease.

Environmental Links to Cancer - An Interview

Adapted from "An Interview with Sandra Steingraber—Ecologist, author, and cancer survivor" **Choices: The Newsletter of the Ithaca Breast Cancer Alliance** No.21, Spring 2000

Sandra Steingraber, Ph.D., is an internationally recognized expert on the environmental links to cancer. She is the author of *Post-Diagnosis*, a volume of poetry, co-author of a book on human rights and ecology in Africa, *The Spoils of Famine*, and author of the highly acclaimed *Living Downstream: An Ecologist Looks at Cancer and the Environment*.

Sandra wrote: I want people to know that I named my daughter Faith because I do have faith in the future. My adopted mother had breast cancer when she was 44 and I had cancer when I was 20, but I wish a cancer-free life for my daughter. It's a profound thing for a cancer patient to have a baby, not only because you wonder how being pregnant might affect your own health, but because it's such a long commitment. I had to really think about whether we can turn this situation around, and I think we can and have to.

Q: Why should we be concerned about cancer and the environment?

A. As an ecologist, I look at how all kinds of subtle influences in the environment can impinge on the lives of animals and plants. The chain of cause and effect can be very indirect and web-like with lots of tiny multiple variables that all add up.

Historically, the spotlight of research has been focused on two factors: genetics and lifestyle. The environment, which is the third side of the cause triangle, has remained in the shadows.

The more I learned about cancer biology, the more it became obvious to me that the reasons for neglecting the environment and pouring the lion's share of research dollars and effort into genetics and lifestyle are complex ones that have little to do with the relative importance of each factor.

Looking at genetics and lifestyle is simply an easier kind of science to do because you can do controlled studies. Advances in molecular biology allow us to know with certainty which genes a woman has inherited. Interviews reveal with certainty at what age women begin menstruation, enter menopause, and give birth to their first child. We can reconstruct smoking habits, exercise patterns, and diets. But how do we reconstruct all of the inadvertent, involuntary environmental exposures that a woman has experienced throughout her lifetime?

Public health education based on good environmental studies hasn't been done in the way it has for genetics and lifestyle. In addition to lifestyle factors and a person's genetic makeup, we know a lot of things about the natural environment that might be influencing our risk of breast cancer. Yet somehow, those things haven't been written up in the pamphlets or public service announcements. I'm talking about living near hazardous waste sites, occupational exposures to vinyl chloride, ionizing radiation.

Q. What evidence is there that shows the strongest links between cancer and environment pollutants, and where does breast cancer fit into this?

A. There are at least four main lines of inquiry that together form a body of evidence.

One line of evidence comes from the cancer registry data. Cancer registries have been operating in most states for at least 10 years. Registries measure incidence of cancer, and if you take out lung cancer, registries show that cancer incidence rates have increased. When you include lung cancer rates, the picture looks different since lung cancer rates closely follow smoking patterns and habits.

If you look at all cancers except lung, you see an increase that has been going on probably since World War II, but certainly since 1973. The specific cancers that are rising the most rapidly are the ones for which we have some pretty good evidence for environmental links. Some of these have doubled or tripled over the last few decades.

The second line of evidence involves mapping the data from registries. If the environment were not playing a big role in cancer rates, you would expect to see a random distribution of cancer rates throughout the United States. Instead, consistent patterns show that breast, colon, and bladder cancers tend to be highest in areas with a lot of industry. Non-Hodgkin's lymphoma is concentrated in areas with a lot of pesticides. Association is not causation, but those associations are like little red flags.

The third line of evidence is what's going on inside our own bodies. What happens when we actually measure the exposures in people's tissues? We see some pretty intriguing associations between certain kinds of cancer and people whose exposure can be measured in their blood, fat tissue, or urine. That's really tough research to do because our bodies contain a kaleidoscope of chemicals. Nevertheless, there is a pretty clear relationship between exposure to PCBs and non-Hodgkin's lymphoma, for example.

The fourth line of evidence is the animal studies, not just lab animals but also studies on wildlife. Not only are cancer rates rising in the general human population, but also there is a parallel increase in cancer among certain kinds of wildlife. Wildlife, like fish, get cancer in association with living in environmentally contaminated places. When you look at the same species in unpolluted habitats, they don't have cancer. The great thing about studying wildlife is that they don't smoke, drink, hold stressful jobs, or have a bad diet.

These four lines of evidence—registries, cancer mapping, physical association of cancer with people known to be exposed to certain chemicals, and the parallel cancer epidemic occurring in wildlife—fit together to create a body of evidence which shows an emerging relationship between cancer and the environment.

Q. What message do you have for people who have been diagnosed with breast cancer or are at risk for breast cancer?

A. I think there is a sense among some people that were they to look into the environment, they would just get depressed and anxious and would feel that it is too overwhelming and that there is nothing they can do anyway.

I now believe that there are things that people can do. What is worse is free-floating anxiety about your cancer and the environment. When you look at the specifics, search out information, and become an environmental detective, you feel better rather than worse. If you go to the toxics release inventory, if you find out who is spraying pesticides around you, you feel more powerful. Feeling helpless is worse than going out there and finding out information.

Other human rights causes have been successful. Getting women the right to vote was not easy. Women went to jail, they were beaten on the streets, they fasted, but we got it. Getting rid of slavery was a hundred-year campaign. Our whole economy was once dependent on slave labor. People said that if slavery was abolished, no one would be able to afford cotton anymore. But slavery was wrong. We got rid of slavery, and I think we can get rid of carcinogens.

The Precautionary Principle

Dr. Steingraber, along with many cancer activists, environmental groups and health organizations are calling for our society to use the ***Precautionary Principle*** when deciding public health policy and for guiding human activities in general. This new principle has emerged during the past ten years as an initiative to prevent harm to the environment and to human health. It essentially states that we must protect human life (and all life) from possible toxic danger well in advance of scientific proof of that danger. In other words, when an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically. In this context, the proponent of an activity, rather than the public, should bear the burden of proof.

According to the Wingspread statement,* The Precautionary Principle has four parts:

- I. People have a duty to take anticipatory action to prevent harm. If there is a reasonable suspicion that harm will occur, we have the obligation to prevent that harm.
- II. The burden of proof of harmlessness of a new technology, process, activity or chemical lies with the proponents, not with the public.
- III. Before using a new technology, process, or chemical, or starting a new activity, people have an obligation to examine a full range of alternatives.
- IV. Decisions applying the precautionary principle must be open, informed and democratic and must include affected parties.

* The Wingspread Statement was written in January, 1998 at the Wingspread Conference Center, Racine, WI (Johnson Foundation headquarters) by 32 authors, including treaty negotiators, scientists, scholars and activists.

For more information on the Precautionary Principle see the sources listed below:

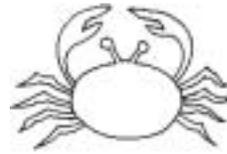
Rachel's Environment & Health Weekly, #658, July 8, 1999. (An on-line newsletter providing news and resources for environmental justice)

The Precautionary Principle in Action: A Handbook. Science and Environmental Health Network, 1999.

Protecting Public Health & The Environment: Implementing the Precautionary Principle. Science and Environmental Health Network (SEHN), Island Press, 1999.

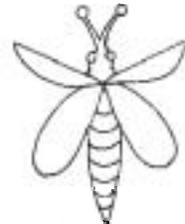
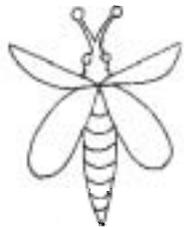
An anthology that includes an essay by Dr. Steingraber, *Why the Precautionary Principle? A Meditation on Polyvinyl Chloride (PVC) and the Breasts of Mothers*.

Rethinking Breast Cancer Risk and the Environment: The Case for the Precautionary Principle. Devra L. Davis, Deborah Axelrod, Lisa Bailey, Mitchell Gaynor, Annie Sasco, *Environmental Health Perspectives, Commentaries*, Vol. 106, No. 9, September, 1998.



You must do the things you think you cannot do.

Eleanor Roosevelt



During the past ten years, breast cancer survivors and activists have made a significant impact on cancer care policies at the local, state and federal levels. Breast cancer activists are now at the forefront of shaping cancer research programs, advancing relevant legislative issues, and advocating for better medicine and higher quality of care. Cancer survivors now sit on some national and state government advisory panels; they participate in some state and national cancer research programs; and they actively advocate on the state and local levels for increased funding for research and education, and for a cleaner and safer environment.

As a breast cancer survivor it can be empowering to know that your efforts can effect positive change. You can make a difference, but to do this, you need to know how.

Becoming familiar with your state and federal representatives in government is one of the first steps in that process. Our lawmakers and policy makers need to hear from us. They need to know how many of their constituents' lives are affected by breast cancer (and other cancers). They need to hear that we want high quality, comprehensive care for cancer survivors as well as the eradication of cancer to be top national and state priorities. We need to educate our legislators about all the issues surrounding breast cancer, so that they can enact bills and policies that are clear and comprehensive solutions to the breast cancer epidemic.

There are a number of ways in which we can make sure that our representatives hear us. We can participate in national and state advocacy and education events, and we can lobby. We can call or write (including e-mail) our representatives; attend Town Hall meetings or other public events where representatives are making appearances; call in to local radio talk shows where representatives are speaking; participate in live on-line forums or chats when representatives are appearing on the internet; and write letters-to-the-editors of local newspapers.

If you would like further information about participating in the legislative process, contact **CRAAB!** for suggestions, and ask about the **Annual New York State Breast Cancer Network Advocacy Day**, which is generally held in March.

During the election season, your vote can also make a difference in the cure for breast and other cancers. From our local village, town and city officials, to the United States President and members of Congress, we need to voice our opinions regarding the issues which are important to us, and make our vote count by electing those officials whose platforms and agendas reflect our own beliefs. These elected officials include our state representatives as well, all of whom can make critical decisions about funding, research, and provision of quality care related to breast and other cancers.

The following organizations can assist us with becoming familiar with the political process, from ensuring a fair campaign process and supporting voter registration, to educating the public regarding policy issues and the candidates.

New York State Board of Elections

The State Board of Elections was established in the Executive Department June 1, 1974 as a bipartisan agency vested with the responsibility for administration and enforcement of all laws relating to elections in New York State. The Board is also responsible for regulating disclosure and limitations of a Fair Campaign Code intended to govern campaign practices. In conducting these wide-ranging responsibilities, the Board offers assistance to local election boards and investigates complaints of possible statutory violations. In addition to the regulatory and enforcement responsibilities, the board is charged with the preservation of citizen confidence in the democratic process and enhancement in voter participation in elections.

*Swan Street Building, Core 1
6 Empire State Plaza, Suite 201
Albany, NY 12223-1650*

*Commissioners: (518) 474-8113
Public Information/ Voter Registration: (518) 474-1953*

*Website: www.elections.state.ny.us
E-mail: ldaghlian@elections.state.ny.us*

The League of Women Voters

The League of Women Voters, a nonpartisan political organization, encourages the informed and active participation of citizens in government, works to increase understanding of major public policy issues, and influences public policy through education and advocacy.

Of the United States:

Suite 1000, 1730 M Street, NW, Washington, DC 20036-4508
(202) 429-1965; Fax: (202) 429-0854; Website: www.lwv.org

Of New York State:

35 Maiden Lane, Albany, NY 12207-2712
(518) 465-4162; Fax: (518) 465-0812; Website: www.lwvny.org; E-mail: lwvny@lwvny.org

Federal and State Representatives

The following list of federal and state government representatives is not exhaustive, as we have chosen to limit the list to representatives of the Capital District and immediate surrounding areas. If you are not sure who your representatives are, if they are not included on this list, or if offices have changed due to the latest elections, use the main telephone numbers and/or web sites for the United States Senate and Congress, the New York State Senate and Assembly, and THOMAS/ U.S. Library of Congress, as follows:

U.S. Federal Government

U.S. Senate (106th Congress)

Capitol Switchboard: (202) 224-3121

Web Sites:

U.S. Senate: www.senate.gov

U.S. Congress: www.capweb.net

THOMAS/ U.S. Library of Congress: thomas.loc.gov

(legislative information on the internet)

Senator Hillary Rodham Clinton (D)

E-mail: senator@hrc.senate.gov; Website: www.senate.gov/~clinton

Washington Office:

464 Russell Senate Office Bldg., Washington, D.C. 20510-3201

(202) 224-4451; Fax: (202) 228-0406

New York City Office:

405 Lexington Avenue, Suite 6200, New York, NY 10174-6200

(212) 661-5150

Senator Charles E. Schumer (D)

E-mail: senator@schumer.senate.gov; Website: www.senate.gov/~schumer

Washington Office:

313 Hart Senate Office Bldg., Washington, D.C. 20510

(202) 224-6542

New York City Office:

757 Third Avenue, Suite 17-02, New York, NY 10017

(212) 486-4430

Albany Office:

Leo O'Brien Building, Room 420, Albany, NY 12207

(518) 431-4070

U.S. House of Representatives

Capitol Switchboard: (202) 224-3121

Web Sites

U.S. House of Representatives: www.house.gov

U.S. Congress: www.capweb.net

THOMAS/ U.S. Library of Congress: thomas.loc.gov

(legislative information on the internet)

Congressman Sherwood Boehlert (R)

23rd District [all or portions of Broome, Chenango, Delaware, Herkimer, Madison, Montgomery, Oneida, Otsego and Schoharie Counties]

E-mail: Rep.Boehlert@mail.house.gov; Website: www.house.gov/boehlert

Washington Office:

2246 Rayburn House Office Building, Washington, DC 20515-3223
(202) 225-3665; Fax: (202) 225-1891

Utica Office:

Alexander Pirnie Federal Building, 10 Broad Street, Utica, NY, 13501
(315) 793 - 8146; Fax: (315) 798-4099
Toll Free: 1-800-235-2525

Congressman Maurice D. Hinchey (D)

26th District [Hudson Valley, Catskill Mountains, Southern Tier (Ithaca/Finger Lakes Region)]

E-mail: mhinchey@mail.house.gov; Website: www.house.gov/hinchey

Washington Office:

2431 Rayburn House Office Bldg., Washington, D.C. 20515
(202) 225-6335

Ithaca Office:

123 South Cayuga Street, Suite 201, Ithaca, NY 14850
(607) 273-1388

Binghamton Office:

100A Federal Building, Binghamton, NY 13901
(607) 773-2768

Congressman John M. McHugh (R)

24th District [Clinton, Essex (part), Franklin, Fulton, Hamilton, Herkimer (part), Jefferson, Lewis, Oswego, St. Lawrence Counties]

Website: www.house.gov/mchugh

Washington Office:

2441 Rayburn House Office Building, Washington, D.C. 20515
(202) 225-4611; Fax: (202) 226-0621

Johnstown Office:

Fulton County Office Building, 223 West Main Street, Room 10, Johnstown, NY 12095-2389
(518) 762-0379; Fax: (518) 762-0369

Congressman Michael R. McNulty (D)

21st District [Albany, Montgomery (part), Rensselaer (part), Saratoga (part) and Schenectady Counties]

E-mail: mike.mcnulty@mail.house.gov; Website: www.house.gov/mcnulty

Washington Office:

2161 Rayburn House Office Building, Washington, D.C. 20515-3221

(202) 225-5077

Albany Office:

Leo W. O'Brien Federal Building, Room 827, Albany, NY 12207

(518) 465-0700; Fax: (518) 427-5107

Schenectady Office:

U.S. Post Office, Schenectady, NY 12305-1982

(518) 374-4547; Fax: (518) 374-7908

Troy Office:

33 Second Street, Troy, NY 12180-3975

(518) 271-0822; Fax: (518) 273-6150

Amsterdam Office:

2490 Riverfront Center, Amsterdam, NY 12010-4612

(518) 843-3400

Congressman John E. Sweeney (R)

22nd District [Columbia, Dutchess (part), Essex (part), Greene, Rensselaer (part), Saratoga (part) & Schoharie (part), Warren, Washington]

E-mail: john.sweeney@mail.house.gov; Website: www.house.gov/sweeney

Washington Office:

437 Cannon House Office Building, Washington, D.C. 20515

(202) 225-5614; Fax: (202) 225-6234

Saratoga Springs Office:

285 Broadway, Saratoga Springs, NY 12866

(518) 587-9800; Fax: (518) 587-1228

Hudson Office:

560 Warren Street, Hudson, NY 12534

(518) 828-0181; Fax: (518) 828-1657

Glens Falls Office:

21 Bay Street, Glens Falls, NY 12801

(518) 792-3031

New York State Legislature

New York State Senate

Senate Main Line, State Capitol 518-455-2800

Website: www.senate.state.ny.us

Senate Majority Leader Joseph L. Bruno (R)

43rd District [Rensselaer and Saratoga (part) Counties]

E-mail: bruno@senate.state.ny.us; Website: www.senate.state.ny.us

Albany Office:

909 Legislative Office Building, Albany, NY 12247

(518) 455-3191

Saratoga Springs Office:

368 Broadway, Saratoga Springs, NY 12866

(518) 583-1001

Senator Neil D. Breslin (D)

42nd District [Albany County]

E-mail: breslin@senate.state.ny.us; Website: www.senate.state.ny.us

Albany Office:

606 Legislative Office Building, Albany, NY 12247

(518) 455-2225

Senator John J. Bonacic (R)

40th District [Delaware, Greene, Orange (part), Sullivan and Ulster (part) Counties]

E-mail: bonacic@senate.state.ny.us; Website: www.senate.state.ny.us

Albany Office:

815 Legislative Office Building, Albany, NY 12247

(518) 455-3181

New Paltz District Office:

279 Main Street, Suite 202, New Paltz, NY 12561

(914) 255-9656

Senator Hugh T. Farley (R)

44th District [Fulton, Montgomery, Schenectady and Saratoga (part) Counties]

E-mail: farley@senate.state.ny.us; Website: www.senate.state.ny.us

Albany Office:

412 Legislative Office Building, Albany, NY 12247

(518) 455-2181

Senator Stephen M. Saland (R)

41st District [Columbia and Dutchess (part) Counties]

E-mail: saland@senate.state.ny.us; Website: www.senate.state.ny.us

Albany Office:

946 Legislative Office Building, Albany, NY 12247

(518) 455-2411

Poughkeepsie Office:

22 IBM Road, Suite 110, Poughkeepsie, NY 12601

(914) 463-0840

Senator James L. Seward (R)

50th District [Chenango (part), Cortland, Herkimer (part), Otsego, Schoharie, and Tomkins (part) Counties]

E-mail: seward@senate.state.ny.us; Website: www.senate.state.ny.us

Albany Office:

307 Legislative Office Building, Albany, NY 12247

(518) 455-3131

Oneonta District Office:

41 South Main Street, Oneonta, NY 13820

(607) 432-5524

Senator Ronald B. Stafford (R)

45th District [Clinton, Essex, Franklin, Hamilton, Warren and Washington Counties]

E-mail: stafford@senate.state.ny.us; Website: www.senate.state.ny.us

Albany Office:

501 State Capitol Building, Albany, NY 12247

(518) 455-2811

Plattsburgh District Office:

79 Hammond Lane, Plattsburgh, NY 12901

518-561-2430

New York State Assembly

Assembly Main Line, State Capitol: 518-455-4100

Website: www.assembly.state.ny.us

Assembly Speaker Assemblyman Sheldon Silver (D)

62nd District [New York County (part)]

E-mail: speaker@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 932/CAP 349, Albany, NY 12248

(518) 455-3791

District Office:

270 Broadway, Suite 1807, New York, NY 10007

(212) 312-1420

Assembly Majority Leader Assemblyman Michael J. Bragman (D)

118th District [Northern Onondaga County]

E-mail: bragman@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 323, Albany, NY 12248

(518) 455-4567

District Office:

305 South Main Street, North Syracuse, NY 13212

(315) 452-1044

Assembly Minority Leader Assemblyman John J. Faso (R)

102nd District [Albany (part), Columbia (part), Greene (part) and Schoharie Counties]

E-mail: fasoj@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 933, Albany, NY 12248

(518) 455-3751

District Offices:

RD 1, Box 74-14, Hope Plaza, West Coxsackie, NY 12192

(518) 731-1093

RD 3, 106 M 3rd Floor West, Cobleskill, NY 12043

(518) 296-8070

Assemblyman Marc W. Butler (R)

113th District [Fulton, Hamilton and Herkimer Counties]

E-mail: butlerm@assembly.state.ny.us; *Website:* www.assembly.state.ny.us

Albany Office:

Legislative Office Building 628, Albany, NY 12248

(518) 455-5393

District Offices:

126 Mary Street, Herkimer, NY 13350

(315) 866-1632

Johnstown City Hall, 33-41 East Main Street, Johnstown, NY 12095

(518) 762-6486

Assemblyman Ronald J. Canestrari (D)

106th District [Albany (part) and Rensselaer (part) Counties]

E-mail: canestr@assembly.state.ny.us; *Website:* www.assembly.state.ny.us

Albany Office:

Legislative Office Building 731, Albany, NY 12248

(518) 455-4474

Assemblyman Pat M. Casale (R)

108th District [Rensselaer (part) and Saratoga (part) Counties]

E-mail: casale@assembly.state.ny.us; *Website:* www.assembly.state.ny.us

Albany Office:

Legislative Office Building 722, Albany, NY 12248

(518) 455-5777

District Office:

234 S. Central Avenue, Mechanicville, NY 12118

(518) 664-1043

Assemblyman Clifford Crouch (R)

122nd District [Chenango (part), Delaware and Otsego (part) Counties]

E-mail: crouhc@assembly.state.ny.us; *Website:* www.assembly.state.ny.us

Albany Office:

Legislative Office Building 545, Albany, NY 12248

(518) 455-5741

District Office:

21 Liberty Street, Sidney, NY 13838
(607) 563-7981

Assemblyman Robert D'Andrea (R)

100th District [Saratoga (part) and Washington Counties]
E-mail: dandrea@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 320, Albany, NY 12248
(518) 455-5404

District Offices:

6 Academy Street, Greenwich, NY 12834
(518) 692-9658
285 Broadway, Saratoga Springs, NY 12866
(518) 587-5151

Assemblywoman Elizabeth O'C. Little (R)

109th District [Clinton (part), Essex, Franklin (part) and Warren Counties]
E-mail: littlee@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 324, Albany, NY 12248
(518) 455-5565

District Office:

21 Bay Street, Glens Falls, NY 12801
(518) 792-4546

Assemblyman Martin A. Luster (D)

125th District [Tompkins County, City of Cortland and Town of Cortlandville]
E-mail: lusterm@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 526, Albany, NY 12248
(518) 455-5444

District Office:

106 East Court Street, Ithaca, NY 14850
(607) 277-8030

Assemblyman Patrick Manning (R)

99th District [Columbia (part) and Dutchess (part) Counties]

E-mail: manning@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 544

Albany, NY 12248

(518) 455-5177

District Offices:

444 Warren Street, Hudson, NY 12534

(518) 822-8904

585 Route 376, Hopewell Junction, NY 12533

(914) 221-3400

Assemblyman John J. McEneny (D)

104th District [Albany County (part)]

E-mail: mccenenj@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany and District Office:

Legislative Office Building 648, Albany, NY 12248

(518) 455-4178

Assemblyman Dr. Joel Miller (R)

97th District [Dutchess (part), Columbia (part) and Greene (part) Counties]

E-mail: millerj@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 531, Albany, NY 12248

(518) 455-5725

District Office:

22 IBM Road, Poughkeepsie, NY 12601

(914) 463-1635

Assemblyman Robert G. Prentiss (R)

107th District [Albany (part) and Saratoga (part) Counties]

E-mail: prentiss@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

Legislative Office Building 523, Albany, NY 12248

(518) 455-5931

District Office:

*Northway 10, Executive Park, Ballston Lake, NY 12019
(518) 877-7113*

Assemblyman James Nicholas Tedisco (R-C)

103rd District [Saratoga (part) and Schenectady (part) Counties]
E-mail: tediscj@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

*Legislative Office Building 402, Albany, NY 12248
(518) 455-5811*

District Office:

*12 Jay Street, Suite No. 1, Schenectady, NY 12305
(518) 370-2812*

Assemblyman Paul D. Tonko (D)

105th District [Montgomery and Schenectady (part) County]
E-mail: tonkop@assembly.state.ny.us; Website: www.assembly.state.ny.us

Albany Office:

*Legislative Office Building 713, Albany, NY 12248
(518) 455-5197*

District Office:

*366 West Main Street, Guy Park Manor, Amsterdam, NY 12010
(518) 843-0227*

New York State Breast Cancer Network

Along with other grassroots advocacy groups in New York State, CRAAB! initiated the formation of the New York State Breast Cancer Network (NYSBCN, or The Network) in 1998. To date, the Network is comprised of 26 active organizations and is still growing!

The purpose of the Network is to ensure that cancer survivors and their supporters have a prominent voice in cancer-related issues and policies in New York State. We want to have a say in decision-making, policy implementation, education and legislation affecting breast cancer research, prevention, detection and treatment.

In 1999 and 2000, the Network sponsored two Breast Cancer Advocacy Days at the State Capitol in Albany, New York. Hundreds of survivors and other concerned citizens gathered to advocate for specific bills and policies that affect breast cancer prevention and care. Key state legislators presented their views and we advocates made sure the politicians listened to ours. With these annual events, we have successfully opened an on-going dialog between the state government and breast cancer advocates from all regions of the state. Centered in Albany, CRAAB! is playing a key role in the Network's efforts to maintain this dialog and to improve all aspects of cancer care throughout New York State.

The Network meets regularly to share educational information and plan advocacy events. We have established an e-mail communication system to share local, state and national information on key issues, recent research, relevant lectures and publications.

The following Network groups (as of March 2000) are recognized in their communities as leaders in providing breast cancer advocacy, education and support services. As a network we are dedicated to eradicating breast cancer in our lifetime so that our children and grandchildren do not have to fear the breast cancer epidemic that confronts us today.

Babylon Breast Cancer Coalition, *Long Island*

Breast Cancer Coalition of Rochester

Breast Cancer Help, *Stony Brook, LI*

Breast Cancer Network of Western New York, *Buffalo*

Brentwood/Bayshore Breast Cancer Coalition, *Long Island*

Cancer Awareness Coalition, *New Paltz*

Capital Region Action Against Breast Cancer (CRAAB!), *Albany*

Coalition Organized to Protect the Environment (COPE), *Garden City, LI*

Environmental Advocates, *statewide*

Great Neck Breast Cancer Coalition, *Long Island*

Huntington Breast Cancer Action Coalition, *Long Island*

Ithaca Breast Cancer Alliance

Judges and Lawyers Breast Cancer Alert (JALBCA), *statewide*

Long Beach Breast Cancer Coalition, *Long Island*

Mid Hudson Options Project, *Kingston*

New York Public Interest Research Group (NYPIRG), *statewide*

1 in 9: Long Island Breast Cancer Action Coalition

Pen & Palette, *Albany*

Plainview/Old Bethage Breast Cancer Coalition, *Long Island*

St. Lawrence Environmental Action

SHARE (Self-Help for Women with Breast or Ovarian Cancer), *NYC*

South Fork Breast Cancer Coalition, *Long Island*

Town of Islip Breast Cancer Coalition, *Long Island*

WEDO (Women's Environment and Development Organization), *NYC*

West Islip Breast Cancer Coalition, *Long Island*

Young Survival Organization, *national*

Notes

Reading List: Books and Periodicals 99

The following list of books and periodicals contain a variety of information that will interest people concerned about breast cancer. These sources are not intended as medical advice or instruction. Consult a health professional for advice relating to medical conditions or problems.

Look for these books and periodicals at your library, or ask your librarian to get them through interlibrary loan.

Austin, Steve, and Cathy Hitchcock. *Breast Cancer: What You Should Know (But May Not Be Told) About Prevention, Diagnosis, and Treatment*. Rocklin, California: Prima, 1994.

Barasch, Marc Ian. *The Healing Path: A Soul Approach to Illness*. New York: Penguin Arkana, 1993. *The spiritual journey of Barasch after being diagnosed with thyroid cancer.*

Batt, Sharon. *Patient No More: The Politics of Breast Cancer*. Charlottetown, Prince Edward Island, Canada: gynergy books, 1994. *Comprehensive, carefully researched, passionately written critique on the politics of breast cancer by journalist and breast cancer survivor.*

Beardsley, Tim. "Trends in Cancer Epidemiology: A War Not Won." *Scientific American*, January 1994: pp. 130-38.

Berg, E. *Talk Before Sleep*. New York: Random House, 1994. *What do women talk about when they know they don't have forever? Deeply moving novel about the grit and power of female friends.*

Benson, H. *The Relaxation Response*. New York: Avon Books, 1985.

Brady, Judy. *1 in 3: Women with Cancer Confront an Epidemic*. Pittsburgh: Cleis Press Inc., 1991. *This book has many short pieces by various authors including Steingraber, Batt, and Lorde.*

Brinker, N. *The Race is Won One Step at a Time*. St. Louis, Missouri: Simon & Schuster, 1990. *Shows how individuals who are informed and resourceful can take an active role in their personal health.*

Brookes, Tim. *Signs of Life: A Memoir of Dying and Discovery*. New York: Times Books, 1997. *Brookes, an author and commentator on National Public Radio had started a research project on the role of hospice and dying when his mother was diagnosed with pancreatic cancer. This book is his account of his own journey as he is involved with her dying. The beginning of the book briefly describes the death of his father 20 years earlier, an experience that was an example of the worst kind of death.*

Broyard, Anatole. *Intoxicated by my Illness and other Writings on Life and Death*. New York: Fawcett Columbine, 1992.

Broyard was a writer, book critic and an editor of The New York Times Book Review. He was diagnosed with metastatic prostate cancer in 1989 and died 14 months later. This book contains several essays he wrote during that time including "Intoxicated by My Illness" and "The Patient Examines the Doctor." The writing is both powerfully funny and serious.

Burt, J., G. White, and J. Casley-Smith. *Lymphedema: A Breast Cancer Patient's Guide to Prevention and Healing*. Alameda, California: Hunter House, 2000.

Cameron, Julia. *The Vein of Gold: A Journey to Your Creative Heart*. New York: Jeremy P. Tarcher/Putnam, 1996.

Cassileth, Barrie R. *The Alternative Medicine Handbook: The Complete Reference Guide to Alternative and Complementary Therapies*. New York: W. W. Norton, 1998.

Colbin, Annemarie. *Food and Our Bones: The Natural Way to Prevent Osteoporosis*. New York: Penguin, 1998. *A natural, no-drug, no-supplement approach by a food therapist and expert on natural food and healing.*

Colborn, Theo, Dianne Dumanoski and John Peterson Myers. *Our Stolen Future: Are We Threatening Our Fertility, Intelligence, and Survival? A Scientific Detective Story*. New York: Dutton, 1996.

Conway, Kathlyn. *Ordinary Life: A Memoir of Illness*. New York: W. H. Freeman Press, 1997. *An honest description of the struggle with breast cancer.*

Cousins, Norman. *Anatomy of an Illness*. New York: Bantam Books, 1981.

Norman Cousins' account of his successful fight against a crippling disease. He demonstrates what the mind and body working together can do to overcome illness.

Dackman, Linda. *Affirmations, Meditations, and Encouragements for Women Living with Breast Cancer*. Los Angeles: Lowell House, 1991.

For the woman who has just been diagnosed, the woman recuperating in her hospital bed, and the woman coming to terms with her new body and how it affects her sexual relationships.

Dackman, Linda. *Up Front: Sex After Mastectomy*. New York: Viking, 1990.

Degregorio, W., and V. Wiebe. *Tamoxifen and Breast Cancer, 2nd edition*. New Haven, Connecticut: Yale UP, 1999. *Tamoxifen is one of the most widely prescribed drugs used to prevent the recurrence of breast cancer. This book takes an investigative look at this drug.*

Dodd, M. *Managing the Side Effects of Chemotherapy and Radiation*. Upper Saddle River, New Jersey: Prentice Hall, 1996.

Describes all chemotherapy and radiation side effects and explains how these can be alleviated, managed, or minimized.

Dossey, Larry. *Healing Words: The Power of Prayer and the Practice of Medicine*. New York: Harper San Francisco, 1993.

"The answer to a prayer: the most thoughtful, eloquent, and interesting book on prayer, health, and healing that I have ever read." Dean Ornish, M.D.

Epstein, Samuel S. and David Steinman. *The Breast Cancer Prevention Program*. New York: Macmillan, 1997. *A critical view of mammography recommendations by American Cancer Society and the National Cancer Institute as well as other issues.*

Epstein, Samuel S. *The Politics of Cancer Revisited*. Fremont Center, New York: East Ridge Press, 1998.

Fallowfield, Lesley with Andrew Clark. *Breast Cancer*. London, Routledge: 1991. *Uses verbatim accounts by women to examine the psychosocial impact of breast cancer.*

Feldman, C. *You Don't Have to be Your Mother*. New York: W. W. Norton, 1994.

Personal story of a woman who discovered she had breast cancer while pregnant.

Fintel, William, and Gerald McDermott. *A Medical and Spiritual Guide to Living with Cancer*. Dallas, Texas: Word Publishing, 1993.

Contains easy to understand answers to tough medical and spiritual questions.

Frank, Arthur W. *At the Will of the Body: Reflections on Illness*. New York: Houghton Mifflin, 1991.

Frank is a Professor of Sociology at the University of Calgary. This book describes his analysis of what it is like and what it means to be sick based on his experience with a heart attack and testicular cancer at ages 39 and 40. In very few words he gets to the core of many issues that surround being sick.

Frank, Arthur W. *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago, 1995.

Frank describes the need of ill people to tell stories in order to heal themselves. Using the writing of Lorde, Broyard and others, identifies 3 types of illness narratives and helps us see which of these types of stories are acceptable in our culture and so are allowed to be told.

Fugh-Berman, Adriane. *Alternative Medicine: What Works*. Baltimore, Maryland: Williams and Wilkins, 1997.

Geffen, Jeremy, MD. *The Journey Through Cancer*. Crown Publishers, 2000.

Dr. Geffen is an oncologist, director of Geffen Cancer Center in Florida and self-described student of Buddhism, Ayurvedic and Tibetan medicine. This book reflects his practice of treating the person as a whole with complementary practices, with emphasis on addressing emotions as well as spiritual and philosophical issues.

Goldberg, George. *Enough Already! The Overtreatment of Early Breast Cancer*. Tucson, Paracelsus Press, 1996. *Challenges the use of axillary node dissection, radiation and chemotherapy for early breast cancer. Clear statement of controversies and well-referenced.*

Goodare, Heather (Ed.) *Fighting Spirit: The stories of women in the Bristol breast cancer survey*. London, Scarlet Press, 1996. *Interesting case of controversy surrounding women in Bristol, England who took part in study of complementary therapies and challenged the way the research results were used.*

Gordon, James S. *Manifesto for a New Medicine: Your Guide to Healing Partnerships and the Wise Use of Alternative Therapies*. Reading, MA: Addison-Wesley, 1996. *Wise text on alternative medicine.*

Gordon, S. *Is There Anything I Can Do?* New York: Delacourt Press, 1994.
Ways to help a friend and yourself when times are tough.

Greaves, Mel. *Cancer: The Evolutionary Legacy*. Oxford: Oxford University Press, 2000.

Gross, A., and D. Ito. *Women Talk About Breast Surgery: From Diagnosis to Recovery*. New York: Potter Publishing, 1990.
Written from in-depth conversations conducted with women who have been through breast surgery. They relate their mistakes as well as their triumphs and offer lessons in how to be the smartest possible patient, how to get the best possible care.

Harpham, W. Schlessel. *After Cancer: A Guide to Your New Life*. New York: W. W. Norton, 1994.
All about life after cancer by a physician and a cancer survivor.

Harpham, W. Schlessel. *Diagnosis Cancer: Your Guide Through the First Few Months*. New York: W. W. Norton 1992.
Written by a physician who had cancer. She teaches women how to ask the right questions and make the best decisions for themselves.

Helping Your Mate Face Breast Cancer. Columbia, South Carolina: EduCare Publishing, 1995.
A guide to helping a loved one face breast cancer. Contains tips for becoming an effective support partner. Order from EduCare Publishing, Post Office Box 280305, Columbia, South Carolina 29228; Website: cancerhelp.com

- Hirshberg, Caryle and Mark Ian Barasch. *Remarkable Recovery: What Extraordinary Healings Tell Us About Getting Well and Staying Well*. New York: Riverhead Books, 1995.
A careful look at the medical histories of people who recover against the odds from terminal illness.
- Hoffman, Barbara, JD. (Ed.) *A Cancer Survivor's Almanac: Charting Your Journey*. National Coalition for Cancer Survivorship, Chronimed Publishing, 1996.
A guide written by survivors and professionals to help survivors, caregivers, families and friends, with information on diagnosis, treatments, long-term effects, pain management, insurance, financial and employment issues, communication and support groups, advocacy.
- Jordan, V. Craig. (Ed.) *Tamoxifen For the Treatment and Prevention of Breast Cancer*. Melville, NY: PRR, 1999. *Book celebrates history and benefits of tamoxifen.*
- Kahane, D. H. *No Less a Woman: Ten Women Shatter the Myths About Breast Cancer*. Upper Saddle River, New Jersey: Prentice Hall, 1990.
Provides a positive look at an aspect of breast cancer that no one really talks about. Inspirational.
- Kaye, Ronnie. *Spinning Straw into Gold: Your Emotional Recovery from Breast Cancer*. New York: Simon & Schuster, 1991.
Written by a woman psychotherapist who won her own battle with breast cancer; comprehensive guide to emotional recovery.
- Kelly, Patricia T. *Assess Your True Risk of Breast Cancer*. NY: Henry Holt and Co., 2000.
Kelly, a medical geneticist who specializes in cancer risk assessment and counseling, understands the limits of genetic counseling and the research on which it is based. This book explains how to make sense of the often conflicting information, and clearly describes what is known about hereditary and non-hereditary breast cancer risk. Also explains key issues about hormone replacement therapy and tamoxifen use, genetic testing and prophylactic mastectomy.
- Kneece, J. *Finding a Lump in your Breast Where to Go, What to Do*. Columbia, South Carolina: EduCare Publishing, 1996.
A guide for the woman concerned about her risk for breast cancer. Contains assessment sheets and lists medications and dietary products that can cause lumps. Order from EduCare Publishing, Post Office Box 280305, Columbia, South Carolina 29228; Website: cancerhelp.com
- Komarnick, L., A. Rosenberg, with M. Betancourt. *What to do if You Get Breast Cancer*. Boston, Massachusetts: Little, Brown & Co., 1995.
Step-by-step guide through the treatment process, from diagnosis to recovery.

Kubler-Ross, Elizabeth. *On Death and Dying*. New York: Macmillan, 1969.

A classic work.

Kushner, P. *When Bad Things Happen to Good People*. New York: Schocken Books, 1981.

"Offers a moving and humane approach to understanding life's windstorms. It raises many questions that will challenge your mind and test your faith regarding the ultimate questions of life and death." Elizabeth Kubler-Ross.

Kushner, R. *Breast Cancer: A Personal History & Investigative Report*. Harcourt Brace Jovanovich, Inc.

The author extends her personal experience into a sustained investigative report on the status of breast cancer research and care in the U.S. and abroad.

Leopold, Ellen. *A Darker Ribbon: Breast Cancer, Women, and their Doctors in the Twentieth Century*. Boston, Beacon Press, 1999. *A social history of breast cancer using two women patients as examples.*

Lerner, Michael. *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer*. Cambridge, Massachusetts: MIT Press, 1994. *Thoughtful and compassionate, a must read.*

LeShan, Lawrence. *Cancer As A Turning Point: A Handbook for People with Cancer, Their Families, and Health Professionals*. New York: Plume, 1994. *Chapter on how to survive in a hospital especially helpful.*

Lifshitz, L. *Her Soul Beneath The Bone*. University of Illinois Press, 1988.

An anthology of women's poetry on breast cancer.

Lorde, Audre. *The Cancer Journals*. San Francisco, California: Aunt Lute Books, 1997.

Lorde's words of love and wisdom give courage and strength to others struggling with breast cancer.

Lorde, Audre. *A Burst of Light*. Ithaca, NY: Firebrand Books, 1988. *Includes her journal entries while dealing with breast cancer recurrence.*

Love, Susan M. *Dr. Susan Love's Breast Book*, 3rd Edition. Reading, Massachusetts: Addison-Wesley, 2000. *Addresses all conditions of the breast from benign to malignant; provides a balanced view of treatment options.*

Mayer, Musa. *Examining Myself: One Woman's Story of Breast Cancer Treatment and Recovery*. London: Faber and Faber, 1993.

A beautifully crafted memoir chronicling the author's experiences with cancer over the past several years.

- Mayer, Musa. *Holding Tight, Letting Go: Living with Metastatic Breast Cancer*. Cambridge, Massachusetts: O'Reilly and Associates, 1997.
- McCarthy, and J. Loren. *Breast Cancer? Let Me Check My Schedule*. Boulder, Colorado: Westview Press, 1997.
- Metzger, Deena. *Tree (& The Woman Who Slept With Men To Take The War Out Of Them)*. Oakland, California: Wingbow Press, 1978.
Tree is Metzger's journal and story of her diagnosis with breast cancer and mastectomy in 1977. At some point after her mastectomy, Metzger (also a therapist) had a tattoo of the tree of life done along her mastectomy scar. A photo of her torso, showing scar and tattoo has been made into a poster.
- Middlebrook, Christina. *Seeing the Crab: A Memoir of Dying*. New York: Basic Books, 1996.
Middlebrook is a Jungian analyst who was diagnosed with metastatic breast cancer in her 40's and given a 50% chance of living 2 years. She was treated with high dose chemotherapy and a bone marrow transplant. This is a "searingly honest, personal book about living with advancing cancer and the rigors of its treatment. This is not one more success story about cancer, unless you realize that success is also the ability to take one's death sentence with strength and clarity of mind." (quotes from D. Speigel and S. Drakulic)
- Moses, Marion. *Designer Poisons: How to Protect Your Health and Home from Toxic Pesticides*. San Francisco: Pesticide Education Center, 1995.
- Moss, Ralph W. *Questioning Chemotherapy*. Brooklyn, NY: Equinox, 1995.
- Moyers, Bill. *Healing and the Mind*. New York: Doubleday, 1993. *Describes the power of the mind/body connection as a healing force.*
- Murcia, Andy. *Helping the Woman You Love Recover from Breast Cancer*. New York: St. Martin's Press, 1991.
- New Our Bodies, The*. The Boston Women's Health Book Collective, Simon & Schuster.
A book by women for women, updated and expanded for the 90's. Courageously discusses the difficult topics and provides the most complete sourcebook available on women's health care issues. Includes breast reconstruction after a mastectomy.
- Null, Gary and Barbara Seaman. *For Women Only! Your Guide to Health Empowerment*. Seven Stories Press, New York, 1999. *Two books in one, an alternative health guide and collection of essays on women's health.*

Pelton, Ross and Lee Overholser. *Alternatives in Cancer Therapy: The Complete Guide to Non-traditional Treatments*. New York, Simon & Schuster, 1994.

Potts, Laura K. (Ed.) *Ideologies of Breast Cancer: Feminist Perspectives*. New York, St. Martin's Press, 2000.

Potts, Morra E. *Choices: Realistic Alternatives in Cancer Treatment*. New York: Avon Books, 1994.
Question-and-answer style handbook covering everything from medications to modern therapies.

Price, Reynolds. *A Whole New Life: An Illness and A Healing*. New York: Plume/Penguin, 1995.
Price, a literature professor and author of novels and plays, learned he had a 10 inch-long tumor of the spinal cord in 1984. This is the story of his surgery, radiation, drugs, biofeedback, and agonizing pain. It is powerful, fiercely honest, spiritual and deeply intelligent.

Remen, Rachel N. *Kitchen Table Wisdom: Stories that Heal*. New York: Riverhead Books, 1996.

Rich, Katherine. *The Red Devil: To Hell with Cancer and Back*. New York: Crown Publishing, 1999.
The traditional approach to cancer treatment covers diagnosis and treatment, supportive care, new advances in research and treating the common cancers and includes a 26-page chapter on breast cancer.

Royak-Shaler, and B. L. Benderly. *Challenging the Breast Cancer Legacy*. New York: Harper-Collins, 1992.
This guide offers psychological insight and medical information for the more than two million daughters, sisters, and mothers living with the legacy and risk of breast cancer.

Sherman, Janette D. *Life's Delicate Balance: Causes and Prevention of Breast Cancer*. New York: Taylor & Francis, 2000. *Discussion of possible roles of radiation, hormones, and pesticides in causing breast cancer. Includes discussion of Long Island study.*

Siegel, Bernie S. *How to Live Between Office Visits*. New York: Harper-Collins, 1993.
Answers questions and gives support. Shows us how to look into our hearts, listen to ourselves, and draw on our strength and that of our loved ones.

Soffa, Virginia M. *The Journey Beyond Breast Cancer: From the Personal to the Political*. Rochester, Vermont: Healing Arts Press, 1994.
This book is a call for women's rights in health care: how to reclaim our bodies by taking charge and taking responsibility.

Sonnenschein, C. and Soto, A.M. *The Society of Cells: Cancer and Control of Cell Proliferation*. New York:

Springer-Verlag, 1999. *Authors take historical approach to theories of cell proliferation and cancer cells and suggest the theory that cancer is a defect in tissue organization rather than the somatic mutation theory would be more promising approach to cancer research.*

Sontag, S. *Illness as Metaphor and AIDS and Its Metaphors*. New York: Bantam-Doubleday-Dell, 1990. *Presents Sontag's two essays: the first was written in 1978 while she was recovering from cancer; the second was written ten years later. Powerfully written.*

Spiegel, D. *Living Beyond Limits*. New York: Ballentine Books, 1994. *Written by a doctor who published the landmark study on the benefits of group therapy for breast cancer patients; explores the mind/body connection to enhance quality of life.*

Steingraber, Susan. *Living Downstream: An Ecologist Looks at Cancer and the Environment*. Reading, Massachusetts: Addison-Wesley Publishing, 1997.

Steinbach, Claudia. *Now Breathe: A Journal of Life After a Cancer Diagnosis*. Seattle, Washington: Whiteacker Press, 1999.

Swirsky, J., and B. Balaban. *The Breast Cancer Handbook: Taking Control After You've Found a Lump*. 2nd Edition. Staten Island, New York: Power Publications, 1998. *This user-friendly guide is full of practical information for the woman who thinks she may have breast cancer, or has just been diagnosed as having breast cancer.*

Tarken, Laurie. *My Mother's Breast: Daughters Face Their Mother's Cancer*. Dallas, Texas: Taylor Publishing Company, 1999.

Wadler, J. *My Breast*. Reading, Massachusetts: Addison-Wesley, 1992. *The remarkable story of a smart, savvy, very human forty-something New York writer who is also a breast cancer survivor.*

Weil, Andrew. *Spontaneous Healing: How to Discover and Enhance Your Body's Natural Ability to Maintain and Heal Itself*. New York; Knopf, 1995. *Weil's many books offer many practical suggestions for a more natural approach to medicine.*

Wilber, Ken. *Grace and Grit: Spirituality and Healing in the Life and Death of Treya Killam Wilber*. Boston: Sjambhala, 1991. *This book is a combination of Treya's journals and Ken's description of the 5 years of their journey through her experience of diagnosis, treatment and dying from breast cancer. This is a love story as well as a cancer story. It is unique in its thoughtful treatment of western and alternative medicine, the role of caregivers, and in its intensely honest look at the toll of illness on intimate relationships.*

Yalom, Marilyn. *A History of the Breast*. New York: Knopf, 1997. *Scholarly treatment of the breast in religion, politics, art, psychology, advertising and medicine.*

Zuckweiler, Becky. *Living in the Postmastectomy Body: Learning to Live In and Love Your Body Again*. Point Roberts, WA: Hartley & Marks, 1998. *An honest look at recovery from mastectomy by nurse and psychotherapist who does not have breast cancer but who had prophylactic double mastectomy with silicone implants and later had implants removed.*

Books for Children

Blake, C., E. Blanchard, and K. Parkinson. *The Paper Chain*. Santa Fe, New Mexico: Health Press, 1998.

Fine, Judylyaine. *Afraid to Ask: A Book for Families to Share About Cancer*. Beech Tree Books, 1991.

McCue, Kathleen. *How to Help Children Through a Parent's Serious Illness*. New York, New York: St. Martin's Press, 1994.

Parkinson, Carolyn Stearns, and Elaine Verstraete (illustrator). *My Mommy has Cancer*. Park Press, 1991.

Terkel, Susan N., Marlene Lupiloff-Brazz, and Annette Shaw (illustrator). *Understanding Cancer*. F. Watts, 1993.

Vigna, Judith. *When Eric's Mom Fought Cancer*. Albert Whitman & Co., 1993.



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*N*ever doubt that a small
group of thoughtful, com-
mitted citizens can change the
world; indeed, it's the only thing
that ever does.

Margaret Mead

CRAAB!

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