THE BREAST CANCER GENE: A SCIENTIFIC DISCOVERY OFFERING MORE QUESTIONS THAN ANSWERS

Submitted by Mary Jo Kahn

When I was diagnosed five years ago, I was told there would be “a test for the breast cancer gene in 5 years”. The estimated time for this discovery was nearly accurate; my expectations of what this test would mean to me and my family was not. Within the next 12 months it is expected that one of the first breast cancer susceptibility genes, BRCA1, will be identified. Shortly after it is identified, a blood test will be developed that can determine if a genetic defect is present in this particular location on the chromosome. For all of us who worry constantly about what our breast cancer diagnosis may mean to our sisters and daughters, this test sounds like a panacea. What we wouldn’t give for a test that would give us peace of mind for our loved ones.

Genetics is not a simple science and breast cancer is not a simple disease. A test that will give us a guarantee that breast cancer will not strike an individual may never exist. A test to identify who will likely get breast cancer is a possibility. The discovery of BRCA1 will greatly speed the progress of this research. In fact, as genetic discoveries advance our knowledge of breast cancer, we should eventually not only be able to determine which women are genetically predisposed to breast cancer but be able to provide treatments for these defects that will prevent clinical disease.

The location of BRCA1 is being narrowed by doing gene linkage studies on families that have four premenopausal women affected with either breast or ovarian cancer. In a linkage study, DNA from many relatives, usually a minimum of eight, is analyzed. Now that the general location of BRCA1 is known, it is possible to tell if that area of the chromosome has been inherited from the affected parent or the healthy parent. Men can also inherit the BRCA1 gene even though they do not develop breast cancer as a result of it. (Male breast cancer is probably caused by a different genetic defect.) However, men can just as easily pass the defect on to their children as the affected mother can.

Once the exact location of BRCA1 is identified, blood samples from numerous family members will no longer be necessary. Companies are gearing up to offer the blood test as soon as it is available. There is much concern among genetic researchers that offering this test on the open market is preceding the necessary science that must be done to properly interpret the test.

First of all, any test for a genetic defect must be reasonably accurate. To prove any laboratory test accurate, results must be collected and studied for some period of time. Almost all tests have a range of false positives and false negatives. Before any test as significant as a test for BRCA1 can be marketed, it should be required that patients be informed of the test’s validity. A test with only a 75% accuracy rate will be viewed very differently from a test that is 99% accurate.

However, having the technology to accurately perform the test is still not the same as providing accurate test results. A good test done by a

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For several months, National Breast Cancer Coalition leaders have been considering an official position about the role of the woman with breast cancer and her advocates. VBCF has constructed a position paper which essentially demands involvement of patient consumers in decision making at every level of the research process, from determining what is funded through translation to clinical practice.

The move toward inclusion of consumers understandably may make those in the research and clinical community anxious. After all, the average consumer does not have benefit of the vast education and years of experience; most are not even familiar with the vocabulary much less the abbreviations. And research investigators have more than enough hoops to jump through, from massive grant proposals to volumes of regulations, without having to add more.

As frustrating as it might be to include us, investigators and clinicians just beginning to get a glimpse of what we can do for them. For instance, there is a crucial need for tumor and breast tissue for testing. So, we’ve begun a dialogue to address ways to make this tissue available. We’ve already demonstrated that we can influence increases in research funding. We can educate ourselves, the newly diagnosed, those at risk and the general population. We can get the word out about new treatments and fill up clinical trials.

The partnership between scientists and consumers has maturing to do. We must work hard to keep the communication lines open; an inclusive relationship is bound to bring the right answers more quickly.

by Kendra McCarthy

It is always good news when researchers find something that reduces the risk of breast cancer, and now two recent studies show that there is a decreased risk of breast cancer among premenopausal women who have breast fed one or more babies. This is not true for postmenopausal women who had lactated; they showed no benefit. The first study, conducted in the United States, compared 2376 pre and postmenopausal women under age 75 from four states with diagnosed breast cancer, with 3422 controls who did not have breast cancer. The variables studied included age at menarche, age at delivery of first child, family history of breast cancer or benign breast disease, body-mass index, lactation history, and age at menopause, if reached.

Results showed that the women with breast cancer had more of the expected risk factors: younger mean age at menarche, older at delivery of first child, more likely to have a positive family history of breast disease, higher mean body-mass index, and older age at menopause. Women with a history of lactation showed a 22% reduction in risk of breast cancer compared with women who had never lactated. The risk was even lower for women with a longer duration of lactation; that is, breast feeding over longer time periods and during multiple pregnancies. Women who first lactated before age 20 and continued for six months, showed even lower risk of breast cancer: 46% lower than that of women who had never lactated. Risk of breast cancer was slightly but significantly increased among postmenopausal women who had taken hormones to inhibit the flow of milk after at least one pregnancy, but was not significant among premenopausal women.

An explanation for the protective effect of lactation on breast cancer is that lactation may reduce risk by interrupting ovulation and producing amenorrhea or by modifying pituitary and ovarian hormone secretion. Direct physical changes

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The Breast Cancer Gene... Cont'd

bad technician is still not reliable. Quality assurance of the laboratories offering genetic testing is as important as ensuring the quality of mammography centers. At present, the Food and Drug Administration does not seem eager to press for such quality assurance standards. How the technicians are trained, what safeguards are instituted to assure accuracy and how paperwork is handled to prevent clerical errors are all part of quality assurance. In clinical studies, genetic researchers have traditionally done gene linkage studies on two samples to assure accuracy. Human error is always a source of inaccurate laboratory findings. There is no requirement that companies offering genetic testing to the public must perform repeat tests to compensate for human and equipment error although the seriousness of such a mistake to the patient is incalculable.

More important than the accuracy of the test itself is the difficulty medical geneticists will have in interpreting the findings into a meaningful risk assessment for an individual. Thus far, only very affected families, those having four or more members with premenopausal breast or ovarian cancer, have been extensively studied. It is clear that whatever genetic defect is present in these families, it is very likely to cause disease. If the family is affected by a defect at BRCA1, and a woman inherits the defect, researchers predict her risk of developing breast cancer is 50% before menopause and 80% before age 65. Affected women do not have a 100% risk of developing invasive breast cancer because there are other steps necessary in the process besides inheriting the susceptibility gene. Some other genetic defect or environmental insult must be present for the clinical disease to occur. More research will be needed to determine what these other factors are and how they interact with the inherited gene defect that enhances susceptibility.

Another unknown is how many possible defects can occur at the location BRCA1. One defect may be more lethal than another but all look the same on a blood test. For instance, in some families there may be an 85% inherited risk, and in others, only a 25% inherited risk even though both have a defect occurring at the BRCA1 location. Because more than one defect can exist, less affected families, for instance those in which only two premenopausal breast cancers have occurred, cannot draw the same conclusions about risk as those in more affected families.

Another factor that will confuse the interpretation of this test is the likelihood that other breast cancer susceptibility genes will be discovered in the future. There are families who have multiple members affected by breast cancer in which all members test negative for BRCA1. This does not mean they do not have an inherited risk of breast cancer, but that they may have a gene defect at a location other than BRCA1. Before they are finished, researchers may find dozens of breast cancer genes, all with different risks associated with them. Once the test for a BRCA1 defect is available, a woman who tests negative may have an equally high risk of developing breast cancer as a woman who tests positive. If we were hoping for something that would allow our daughters to forgo mammography, self breast exams, and a life of worrying about breast cancer, genetic testing will not be the answer.

Even for women in very high risk families who carry the BRCA1 lesion and have an 85% risk of breast cancer, there are no known effective methods of prevention or early detection that can be recommended to them. Prophylactic mastectomies or oophorectomies (removal of the ovaries) are two methods of prevention currently being used. The effectiveness of these last resort techniques has never been documented by clinical trials. Some researchers argue that too much radiation exposure resulting from beginning annual mammography exams too early may actually increase the woman's risk of developing the disease. Determining the best management plan for women found to be at genetic risk for breast cancer is imperative.

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The Breast Cancer Gene... Cont'd

Last, but certainly not least important, is the issue of confidentiality. Unless health care reform or legislation is enacted to address the issue, a person undergoing genetic testing for breast cancer is in danger of losing her ability to purchase both health insurance and life insurance. Employment discrimination based on genetic defects is not clearly protected under the Americans with Disabilities Act. Pre-test counseling before genetic testing is done must alert the individual to the very real risk of learning more about themselves than is safe to know at this time. A person has a right to information about what the test can tell them, what it cannot, what little is known about appropriate follow-up should they test positive, and what risk to their insurance this information poses before agreeing to undergo testing.

In the future, breast cancer advocates should be hopeful that genetic testing following a full informed consent will be widely available in centers that can offer proper education, counseling, and interpretation. All laboratories providing testing should meet the highest standards of quality. Management following diagnosis of inherited susceptibilities to breast cancer will be based on scientific study of the options. Information gathered from such testing will be available for all who desire testing without fear of discrimination in health care benefits or other important areas of their lives. Most importantly, we should hope that future treatments can address the microbiology of breast cancer and spare women from ever having to cope with the full blown disease. There is much we do not know about BRCA1 today but it is a scientific breakthrough that holds great promise for the future of breast cancer.

In the near term, families who are concerned about their level of risk should seek genetic counseling. Even though we do not yet have a test for a particular gene, we do have an ever growing body of knowledge about the predictability of risk in affected families. For instance, women who develop breast cancer late in life are unlikely to have inherited a susceptibility gene and therefore their daughters are no more at risk than the general population (an unacceptably high 1 in 9!!). Many such women have been declared high risk by their physicians resulting in unnecessary anxiety. Genetic counseling should be everyone's first step in learning their genetic risk for breast cancer, and for many, it may be all that is ever necessary.

For more information on genetic counseling, call 1-800-4CANCER or ask your physician for a referral.

Mary Jo Kahn, past president of VBCF, recently participated in a sub-committee of the American Society of Human Genetics that was exploring the clinical applications of BRCA1 testing. The committee consisted of a group of internationally renowned researchers in the area of medical genetics. Two breast cancer advocates were included in the committee. Elizabeth Hart, a representative from the Komen Foundation, was also a participant. Consumer participation in policy making committees such as this one is a goal of the Virginia Breast Cancer Foundation. Following the very successful cooperative efforts between scientists and consumers at the Conference to Establish a National Plan for Breast Cancer, more scientists are reaching out to consumers to help them solve the very complex problems facing breast cancer research and clinical care today. For instance, prevailing upon the Food and Drug Administration to enforce their regulatory authority to permit genetic testing only in laboratories that meet certain standards of quality is more effectively performed by consumers than by scientists. Our joint efforts are necessary to ensure that when genetic testing for breast cancer is available, this new technology will provide useful information to individuals anxious to better understand their risk.

VBCF members who would like to participate as a consumer representative in policy making committees should submit their resumes to the VBCF office. As requests are made for representatives to attend meetings or represent us on committees, we need a list of potential volunteers we can contact to discuss the requests. Generally, expenses are paid by the sponsoring organization. Time commitments may vary from one meeting to many. Please consider this important volunteer commitment to VBCF.
Breast Feeding ... Cont’d

in the breast that accompany milk production may also be protective. No reasons could be found why postmenopausal women who had lactated were not protected against breast cancer.

It is suggested that if younger women were to breast-feed for 4 to 12 months, breast cancer among premenopausal women could be reduced by 11%, and if they lactated for 24 months or longer, the reduction in incidence could be nearly 25%. The reduction would be even greater for women who first lactate before age 20.

The second report was based on a national matched case-control study done in Great Britain to determine whether breast feeding is related to development of breast cancer. In this study, 755 women diagnosed with breast cancer before age 36 were each matched with a non-breast cancer patient whose age was within six months of the case. Use of oral contraceptives were compared as well as duration of breast feeding and number of babies breast fed. Use of combined oral contraceptives was clearly related to risk of breast cancer. Women who breast fed a baby for three months had a relative risk of breast cancer of 78% per baby fed, a reduction of 22% below women who did not breast feed a baby. If breast feeding extended beyond three months, no additional reduction in risk occurred, but breast feeding several babies for at least three months conferred additional protection. Risk was increased for women who did not breast feed their babies. Taking hormones to suppress lactation did not increase risk of breast cancer.

The authors developed the following public health implications from the results of their study:
- Breast feeding protects against breast cancer in young women;
- The risk decreases with increasing duration of breast feeding, and breast feeding each baby for three months or longer gives greatest protection;
- Risk of breast cancer was not linked to number of births;
- Breast feeding is good for the mother as well as the baby.

Sources:

IS THERE A BREAST CANCER GENE?

Family history is one of the few established risk factors for breast cancer, and some families have had more than their share of cases. Some women in high-risk families do not inherit the gene, but until recently there was no way to determine who carries the gene and who does not.

After nearly twenty years of work, geneticist Mary-Claire King and others have found a faulty gene that they linked to breast cancer in 80 percent of over 200 high-risk families. Women with the abnormal gene, named BRCA1 for Breast Cancer 1, have a 60 percent chance of developing breast cancer by the time they are 50, compared with 2 percent for women without the defect. The chances rise to 80 percent by age 65. The genetic link to breast cancer appears to be much stronger in premenopausal women. Although the defective gene has neither been isolated nor made visible, King has found an abnormal area in chromosome 17 of high-risk families that can be seen under powerful magnification.

If researchers can find a way to identify BRCA1 within the next year as expected, they may be able to test a woman with two or more stricken relatives to estimate her own risk. This would be the equivalent of a "molecular mammogram", except that it would never need to be repeated. Until that time, three future avenues may open to protect premenopausal women with strong family histories of breast cancer: Geneticists could either look for the inherited defective chromosome or estimate

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MARKETERS LINK WOMEN’S PRODUCTS TO BREAST-CANCER AWARENESS

Manufacturers of cosmetics and women’s fashions have discovered a powerful selling strategy in attaching their names to breast-cancer awareness. Several major companies have found that distributing the pink ribbon, a symbol of breast-cancer awareness similar to the red AIDS ribbon, effectively gets the attention of female customers. Avon Products, a Fortune 500 company, is beginning a five-year plan to equip its 415,000 Avon Ladies with pink-ribbon pins and 15 million brochures and is encouraging them to talk with customers about the disease. In Great Britain, Avon has discovered that this approach has had a substantial impact on sales due to the female-to-female bonding and linkage that takes place during the discussion about breast cancer. The Avon representatives there sold the pink-ribbon pins to raise funds for research.

Estee Lauder is also distributing pink ribbons at 2,000 of its retail outlets. Sara Lee Corporation’s Hanes Hosiery division is wrapping stockings around cards that explain the method of performing breast self-examination in the shower. Two models, Lauren Hutton and Veronica Webb, are being financed by Revlon to tour the country collecting signatures on a petition calling for a national breast-cancer agenda.

So far breast-cancer patients and advocacy groups support the campaigns, although there is concern about underlying commercial motives. Fran Visco, president of the NBCF, said, “I wish more companies put more money into research and weren’t quite so concerned about their corporate image.” One manufacturer of lingerie, Warnaco Group, Inc., declined the American Cancer Society’s suggestion to put tags on its products explaining how to do a breast self-exam because “customers indicated that they thought it was detrimental to have warning, so to speak, on a bra.” This statement came from the chief executive of Warnaco, Linda Wachner, whose sister died of breast cancer. Apparently there are some sensitivity issues that need to be overcome.


Is There a Breast Cancer Gene... Cont’d

risk from the woman’s genetic profile; young women thought to be carriers of the gene could obtain periodic screening-mammograms; and someday, possibly, the estrogen-blocking drug tamoxifen may be used to prevent tumors. This is now being studied in clinical trials in the United States and Britain.

Even though BRCA1 is responsible for breast cancer in women, the gene can be transmitted by either parent. If one parent transmits the gene to a daughter, she can be expected to develop breast cancer 50 percent of the time. Inheriting a BRCA1 gene does not guarantee that breast cancer is inevitable because essential triggering or other environmental factors may not be present. Experts estimate that only about 10 percent of the annual 180,000 new cases of breast cancer are related to heredity; causes of the majority of cases remain unknown.

DIGITAL MAMMOGRAPHY: STATE-OF-THE-ART IMAGING

Based on presentations at the National Cancer Institute workshop on breast imaging, held 1991, and on review of literature, the workshop faculty is calling for research to study digital mammography and its integration into related technologies: image processing for improved lesion contrast; automated computer-aided diagnosis for enhanced breast cancer detection and characterization; and teleradiology for facilitated radiologic consultation with experts in the field. They proposed that a National Digital Mammography Development Group be formed to carry out these studies.

Digital mammography was identified in the NCI workshop as "the most fertile territory for major advances in the x-ray detection and diagnosis of minimal breast cancers" and the technology with the greatest potential to impact the management of breast cancer. At present, digital mammographic techniques are still experimental, but the method can detect malignant microcalcification clusters equal to state-of-the-art conventional mammography, but with lower resolution. Advances in higher contrast and spatial resolution are needed before digital mammography is ready for general use.

If image quality is improved, image processing to enhance lesion-background contrast in patients with dense breasts would become possible. It would also make possible computer assisted diagnosis in which the breast image is directly analyzed by computer to detect, localize, and quantify abnormalities shown in the X ray. This would enable high volumes of mammography screening X rays to be processed, and would increase visualization of findings, such as microcalcifications, that are now difficult to recognize. Improving the lesion-background contrast would open up the possibility of electronic image transmission for rapid radiologic consultation; but much research is needed before this is feasible.

The National Cancer Institute (NCI) announced that it would issue a call for grant applications to form the National Digital Mammography Development Group, which will study aspects of this new form of imaging: digital mammography, image processing, computer assisted diagnosis, teleradiology, and preclinical and clinical technology evaluation. To this end, the group will promote collaboration among NCI, the academic community, and industry.


"Healing Legacies" A Collection of art & writing by women with breast cancer

The Breast Cancer Action Group (BCAP) of Vermont has created a slide registry representing professional and non-professional artists with breast cancer as its common thread. This registry is becoming one of the largest data bases of its kind in the world. Works are continuously solicited. BCAG serves as the liaison between exhibit sites and artists. They provide slides of the artists work, biographies and related publicity materials. For further information, write to BCAG at P.O. Box 5605, Burlington, VT 05402.

Mammography Standards

President Clinton signed an amendment to the 1992 Mammography Quality Standards Act last month authorizing the FDA to publish new quality standards. All mammography centers must be in compliance by October 1, 1994. Approximately 60% of all centers are now accredited by the American College of Radiology. The ACR hopes to receive approval from the FDA to be the approved accrediting authority.
EXPERTS Respond TO NEW MAMMOGRAPHY GUIDELINES

There has been a spate of articles recently reporting studies showing that there is no reason to promote screening mammography in women under age 50. This has caused consternation in the United States because this country has been the lone supporter for routine screening of asymptomatic women under age 50. Two experts, Susan Love, a physician specialist in breast diseases at the UCLA Breast Center, with Devra Lee Davis, Assistant Secretary for Health in the US Department of Health and Human Services and a specialist in health policy, reviewed a compilation of all relevant studies ever conducted on mammographic screening of asymptomatic women. They found that there was a 30% reduction in deaths among women over 50 who were screened every year or two, but no basis for routinely screening younger women. Women under age 50 have fewer than 20% of all breast cancers, but three times as many diagnostic procedures for every cancer diagnosed and 2.5 times as many biopsies, only 10% of which are cancerous, compared with women aged 50 and older.

Even though screening is efficacious for women aged 50 and over, in 1990, 40% of women in this age group had never had a mammogram and the proportion of women seeking mammograms fell from about 47% to 33% between 1985 and 1992; at the same time, the proportion rose for women under 50 from 53% to 67%. In addition to the unnecessary expenditures for the procedure, there are health hazards connected with radiation exposure; and it is estimated that one cancer in 25,000 is induced by radiation exposure.

Much of the overuse of mammography with its limited value in younger women could have been avoided if efficacy studies had been conducted before recommending that all women have regular mammograms. The authors believe that imaging may not be the best screening modality for young women because of the density of their breast tissues and it is time to develop alternative screening tests that would detect early cancers in young women without the use of x-ray imaging. This would help to reduce the burden of breast cancer in the 20% of women under 50 who now fall victim to it, without exposure to radiation.


Taxol Update

An FDA committee has recommended approval of Taxol for use for metastatic breast cancer. Clinical trials resulted in response rates ranging from 22% to 57%. Data indicates that women using Taxol experience improved quality of life. Until the FDA formally approves this drug for treatment of breast cancer, insurance companies can continue to deny coverage of it for this disease.

Book by Sherry Kohlenberg Published

Sherry Kohlenberg, co-founder of Virginia Breast Cancer Foundation finished an important book before her death last July. Sammy's Mommy Has Cancer an important book to help gently prepare children to deal with a parent with cancer. Illustrated by Lauri Crow, Sherry's full life with cancer is portrayed with a story that explains each challenge of cancer diagnosis and treatment. The book shows that the whole family shares the same feelings, and that they can cry and laugh together. Whether read by the family together, or by a child alone, the book is designed to offer a sense of safety and encouragement even in a very frightening time, without ignoring the realities of the situation. The book is published with 20 full color illustrations and is available in paper cover ($8.95) or hard cover ($16.95) versions. Copies can be ordered from Brunner/Mazel Publishers, 19 Union Square West, New York, NY 10003 or call 1-800-825-3089.
SHOULD WOMEN AGED 30-39 HAVE SCREENING MAMMOGRAMS?

Numerous studies have shown the value of mammography screening in women aged 50 and older, based on improved survival rates from breast cancer. There are a few studies showing that mammography benefits women aged 40 - 49, but there is only one study so far, the Breast Cancer Detection Demonstration Project (BCDDP), that has shown benefit for women below age 40. The now famous Canadian Breast Screening Study failed to show mortality reduction in a 7-year follow-up study of women 40-49. Other studies have just not included women under 40 in their studies, so no recommendations can be claimed for screening younger women based on available research.

Since the BCDDP results were published in 1987, breast cancer in young women seems to be increasing and the technical aspects of mammography have improved. Better quality films are more likely to show breast abnormalities in spite of the higher density of younger women's breast tissues. Lower doses of radiation make mammography safer than ever. These technical improvements provided reasons for researchers at the Sloan-Kettering Cancer Center to study 25,000 screening examinations on women up to 49 years of age between January 1989 and December 1991, and to make comparisons between women 35-39 and those 40-49. There were 5,100 screenings of women 35-39 out of the total 25,000.

If evidence of tumor was found by mammography, follow-up biopsy or other test (repeat mammogram in 4-6 months, sonogram, or coned views) was done to confirm or reject a diagnosis of breast cancer. There was found to be no statistically significant difference in detection rates between the two age groups at p=.05: 1.6 cancers were detected per 1,000 screenings of women 35-39 and 1.4 per 1,000 women 40-49.

This results of this study are similar to those of the BCDDP; however there were 134,000 women 35-39 in the BCDDP study instead of 5,000, and physical examination was used by BCDDP researchers to detect tumors, in addition to mammography.

Even though the American College of Radiology, the American Cancer Society, and 10 other organizations recommend that mammographic screening begin at age 40, the Sloan-Kettering study showed that breast cancer can be detected early in women 35-39 on screening mammograms. If the data from this study can be confirmed by other studies using a larger number of women 35-39, the earliest age at which screening is recommended may need to be revised.


TRIAL STUDIES HOT FLASHES

Postmenopausal women receiving tamoxifen therapy for breast cancer may be eligible for a study (URCC1190M) to assess the effect of clonidine on the hot flashes and related symptoms caused by tamoxifen. Eligible women will be randomized to receive clonidine or placebo, taking one tablet at bedtime by mouth daily for two months. Women will be expected to keep a diary recording the severity, frequency and duration of hot flashes and to complete several questionnaires. Participants also must agree not to take other medications for hot flashes during the study. For further information, contact Christopher E. Desch, M.D., principal investigator at the Medical College of Virginia Massey Cancer Center (804) 786-0450.

INSURANCE INFORMATION WANTED

VBCF needs to get liability insurance. If you know of anyone in this field who can help, please call the office.
(Patti Goodall submitted the following articles which appeared in the May 1993 issue of the Duke Cancer Report, published by Duke University Comprehensive Cancer Center.)

**Can Mental State Reduce Cancer Risk or Influence Cure?**

Much recent attention has focused on the notion that mental state can influence health. Books suggest that the right “mind set” can reduce the risk of cancer or influence its cure. A television series, “Healing and the Mind” and a subsequent book of the same name, while not dealing specifically with cancer, made similar suggestions.

One author suggested that professional athletes are better able to fight cancer because of their mental ability to concentrate on conditioning and physical tasks. Another invented a “Type C personality” said to be at higher cancer risk. At the same time, however, the author says Type C people may, “with blazing determination” and modified behavior patterns, overcome the disease.

TB and other diseases similarly were attributed to personality or emotions before their causes were found. Such ideas lack substantiation. Indeed, sound scientific research concludes to the contrary that there is no relationship between one’s mental state and cancer diagnosis or survival.

The belief that cancer can be controlled or cured by some mental capacity actually may be hurtful, causing patients to feel guilt or inadequacy for becoming cancer victims or for failing to bring about a cure.

Although links between body and mind are well-established, this does not extend to the ability to prevent or cure major diseases such as cancer.

(Note: Of interest to women diagnosed with breast cancer is the study conducted by Dr. David Spiegel of the Stanford School of Medicine in California which showed that women with metastatic disease who attended weekly support groups lived eighteen months longer than those who did not attend. Currently there are only anecdotal rather than scientific data which support the notion that an individual is capable of preventing or bringing about the cure of a life threatening disease. Perhaps the breast cancer establishment should consider this a viable direction for consumer-focused research in alternative treatments? PG)

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Duke University Researchers participated in an effort to find ways to reduce the discomfort of mammography. The resultant study shows that women suffer less pain when they themselves control breast compression. A total of 109 women each compared self- versus technician-controlled breast compression and 44% perceived a difference in pain levels. Of that subgroup, 71% described self-compression as significantly less painful. Earlier studies found that fear of pain kept many women from scheduling regular mammograms. With less pain, it is assumed, women will be more likely to obtain their annual mammograms. The self-compression technique is now used routinely at Duke.
SURVIVING THE LANGUAGE
OF BREAST CANCER

by Patti Goodall,
a woman diagnosed with breast cancer

The following news item in the Duke Cancer Report prompted me to think about the terminology that is used by and about women diagnosed with breast cancer:

“Virginia Kelley, President Bill Clinton’s mother, is one of many breast cancer survivors in the U.S. today. She was honored in March at a meeting of more than 300 people sponsored by the National Alliance of Breast Cancer Organizations in New York City.”

Unfortunately, Virginia Kelley died in January, three years after her initial diagnosis in 1990. Survivor? How can we identify a woman whose life was taken in three years by breast cancer as a survivor of the disease? According to my dictionary, to survive is to live or exist longer than or beyond the life or existence of; outlive; to continue to live after. Perhaps it would be more accurate to say that a woman is a survivor of a breast cancer diagnosis or that she survived breast cancer treatment - but a breast cancer survivor?

Many women truly do survive breast cancer. However, even if the immediate physical threat of cancer has been removed, we live the rest of our lives with the anxiety, however subtle, that the cancer may return to wreak havoc. Medical science is not yet able to say with 100% certainty that we are completely free of cancer or that it will not recur. Instead, we are described as being free of discernible disease or as having no observable symptoms.

I personally do not refer to myself as a breast cancer survivor. Not because I think I am doomed or because I have a negative mental attitude. I feel uncomfortable calling myself a survivor because the truth is, I do not know if I will be among the 50% who survive breast cancer or the 50% who will die from it. It is also a way for me to make a political statement. I believe that to call myself a survivor of breast cancer is to imply, wrongly, that I and many others are able to triumph over this disease through sheer determination and courage. Unfortunately, women often face two challenges following a breast cancer diagnosis: the disease itself and a “blame the victim” culture in which a woman’s winning mental attitude is expected to carry her to victory. If this were true, why are 46,000 of us dying from breast cancer every year? One of my closest friends, Sherry Kohlenberg, and I faced breast cancer together in 1990. We shared misgivings when people remarked that we were brave or courageous or had a great attitude. The truth is, like thousands of other women in our situation, we were angry and sad and afraid of dying. We both desperately wanted to survive the disease and watch our children grow, age gracefully with our husbands, and continue to enjoy our friendship. After undergoing three years of rigorous treatment, Sherry became one of the 46,000 women who died from breast cancer last year.

My own breast cancer diagnosis is three years old, but do not call me a survivor of this disease. Not unless I achieve a woman’s average life expectancy or die of something other than breast cancer or a breast cancer related disease. Call me a woman diagnosed with breast cancer. Or a woman living with breast cancer. Or a victim. I believe we must use the language surrounding breast cancer to assure that we do not euphemize or gloss over the devastation of this disease, but that we consciously and continually call attention to the increasing toll on women and their families: the fact is, 46,000 of us a year do NOT survive. All of us who face this disease struggle to live our lives as fully as we can, but only about 50% of us will truly survive breast cancer. Until all women can expect to survive this disease, I will use my words to express the anguish and anger of the thousands of women who have no chance.

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Surviving the Language... Cont'd

Alternative Terms

woman diagnosed with breast cancer
woman affected by breast cancer
woman living with breast cancer
survivor of breast cancer diagnosis
survivor of breast cancer treatment
individual challenged by breast cancer
breast cancer activist
breast cancer advocate
victim

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Thanks, we needed that! It's nice to get feedback like these recent comments from VBCF members:

"Every time I receive a Virginia Breast Cancer Foundation notice I think about what good work you are doing - you are making a difference!" -- Dr. Karen Rucker

"I am very proud of you. I remember the first meeting (of VBCF) and continue to be amazed with your energy and growth." - Frank Cowan

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It's Enough to Make You Sick:

...A recent study found 39 percent of all Latinos lack health insurance, a rate three time that of whites and nearly twice that of blacks...

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VBCF Leadership Holds Retreat

The end of January brought VBCF board members and committee chair together to prioritize activities for 1994. It was decided that our top priority was to increase membership. Filling vacant leadership and committee positions and participating in national activities were also high on the list. Of course, fundraising is always a priority. Because of the NBCC advocates conference in Washington in early May, and our own Legal Conference later in May, it was decided there would be no Mother's Day Event. National Survivors Day in June, a booth at the State Fair in September and participation in National October Events are planned for the balance of the year. This is, of course, in addition to the countless other education and outreach programs we’re invited to participate in throughout the year.

Another issue discussed was a proposal to break up the Tidewater District into two chapters. When we formed the organization, we recognized that as districts became more active, it would make sense to break them down into smaller groups. Because of the vast distance and the population density of the Tidewater region, it makes sense to break it down at this time. The two areas will be separated by Hampton Roads.

A small committee was also assembled to look at our organizational structure and review the bylaws for needed changes. If you have ideas for changes needed, give us a call or send a note to the VBCF office.

In the next newsletter you’ll see the details of our membership drive. We’ll be asking you to identify others who share our desire to see breast cancer eradicated. Why not start now?

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STAFF

Editor: Barbara Parker
Research Articles: Phyllis Tyzenhouse
Graphics: Karen Pfister
REVIEWING THE BASICS:

One of the things that has changed in recent years is the role the woman diagnosed with breast cancer has taken in her treatment. With books like those Dr. Susan Love and others have written, those newly diagnosed and those at high risk have become empowered to be more outspoken and take a greater role in making decisions about their treatments.

Many women are going further than the basics found in Dr. Love’s book. They find and inform their physicians of new research, new clinical trials and alternative therapies which show promise. This kind of partnership, while perhaps somewhat disconcerting at first to some physicians, can only make the treatment team stronger.

The availability of medical and scientific information has never been greater. Women taking an active role in assessing this information are retrieving it from libraries, on-line databases and sometimes directly from the principle investigator performing the research. Over the next year, VBCF plans to publish articles in this newsletter which are intended to help you access information, determine its value and analyze its applicability to you. We will offer explanations of research and clinical terms which may be used, review some of the basic principles of the scientific process and help you remember old, or understand new, vernacular.

Please give us feedback as to the value of this information to you, or contact the newsletter editor, Barbara Parker, with specific questions you would like to see addressed.

BASIC STEPS OF SCIENTIFIC RESEARCH
The steps in scientific research are:
a) specifying the topic 
b) reviewing the literature 
c) defining the variables to be measured
   - independent variables -- those that are 
     manipulated by the researcher
   - dependent variables -- those that are outcomes
d) developing a hypothesis -- “I will prove that... 
e) selecting a research strategy 
f) conducting the study 
g) analyzing the results, which involves
   - descriptive statistics -- those that are numerical measures
   - inferential statistics -- those that are used
   in judging the probability that the results are due to chance 
h) reporting the findings of the research

FROM THE EDITOR:

I sincerely regret the number of typos and other inaccuracies (including the January date and the information on the “upcoming” retreat) in the last newsletter. The corrected copy was stolen from Renee’s car and never made it to the typesetter. I do continue to try for accurate, timely information!

Speaking of typesetters, our welcome to Karen Pfister. We’re really pleased to have her help.

As always, Phyllis Tyzenhouse’s synopses are invaluable. If you have any topic that would be of particular interest to you, please call Phyllis or me.

We are desperately looking for a way to upgrade this newsletter. A year and a half ago I said that we would have a new, folded format soon. Well, it hasn’t happened yet, but that is still the goal! I have been hoping to find a way to have this offset print on 11 x 17 paper, collated and folded. The result will be a far more professional letter, one which we can use to demonstrate our level of professionalism as an organization. Financing is the problem. Offset printing costs far more than copying. If you know of someone who will print our newsletter for a very nominal charge (or even for free), please contact me.

Barbara Parker, 741-3807
LEGISLATIVE REPORT

STATE LEGISLATIVE NEWS

Report submitted by Margaret Borwhat

ABMT BILL PASSES HOUSE

Breast cancer advocates provided strong support of House Bill 240 sponsored by Delegate Mary Christian regarding autologous bone marrow transplants and stem cell transplants used in the treatment of breast cancer. At the time this newsletter goes to press, the bill had passed the House of Delegates by a vote of 97-1. The bill will then be considered by the Senate Committee on Education and Health.

If the bill is passed by the Senate, insurance companies licensed in Virginia must offer coverage for this procedure beginning January 1, 1995. Beginning July 1, 1994, insurance companies that do not already provide coverage for this procedure must make known to all those newly insured or those renewing their policy that this coverage is available to them at an additional charge. However, a previous diagnosis of breast cancer would preclude coverage. For those whose insurance companies already provide coverage for ABMT, no increased cost is anticipated. Some may be disappointed with the scope of this bill, but should remember that this is only a first step. We will keep you posted on future activities related to this issue.

OFF-LABEL DRUG USE BILL

Breast cancer advocates also supported Senate Bill 403, sponsored by Senator Clarence Holland, which provides insurance coverage of off-label uses of drugs for cancer treatments. “Off-label” drug use refers to instances in which drugs that have been proven safe and effective for some clinical conditions are used to treat conditions other than those indicated by the Food and Drug Administration. Once a drug is approved, physicians can use it in any medically appropriate way and not solely for “labeled” indication.

Thousands of cancer patients already receive chemotherapy, however they often can’t take advantage of new discoveries due to insurance company reimbursement practices. Senate Bill 403 prohibits insurance companies who provide coverage for drugs from denying payment under certain conditions for cancer drugs used in an “off-label” fashion. At the time this article goes to press, the bill had passed the Senate by a vote of 37-0 before going over to the House side of the General Assembly, where it will be considered by the House Committee for corporations, Insurance, and Banking.

NATIONAL LEGISLATIVE NEWS

Report submitted by Margaret Borwhat

On March 1, 1994 the National Breast Cancer Coalition (NBCC) scheduled a Congressional Visitation Day to educate our legislators about health care reform that addresses our needs. Stressed were the need for universal coverage and the elimination of pre-existing condition exclusions. I hope that many of you were able to participate.

On May 2 and 3, the NBCC is also sponsoring an Advocacy Conference in Washington which will include sessions on expanding grassroots organizations and network building and the fundamentals of breast cancer research. On Tuesday morning, May 3, there will be a breakfast to honor those who have championed breast cancer related issues. The conference will be held at the Georgetown University Conference Center, which includes hotel accommodations. Payment for the hotel room and a nominal fee for the conference is required. It is important that as many members attend as possible to enable us to be more informed

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National Legislative News... Cont'd

and effective advocates. Last year’s advocacy conference was a sell out. MARK YOUR CALENDARS! Please contact our Richmond VBCF office (285-1200) if you are interested in attending.

Secretary of Health and Human Resources, Donna Shalala, will soon be issuing the National Action Plan, which will present a comprehensive strategy to fight breast cancer. This was in response to our demand to President Clinton last October. We are very fortunate to have heard Mary Jo Kahn, a co-founder and former president of VBCF, who was an active member of the panel.

YOUR REACTION TO LEGISLATIVE AGENDA

We are reviewing our legislative efforts and need your feedback regarding our recent legislative activities. It is important that we hear from you as to what you thought was effective, what motivated you to action, what you think we could have done better, the reasons you did or did not get involved, and whether or not you supported an issue about which we informed you. Please write or call the VBCF office in Richmond (285-1200) with your opinions.

We truly appreciate all the efforts of our members and we are looking forward to next year’s state legislative efforts.

Margaret Borwah

OUR 1994 (FEDERAL FY ’95) LEGISLATIVE AGENDA

The President’s Cancer Panel Special Commission on Breast Cancer report stated that an appropriation level of $500 million per year would not be too much for breast cancer research. Certainly none of us will argue with that, though as behind as we are in research into the basics, more would be well utilized as well. In December, VBCF and NBCC voted to advocate for the following level of appropriations:

- National Cancer Institute Budget $496 million
- Other agencies $100 million
- Department of Defense Continuation $210 million

Totals appropriations for FY ’94 breast cancer research = $806 million

(“Other agencies” means that we would push for funding from a non-National Institute of Health agency budget, perhaps even EPA)

OTHER LEGISLATIVE ISSUES WHICH WE WILL ADDRESS:

- Support legislation to remove the current hiring freeze for those involved in breast cancer at both the National Cancer Institute and the Department of Defense.
- Support legislation to waive student loan debts for scientists, medical doctors and nurses who agree to do two years in research training and devote two years to breast cancer research.
- Support health care reform that will insure universal access to appropriate screenings and high quality treatment and care, will do away with pre-existing condition restrictions and will cover participation in clinical trials.
- Support legislation that will result from the National Action Plan on breast cancer (the plan that we asked for)!

As of now, the President’s FY ’95 budget request contains decreases in many programs, but for the National Institutes of Health, his budget includes an increase of $517 million or 4.7 percent over FY ’94 appropriations. Of this increase, $383 million is included for breast cancer; this is $84 million more than FY ’94, but about $113 million less than the figure for which we will advocate. We’ll have work to do!!!
**Outcome and Coverage**

In a study of New Jersey State Cancer Registry records, researchers found that rates of survival from breast cancer among patients with local and regional disease were lower for uninsured patients and patients with Medicaid coverage than for privately insured patients. Another study of women with stage II node-positive breast cancer showed that women without private insurance were only half as likely to receive chemotherapy as privately insured women, after adjustment for age and the presence of estrogen receptors in tumor tissue. These findings present a strong argument for healthcare reform.

**Health Care Reform:**

Health Care Reform goals that are shared by most legislation and programs being considered by Congress include:

* Universal Access: most require a date certain to achieve universal access to care.
* Lifetime Limits Prohibition: current maximum benefit limits would be removed.
* Pre-Existing Condition Exclusion: insurance programs would not be able to exclude or drop enrollees due to illness or high risk.
* Portability Guarantee: would allow individuals to carry their benefit package regardless of employment status, could continue access to same benefits.
* Community Rating: premium rates based on broad-based community rating rather than experience-based or cohorts.
* National Standardized Benefit Package: while these benefits vary and range from bare-bones to comprehensive coverage, there is agreement about having standardized packages developed at the national or state level.

**Hospitals Post High Profits and High Costs**

U.S. Hospitals posted their largest profits in four years in 1992, according to Baltimore-based Health Care Investment Analysts (HCIA). This largely was due to staffing level reductions and decreases in salary benefits and overhead expenses as a proportion of total operation expenses. As an industry, U.S. hospital profits increased for the third straight year in 1992, reaching 4.51% up from 3.76% in 1991. HCIA and Deloitte & Touche released the findings in their 1993 edition of Comparative Performance of U.S. Hospitals: The Sourcebook.

According to a recent study reported on by the New England Journal of Medicine, administrative costs in U.S. hospitals accounted for an average of 24.8% of each hospital’s spending in fiscal 1990. Costs ranged from a low of 20.5% in Minnesota to a high of 30.6% in Hawaii. U.S. hospitals administrative costs are nearly twice as high as those in Canada, researchers concluded. Data culled in the research came from hospital Medicare expense reports in such categories as nursing administration and central services (excluding the purchase cost of supplies).

**How Breast Cancer Coverage Looks Under Clinton’s Proposed Health Security Plan**

Medically necessary or appropriate care: Women of any age will receive clinical services, including clinical breast exams and mammograms at any time when they are medically necessary or appropriate with cost-sharing as specified by their plan.

Care for women at risk: Women of any age who are defined to be at risk of breast cancer by the National Health Board will receive additional visits, including clinical breast exams and mammograms at a schedule

*Continued on Page 17*
How Breast Cancer Looks... Cont’d

- Care for all women: All women receive regular clinician visits, including clinical breast exams, every three years from age 20-39 and every two years from age 40-64 with no cost-sharing. All women will also receive routine screening mammograms every two years, beginning at age 50, with no cost-sharing.

The National Breast Cancer Coalition has taken a strong position in support of health care reform. Their priorities in a plan are universal coverage and elimination of pre-existing conditions exclusions.

SERVICES DONATED:
MANY THANKS

Mr. Ron Stenzel, President of Leadership Dynamics, located in Williamsburg, facilitated our January retreat free of charge.

Mr. Richard O’Hare, President of The Risk Management Center, Inc., located in Powhatan, gave VBCF free counseling on insurance and coverage.

Ms. Mollie Picon and Beth Edelstein, from the Hadassah, gave their time and interest.

Beth Oaks and the staff at the Roslyn Center provided wonderful service for our retreat.

ENVIRONMENTAL ISSUES

Pesticides

Were you aware that pesticides manufactured in this country for export are not required to be registered with the Food and Drug Administration (FDA) or the Agriculture Department (USDA)? And, pesticides which are banned for use in the United States can be exported to other countries. FDA and USDA perform very limited testing of produce imported from other countries which may have been treated with banned or unregistered chemicals. According to a GAO report, since manufacturers of unregistered pesticides are not required to provide reference standards and test methods, the lack of timely and complete data on exported unregistered pesticides prevents USDA from testing imported foods. Further, FDA’s current sources of information are inadequate to identify new pesticides promptly.

EPA: Problems Keeping Up

Because toxic chemicals are in such widespread use today, nearly every American’s body contains traces of toxic chemicals as a result of skin absorption or other environmental exposure, says a GAO report in November. Some of the chemicals, such as asbestos, PCPs, and ozone-depleting chemicals, have been found to cause tumors and birth defects as well as to harm wildlife. The Environmental Protection Agency (EPA) is responsible for identifying, assessing, and regulating the risks posed by the approximately 72,000 chemicals in commercial use as well as chemicals proposed for manufacture. The GAO study found that EPA’s information system needs improvement to be able to keep up with chemicals posing the greatest risk to human health and the environment.
MEMBER PROFILE:
VIVIAN & BILL PHILLIPS

Submitted by Kendra McCarthy

It was literally an accident that brought Vivian and Bill together. They didn't let their vehicles keep them separated for long, as they were married a few years later. They've been married 22 years now; Bill's forgiven her for the accident and Vivian has forgiven him for everything else!

Born and raised about 15 miles from each other, their birth home is North Carolina -- readily believed when you hear Vivian's soft southern drawl. Up until the accident, Vivian had planned to leave country life for New York or Chicago. Instead, she prepared for business and went to work in Fieldcrest Mills, while Bill worked for Burlington Industries and served in the National Guard.

Bill worked on his first computer in 1978; at the same time he was getting his pilot's license. He's currently in charge of electrical process control and instrumentation systems for Anheuser-Busch in Williamsburg. Vivian concentrated on raising their two boys, one of whom has now left the nest; the other is still at home, being 16 and publishing his own comic book.

Diagnosed in August of 1991, at the age of 39 and with her fourth surgical biopsy, Vivian says that after problems and biopsies for 6 years she still wasn't expecting to have breast cancer; she never quite believed it would happen to her. Vivian went to look at prosthesis and bras about a week before her mastectomy. It was actually going and seeing what she would be using to fill her bra after her surgery that made reality set in. She went to the park and cried.

Vivian is best known as the member most likely to grab a senator (Chuck Robb will never forget her!) when exiting an elevator in the Russell Building. Her sweet voice and gentle smile disarms and gets our message across with a humanistic approach. Her secret? Her genuine caring for people.

Vivian wants to see VBCF educate every Virginian about breast cancer. As a very active member of the Legislative and Influence Committee, she certainly is doing her part!

In addition to participating in our visits to Washington and attending committee meetings, Bill solves the foundation's computer challenges. He's not only involved; he's committed. He wants to see VBCF be a leader among the grassroots organizations and he is particularly concerned about getting our message through to minority groups.

Vivian and Bill are members living in Williamsburg, located in our Tidewater district. They are a great team and a valuable part of our advocacy effort.

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LUNCHEON* FASHION SHOW* JEWELRY SHOW FUNDRAISER

WHEN: MARCH 12, 1994
WHERE: RADISSON HOTEL, HAMPTON, VIRGINIA
COST: $15 PER PERSON
TIME: 11 AM TO 2 PM

For ticket information call: Ann at 380-8500 or 800-296-5053 or Jean at 868-7018. Please make your plans now to attend!!!

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TELEPHONE SURVEY

Penn & Schoen Associates, Inc., a national market research company, is conducting a telephone survey on Women's Health Issues with women who have or have had breast cancer. They are interested in hearing your opinions and concerns. Your responses will be used as part of a national study among women. All responses will be confidential and used for professional research purposes only. If you would like to participate, please call 1-800-275-3625.
NORTHERN VIRGINIA
DISTRICT NEWS

Submitted by Jean Hoshall

The Northern Virginia district kicked off the new year with a membership meeting on January 15. The meeting’s theme, “Where We Were and Where We're Going”, was reinforced with a 1993 wrap-up and 1994 future report by district coordinator Domicella Rieder. Lyn Carroll, VBCF board member and member of the NBCC, reported on the HHS breast and cervical cancer national planning initiative. Domicella reports that we added five new members!

On June 4, we will participate for the second time in the Arlington Hospital/ American Cancer Society’s annual Breast Cancer Awareness workshop and seminar. Coordinated by Kathy Dorner, staff member at Arlington Hospital and member of VBCF, the workshop has become a prototype for cancer workshops. It was one of the first to feature not only the “experts”, but survivors and their families. Now in its fifth year, the event attracts several hundred attendees. We encourage you to mark your calendars and try to attend this event.

Many of our district members have been lobbying with the Foundation on state legislation. In a recent conversation with district member Mary Dickinson, she reminded us that it is important to thank those who have supported our positions. After Senator Warner so strongly supported funding for breast cancer research, she called his office to thank him. His staff told her that these calls are particularly important, as the Senator frequently hears only from those who oppose his positions. If you cannot make a call, drop a card note or postcard in the mail.

Hats off to member Gail Kurkjian, who was featured in the lead article “Getting On and Beyond”, in the November issue of Life With Cancer’s The Connection.

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TIDEWATER DISTRICT NEWS

Submitted by Susan Fincke

VBCF members from Virginia Beach and Norfolk took part in the Hampton Roads Woman’s Show. Held at the Virginia Beach Pavilion February 4 - 7, the show featured a variety of businesses and organizations of interest to women. Volunteers staffed the booth all weekend, distributing pink ribbons, information on breast cancer and VBCF. Thanks to Katie Byrnes for organizing the volunteers: Susan Fincke, Alice Johnson, Pat Phelan, Ruth Kroskin, Kathleen Baker, Verna Carroll, Corina Zalles, Barbara Stehlik, Susan Smith, Francis Swoop, Rita Lopane, Marilyn Wokeman, Debra Goff, Jim Goff, Ruth Duncan, Pat Augenbaugh, and Karen McClain. In addition, Nancy Schreier and Alice Johnson participated in a panel presentation.

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PENINSULA CHAPTER NEWS

Submitted by Ann H. Wilson

The first official meeting of the Peninsula Chapter was held on February 8, 1994 with 12 members in attendance. We elected the following officers: Chapter Chairman: Ann Wilson; Vice-Chairman: Angela Smith; Secretary: Diane Beilharz; Treasurer: Jean Minor; Public Education Coordinator: Anne T. Wilson; Legislative Coordinator: Vivian Phillips; and Membership Coordinator: Judy Remsberg. Our major topics were increasing membership, public education and fund raising.

Our chapter is busy helping with the Fashion Show/ Luncheon/Jewelry Auction fund raiser to be held March 12, 1994 at the Radisson Hotel in Hampton, Va. For ticket information for this event, call Peninsula #380-8500. Outside Peninsula call 800-296-5053 and ask for Ann. Also, we will have an educational booth in the Mary Immaculate Hospital Health Fair on March 12, 1994 from 10 am to 4 pm.
VIRGINIA BREAST CANCER FOUNDATION CALENDAR OF EVENTS

Activity

Date

May 20
May 20-21
May 17
May 3
May 2
May 1
April 30
April 21-24
April 9
March 22
March 21
March 20
March 18

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