BREAST CANCER IN YOUNGER WOMEN
By Phyllis Tyrenhouse

An important conference on Breast Cancer in Younger Women was held in Bethesda, Maryland, January 1993, to discuss issues of breast cancer that affect women under age 50. Until recently, most knowledge about breast cancer was based on studies of women over 50 because most of the breast cancer cases occur in this population. The goal of the conference was to develop an agenda for future research based on papers presented at the conference and to reach conclusions about the best methods of prevention, detection, and treatment for younger patients. The papers were published in a monograph, cited below. Due to space constraints, I have excerpted portions of some of the papers and invite readers to seek out the monograph itself.

First, a few statistics. The Surveillance, Epidemiology, and End Results Program (SEER) and the National Center for Health Statistics (NCHS) compared data from women aged 20-39 between 1973-1989 with those from older women. Only about 7% of breast cancers occur by age 40 and the risk of developing it has remained fairly stable at less than 1%. However, the incidence rates for women over 40 increased steeply during the 1980s, faster than expected from recent trends. Although the disease tends to occur mainly in older women, it can produce devastating personal and financial consequences for premenopausal women and their families. Survival time after diagnosis for breast cancer was shown to be shorter for younger women, and particularly for younger black women. This finding points to

(continued on page 5, column 2)

UPDATE: SECRETARY SHALALA'S NATIONAL ACTION PLAN ON BREAST CANCER

The National Action Plan on Breast Cancer has been written and adopted by the Co-chairs Committee. Copies can be obtained from the Office of Women's Health, Dept. of Health and Human Services, Humphrey Building, Washington, D.C., 20201 (202-690-7650). Efforts are currently underway to begin implementation of the plan. All government department heads have been given a copy of the Action Plan with instructions to implement all recommendations as soon as possible.

In June, the Co-chairs of the National Action Plan on Breast Cancer met in Washington to select five areas that were felt to be of the highest priority. The Co-chairs were unable to decide between the fifth and sixth area and voted to include both. Co-leaders for the Working Groups were selected, pairing a government employee with a member from the private sector in order to continue the public/private partnership encouraged in the National Plan. The Working Groups were to make a concerted effort to have a well rounded and comprehensive Working Group in place before work was begun. Creative new approaches to problems were emphasized.

The following is a list of the six priority areas.

1. "Information Superhighway": Set up an "Industry Action Council" to disseminate information about breast
President’s Message: Why the DOD?
From Kendra McCarthy

By now you may have heard that the Department of Defense (DOD) FY’95 appropriation includes $160 million for continuation of the breast cancer research begun in 1993. While the project is appropriated $50 million less than the seed funding provided in FY’93, the FY’95 level is more than the $60 million Senate proposed funding originally intended. This is a direct result of a nation wide expression of concern and support by women with breast cancer and those who care for and about them; a genuine example of the democratic process in action.

Throughout the process of educating Virginians about the need for this funding, I sporadically heard that perhaps we should not be seeking any DOD funding for breast cancer research. Virginia's economy, particularly in Northern Virginia and Tidewater, is heavily dependent upon DOD funding, which is already reduced significantly. And, the critics continued, we should not be sacrificing national defense to find a cure for a woman’s disease.

Why not DOD? After all, other military personnel, dependent and veteran health funding is provided through the DOD appropriation. And, aren't there millions of female veterans, dependents and service spouses who are at risk of, or in treatment for breast cancer? In 1990 4.5 percent of all veterans were women—over 1.2 million women. That is a potential of at least 150,000 breast cancer cases. And, by 2040 the percentage of women veterans will expand about 2-1/2 times to 11%.

Is breast cancer merely a domestic disease? Is there something that makes the woman attached to the military immune? Not at all! In fact, according to a 1992 GAO study, women veterans experience an "unusually high incidence" of cancer, including cancer of the breast. A study conducted by Louis Harris and Associates in 1985 showed that the lifetime prevalence of breast cancer among women veterans is nearly twice the rate of that in the total population of adult women. Another study in 1989 by the Bay Pines VA Medical Center showed that nearly 50 percent of the 115 women included in their survey had personal histories of cancer. If the military becomes increasingly dependent upon women in the ranks, doesn't it make sense to have these women unthreatened by breast cancer? And, can't today's research dollars be considered an investment to avoid the negative DOD budget impact that would result from high cost of breast cancer treatment for military women in the future?

Let's get the funding in perspective too. Of the $243.4 billion FY’95 DOD appropriation, only $160 million is earmarked for breast cancer research. That’s less than one one-hundredth of one percent of the DOD budget, actually .0066%!

Most military leaders will tell you that defense is not about guns and rockets. It is about the troops. The troops consist of brave men and women who go into or support the battle, and the spouses and dependents who love and support their effort. Isn't it every bit as important to research the diseases that threaten the people-power as much as researching new methods of fire-power? Absolutely!

SAMMY’S MOMMY HAS CANCER WINS AWARD

The late Sherry Kohlenberg's book, Sammy's Mommy Has Cancer was selected as a recipient of the 1994 Rose Kushner Award in the book category. Elizabeth Smith, Chairperson of this year's award, says "Her book, given the highest ratings in that category, has made a significant contribution to the public and professional awareness of breast cancer".

Sherry's husband Larry and their son Sammy flew out to Phoenix, Arizona to accept the award at a luncheon on November 4, 1994.

Alternatives:

The FDA is expected to approve the use of acupuncture needles as medical devices soon. 29 states have legalized the use of acupuncture, but the FDA has only approved experimental use. Thus, insurers do not usually cover the cost of this alternative treatment, which has been used for pain control, stress relief and other cancer related symptoms and side effects. The FDA approval will increase chances of insurance coverage.

ANOTHER LOOK AT FOOD PRESERVATIVES—BANE OR BLESSING?

Advocates of natural and organically-grown foods have long advised against the use of artificial preservatives. Now comes Dr. Andrew Dannenberg of Cornell Medical College who found that BHA and BHT increase (continued on page 3, column 1)
ANOTHER LOOK AT FOOD PRESERVATIVES
(continued from page 2)

the levels of an enzyme that helps destroy carcinogens before they can trigger tumors. The genes produce more of the enzyme, which protects against cancer-causing substances in the environment. The enzyme, UDP-glucuronosyltransferase or UGT, may be the substance that gives cruciferous vegetables, broccoli, cauliflower, and brussels sprouts, their anti-cancer properties.

Dr. Dannenberg cautioned that the findings do not support adding more of the preservative to foods. Among the commercially available foods containing BHA and BHT are cookies and crackers. He and Dr. Walter Willett, an authority on nutrition and cancer at the Harvard School of Public Health, urge that people eat more of the cruciferous vegetables, as well as spinach, kale, and collards, which are rich in folic acid, another potent anti-cancer fighter.

Dr. Lee Wattenberg of the University of Minnesota is conducting more than 20 studies of diet and cancer, including studies of vitamin A and retinoids. According to Dr. Wattenberg, those studies may show that such feared diseases as breast cancer are preventable. (PT)


ONLY HALF OF OLDER WOMEN ARE GETTING MAMMOGRAMS

Although most of the cases of breast cancer occur in women over age 50, only half of women aged 50-64 reported having a mammogram during 1992; 61% said they had obtained a clinical breast exam, and 53% obtained a Pap test. The percent of women reporting each of these procedures was lowest for uninsured women and highest for women enrolled in HMOs: only 19% of uninsured women reported having mammograms and 38% said they had clinical breast exams. Donna Shalala, US Secretary of Health and Human Services, commented, “These preventive services are known to be of the highest importance in detecting breast and cervical cancer. It is unacceptable that so few women are receiving these services at appropriate times.”

As an added note, the American Cancer Society and other cancer groups, recommend that women over age 50 have annual mammograms. Yet Medicare reimburses only 80% of their approved cost of mammograms every two years. The discrepancy between the recommended frequency of mammograms for older women and Medicare’s reimbursement policy was pointed out at a recent meeting of State Medicare Medical Directors and the Health Care Financing Administration (HCFA), that oversees Medicare. HCFA officials said that they could not consider increasing the frequency of coverage, even for women at high risk, since the level of claims submitted for the biennial mammograms is so low (19% of all beneficiaries). It is imperative that organizations concerned with women’s health urge women to use this important benefit. (PT)

USDHS, CDC, Advance Data, No. 252, August 3, 1994: 1-9; and E. David Perez, MD, Medical Director, Travelers Medicare, Richmond, VA.

About Our Mailing List:

We occasionally receive correspondence from members concerned that we sell or give away our membership list. It is the policy of VBCF to hold our membership list in strict confidence. When legitimate breast cancer organizations have asked to use our mailing list, we have denied the request, or we have included their information with our normal distribution of the newsletter. The only exception to this policy is when we have learned from members that they wish to be invited to special functions. An example of this is a recent press conference with Governor and Mrs. Allen. Only board members, district chairs and officers obtain copies of our mailing list for communication purposes. Each is instructed to protect it as highly confidential. If you feel that information about you has been released, please contact us so that we can look into the incidence.
Breast Cancer Detection: A Blood Test in Development

An Israeli research organization, Medis El, Ltd., is currently developing and performing clinical trials on CellScan, which is a diagnostic system to screen for and detect breast cancer by means of a blood test. The CellScan System, as used for breast disease diagnosis, is designed to provide increased medical efficacy and broader availability at a lower effective cost than existing methods of detection, including mammography. CellScan is also used in cell biology and for the detection of other forms of cancer.

LEUKEMIA SECONDARY TO BREAST CANCER TREATMENT IS UNDER INVESTIGATION

The breast cancer study, B-25, conducted by the NSABP, enrolled 2,548 women between April 1992 and February 1994 into an RCT to prevent cancer recurrence. The study subjects are women with breast cancers that had invaded axillary lymph nodes, who had no post-surgical treatment, and who had significant risk of breast-cancer recurrence. All of the women were given doxorubicin (Adriamycin) and cyclophosphamide (Cytoxan) and women over 50 also received standard tamoxifen. In addition, all women received a blood growth-factor, G-CSF, intended to reduce the toxicity of the chemotherapy. The women in the study received higher than standard doses of chemotherapy. Current standard chemotherapy calls for Adriamycin and Cytoxan at lower doses than those given in the RCT. A large body of scientific evidence supports dose-intensive or high dose regimens because of greater anti-cancer effects than the standard doses.

Careful monitoring of the study subjects revealed that, as of July 26, 1994, five cases of acute myeloid leukemia (AML) occurred, secondary to the Cytoxan given at two to four times the standard dose. This finding was reported promptly to the National Cancer Institute (NCI), who issued a press release on July 29, 1994. The five cases represent a 0.2% rate of AML occurrence in the study population, and it has not been determined what the precise risk of secondary AML is in high-dose treatment or what benefit can be expected from the treatment. Bruce Chabner, MD, Director of NCI’s Division of Cancer Treatment commented, “In all cancer treatments, there is a balance between benefits and risks. Given the therapeutic benefit that may result from dose-intensive therapy, we need to weigh that benefit against a possible increased risk of secondary AML, and this is what we are now carefully monitoring and evaluating.”

In this situation, the investigators acted responsibly by reporting the effects of treatment so that action steps could be taken. The NCI called a meeting of scientists, FDA representatives, patient advocacy groups, and pharmaceutical representatives. One of the participants in the meeting, Deborah Collyar, a board member of Breast Cancer Action, said, “The meeting today is a step in the right direction. It shows the medical community is starting to address the changes that need to be made by including advocate participation.”

As a result of the meeting, a monitoring plan was developed that called for:
- A review to ensure that the informed consent procedure is adequate in every NCI-funded RCT that involves similar chemotherapeutic agents.
- A requirement that all NCI-supported investigators report to the NCI within 30 days of diagnosis any cases of AML that occur in studies of other cancers.
- Development of a monitoring plan to expeditiously obtain reliable estimates of the risk of secondary AML following regimens of dose-intensive chemotherapies. (PT)


SELECTED NSABP TRIALS HAVE BEEN REOPENED

Three randomized clinical trials (RCTs) of the National Surgical Adjuvant Breast and Bowel Project (NSABP) have reopened at selected research sites. The first, NSABP-B-23, is a trial to compare two regimens of adjuvant chemotherapy for patients with node-negative, estrogen-receptor negative breast cancer, one therapy with tamoxifen and one without. The second trial, NSABP-R-03, is an RCT of preoperative versus postoperative radiation and chemotherapy for operable rectal cancer. The third RCT, NSABP-B-26, compares high dose paclitaxel (Taxol) as a 3-hour versus 24-hour infusion for metastatic or locally advanced breast cancer.

Only selected sites approved by the National Cancer Institute (NCI) are allowed to accrue patients into these trials and the lists of approved institutions change constantly. As of mid-August, no accrual sites had been announced for NSABP-B-26 because the protocol was being amended.

A fourth RCT, the Breast Cancer Prevention Trial (BCPT), also coordinated by NSABP, was opened at sc-
NSABP Trials (continued from page 4)  
lected accrual sites for assessment of risk only and not for treatment. When the NCI and FDA (Food and Drug Administration) approve a revised protocol, randomization of women into treatment groups will be resumed. The two treatments being studied are tamoxifen and placebo. (PT)

Source: National Cancer Institute, CancerNet News, 9/94.

Informed Consent in Clinical Research: A Debate Emerges

By Kendra McCarthy

Institutional review boards (IRBs) are authorized by the government to review research protocols, weighing the costs, risks and benefits of proposed research. The fact that IRBs are local makes them highly subjective and sometimes liable to produce differing decisions, even when considering similar research. Depending on the project, IRBs sometimes waive informed consent rules if certain criteria are met. Recently, questions have been raised about whether IRBs have enough justification when they waive the requirement for informed consent. As a result of such questions, some studies are delayed or closed down by the federal organizations that regulate medical research: the Food and Drug Administration (FDA) and the National Institutes of Health (NIH) as well as the NIH Office for Protection from Research Risk (OPPR).

Fears have surfaced that consent is being sacrificed by certain IRBs that are overly anxious to bring in research dollars. As more consumers take charge of their medical treatment, they become alarmed that they were not informed of all of the choices and consequences involved in the experimental treatments they received. An example of this is experimental chemotherapy for young breast cancer patients which results in premature menopause. Some legislators have begun to call for better informed consent regulations for IRBs and researchers. Requests have also been made that IRBs include more non-medical members, so that they can’t be outnumbered and swayed by physician majorities. Breast cancer consumers and advocates are among those asking for positions on IRBs.

Researchers believe that both the NIH and FDA informed consent requirements are ambiguous. When an IRB approves a project, it may meet the NIH rules, but not the FDA’s. NIH and FDA officials have promised to meet this year to review their regulations and make them more clear for IRBs, researchers and hospitals.

NIH allows informed consent to be waived in the testing of unapproved drugs and devices if they determine that the project is of minimal risk, it won’t adversely affect the rights and welfare of the patient, the research could not be practically carried out without the waiver of informed consent and, when appropriate, the research subjects will be given additional pertinent information about their participation. The FDA allows untested treatment only if all alternatives that might save a patient’s life have been exhausted.

The basis of informed consent should be clear communication between the patient and the clinician, yet this doesn’t always happen. So most have begun to think of informed consent as a protection for the practitioner rather than a process of documenting the informed decision making for the patient.

Reports of reams of paper presented to breast cancer patients minutes before surgery cause significant concern. Consent forms replete with medical terms for possible unfavorable outcomes or potential side effects are not the answer. Harnessing the scientist with elaborate patient education processes could paralyze the research so urgently needed by breast cancer patients. Science is progressing faster than we can anticipate consequences and needed protective legislation.

Change is imperative, and at least three elements are required to resolve the debate: an equal partnership between the researcher and the patient, both in the clinical environment and in the IRB process; a genuine and appropriately timed communication between the practitioner and the patient; a commitment by the patient to being informed and taking charge of her own healthcare and a scientist who empowers her to do so. Our role, as advocates, is to make certain these elements become a reality.

BREAST CANCER IN YOUNGER WOMEN

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the need for research to study differences in response to treatment according to age and race, to compare the effects of hormonal status, metabolism, or co-morbid conditions on treatment outcomes.

A startling finding showed that breast cancer patients, aged 20-29 at first diagnosis, were at significantly higher risk of developing a second invasive cancer of the breast, ovary, and lung. Leukemias were found in excess, but these have been shown to be related to radiotherapy and chemotherapy. (See “Leukemia Secondary to Breast Cancer Treatment is Under Investigation” in this issue.) The risk of developing a second invasive cancer was especially high during the first year following diagnosis and decreased with (continued on page 6, column 1)
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(continued from page 5)

age and time. Younger age at diagnosis is associated with poorer outcome of treatment for breast cancer.

Risk factors for breast cancer were found to differ from those for postmenopausal women. Race is a potent risk factor among women under age 40, and the risk is twice as high for black women under 40 as for white women. However, the excess risk for black women under 40 was seen only in higher socioeconomic groups, and excess risk for white women under 40 was seen only in the lower socioeconomic groups. This difference in risk could not be explained. Race (black compared with white), parity, and large body size are associated with greater risk in younger women, but tend to be reversed among women over 40.

One of the studies showed that younger patients presented with more advanced-stage disease than older patients. One of the factors associated with this finding was thought to be the fact that breast tissue in younger women is frequently dense and difficult to evaluate either by mammography or clinical exam. Cyclic hormone changes contribute to the thickening and nodularity of the breast tissues. This observation calls attention to the need to discover more precise screening procedures, especially for younger women.

Young women who develop estrogen deficiency following breast-cancer treatment (surgery, chemotherapy, or radiotherapy) are at increased risk for developing osteoporosis and cardiovascular disease later in life. A majority of these women are advised against estrogen replacement therapy due to concern that estrogen may promote growth of breast cancer. This concern was never substantiated in any clinical trial, so two researchers at the M.D. Anderson Cancer Center began a small randomized clinical trial in 1992 to test outcomes of administering 0.625 mg of Premarin for 25 days a month to one group and no Premarin or other medication to the control group. Both groups will be under close medical supervision for 5 years. Results of their study may well have an impact on decisions about prescribing estrogen replacement therapy for young post-treatment patients.

Several papers addressed the psychosocial and survival issues of breast cancer in younger women who have either had treatment for breast cancer, who are at increased risk for this disease, have altered body image, or impaired psychosocial functioning. In some cases, women who do not adhere to mammography recommendations or who perform breast self-examination infrequently or excessively, experienced psychological distress. These topics have not been studied, and the need for research was highlighted. One concern was that some women, aged 29 and younger, perceived their risk to be above average, and even women with family histories of breast cancer were found to overestimate their risks. Women who were treated with conservative breast cancer treatment were found to rate their body image higher than women who had mastectomies, but there was no difference in general psychological distress, marital satisfaction, and overall sexual function between the two groups. Studies of who is most at risk for psychosocial problems, timing for counseling, and counseling for women at risk for breast cancer were recommended.

Monographs, Journal of the National Cancer Institute, Number 16, 1994, passim.

UPDATE: SEC. SHALALA'S ACTION PLAN
(continued from page 1)
cancer and breast health to scientists, consumers, and practitioners in order to promote better prevention, detection, diagnosis, and treatment of breast cancer.

Co-Chairs: Kay Dickersin, Ph.D., Univ. of Maryland
Col. Irene Rich, DOD

2. Establish comprehensive patient data registries and materials banks as research tools.
   Co-Chairs: Susan Love, M.D., UCLA
               Alan Rabson, M.D., NCI

3. Ensure consumer input at all levels in the development of public health programs, research studies, and clinical trials. Involve advocacy groups and women with breast cancer in setting research priorities, and in patient education.
   Co-Chairs: Jane Reese-Coulbourne, M.S., M.B.A.,
              NBCC
              Janny Hedetiemi, NIH

4. Expand the scope and breadth of biomedical and behavioral research activities related to the etiology of breast cancer.
   Co-Chairs: Nancy Evans, Breast Cancer Action,
              San Francisco
              Susan Sieber, Ph.D., NCI

5. Make clinical trials more widely available to women with breast cancer and women who are at risk for breast cancer. Decrease barriers to participation through consumer-clinician dialogue, reduction of economic barriers, and other strategies.
   Co-Chairs: Zora Brown, BCRC
              Leslie Ford, M.D., NCI

6. Implement a comprehensive plan to address the needs of individuals carrying breast cancer susceptibility gene(s).
   Co-Chairs: Mary Jo Ellis Kahn, R.N., M.S.N.
              Francis Collins, M.D., Ph.D., NCHGR
   Co-chairs will meet with Secretary Shalala again in December or January. Action steps and budget requests for these
SHALALA'S ACTION PLAN (continued from page 6) priority areas will be presented at that time.

Any members who wish more information on the National Action Plan on Breast Cancer or who wish to have input into the process of the plan please contact, Mary Jo Kahn. She can be reached through the office of the VBCF.

MAMMOGRAPHY QUALITY STANDARDS ACT NOW IN EFFECT

By Phyllis Tyzenhouse

The Mammography Quality Standards Act (MQSA) became law on October 1, 1994. Public Law 102-539, passed by Congress October 27, 1992, requires all mammography facilities in the United States, except those of the Department of Veterans’ Affairs, to be certified by the Food and Drug Administration (FDA) in order to operate lawfully. The FDA will issue certificates to qualified agencies, but each facility must apply to an FDA-approved private non-profit or state accreditation body to determine if the facility has met MQSA requirements. The FDA will not perform the on-site inspections. So far, the FDA has approved the American College of Radiology (ACR), Osteopathic Board of Radiology, the Royal College of Physicians and Surgeons of Canada, and the states of Arkansas, California, and Iowa as accrediting bodies. Other states may be added later.

To be accredited, the facility must undergo periodic review of its radiographic images, be surveyed annually by a medical physicist, and meet federally-developed quality standards for personnel qualifications, quality assurance programs, and record keeping and reporting. The following personnel must be accredited: physicians who interpret mammographic images, radiologic technicians who perform mammographic procedures, and medical physicists who survey mammography equipment. Only federally-trained and certified federal or state personnel may conduct the inspections.

In order to facilitate meeting the October 1, 1994 deadline, Congress gave the FDA authority to issue interim certificates to facilities already accredited by private non-profit organizations or state agencies whose existing accreditation programs substantially meet the requirements outlined in the interim standards published in the December 21, 1993 Federal Register.

The FDA is training between 250-330 inspectors, divided among six regions of the United States. Virginia is in the Mid-Atlantic region with headquarters in Baltimore. Inspectors will begin after October 1, 1994, at a cost to each facility of $1,392. If a facility meets the standards, it will receive a certificate that must be prominently displayed, stating that it is a certified mammography facility. The certificate, issued for three years, permits the facility to advertise that it has been FDA certified, not FDA approved. Spanish-language certificates are available. Civil money penalties may be imposed on facilities that fail to obtain a certificate as required or for failure to comply with the standards.

Until now, mammography facilities were not required by federal law to be accredited; ACR accreditation was voluntary, and the individual states were responsible for any standards they wished to impose within their jurisdictions. The Health Care Financing Administration (HCFA) introduced regulations applicable to reimbursement of Medicare beneficiaries for mammograms. Now uniform standards will be in effect across the United States, offering assurance to women that their mammograms will be produced and interpreted competently.

Sources: “FDA’s Mammography Program”, April 29, 1994; Mammography Matters, FDA/CDRH, Summer 1994; Public Law 102-539; Federal Register, December 21, 1993, Part VII.

Bovine Growth Hormone

Many states are passing legislation or creating policies eliminating or restricting the use of milk products that comes from cows given bovine growth stimulating hormones (bST). Any synthetic manipulation of our food chain has potential dangers. While the FDA has researched this product and allowed it to be used, there is some concern that a growth stimulating hormone could have an influence on our hormone systems. Since hormones play a great role in the development of breast cancer, use of the bST hormone is of concern to us.

Many states are requiring milk products to be labeled if they come from a source treated with bST. Vermont law says dairy labels must show whether milk is bST free, and in Maine, only milk from untreated cows may be given a quality seal. Wisconsin has been successful in keeping bST milk out of the public school systems. We are looking for a VBCF volunteer who would like to research this issue and make recommendations about what is done in Virginia. Call the VBCF office if this is an area of interest.
NEW TESTS FOR BREAST CANCER ON THE HORIZON

Although mammography can lead to reduction in breast-cancer mortality rates by 30% in women over 50, the technology is 40 years old and not at all perfect. Now military technology, developed during the cold war to spot missiles and camouflaged enemy trucks, is being developed to improve imaging techniques for analyzing mammograms. The system, so precise that it can help eliminate false positives, is being developed by defense contractor, Martin Marietta (now Lockheed Martin). The project would keep costs down by allowing regional centers to electronically evaluate mammograms sent in from mammography sites in the area. This was announced at a briefing sponsored by the Office of Women's Health in the DHHS by Dr. Susan J. Blumenthal, Deputy Assistant Secretary for Women's Health and Assistant Surgeon General, but it will not be in use for about four more years.

Other researchers are at work perfecting a simple test that will find clonal markers for cancer in the DNA of a patient’s body fluids. Clonal markers, or repetitive genetic errors, would be used to detect the presence of cancer in different organs, including the breast. For some cancers, sputum, urine, or blood would be examined, but several drops of fluid might have to be drawn from the breasts to check for breast cancer. This would require the use of a breast pump. So far, researchers at John Hopkins have not pinpointed the exact markers for the cancers, but predict that such a test could replace the use of mammography some day. (PT)


RACIAL DIFFERENCES IN BREAST CANCER SURVIVAL
By Phyllis Tyzenhouse

Once diagnosed, black women had twice the risk of dying from breast cancer, compared with white women, in a study of 1130 women in three cities. Five years after diagnosis, 62% of black women and 79% of white women were still alive. The women studied were aged 20 to 79, living in metropolitan Atlanta, New Orleans, and San Francisco-Oakland, and diagnosed with primary invasive breast cancer.

Based on the study, several variables, not related to treatment, were linked to poorer survival of the black women, and they can be considered predictors of mortality. Factors associated with race were:

- More advanced stage of disease at time of diagnosis: 30% of black women presented with larger tumors and a larger number of positive axillary lymph nodes, compared with 17% of whites.
- Black women were more apt to have tumors that were poorly differentiated and that were estrogen-receptor negative.
- 37% of the black women were overweight, based on body mass indexes, compared with 12% of the whites.
- Coexisting diseases that had a negative impact on breast cancer survival were more prevalent among black than white women. These diseases included hypertension, heart disease, and diabetes.

Other factors associated with greater risk of death were: 
- Lack of health insurance: women with no health insurance or public medical insurance had a 2.3 times greater risk of death than women with any private health insurance.

- Women who were divorced, separated, or never married had a greater risk of death from breast cancer than those who were married or widowed.

The authors concluded that the best way to improve breast-cancer survival is by promoting earlier detection of the disease. Strategies to achieve this are better community education, improvement in access to primary care and mammography, and increased adherence to current screening recommendations.


UKROP'S GOLDEN GIFT PROGRAM

Ukrop’s has made it even simpler for us to benefit from their generous program. From September 26 to December 3, 1994, purchases will be recorded using the Valued Customer Cards. In the January Ukrop’s Valued Customer newsletter, each customer will receive a Golden certificate showing the Golden Gift total in his or her account. These certificates must be submitted to VBCF before Feb. 15, 1995. Remember, too, that you must have a Valued Customer Card to participate. For further information, call VBCF at 285-1200 or 800-345-VBCF
New Drug in Development Shows Promise

Preclinical evaluations of a novel anticancer drug, XR5000, show promise say the developers, Xenova Group. Research demonstrated the ability of XR5000 to inhibit cancer cell proliferation and overcome drug resistance associated with chemotherapy. The studies have suggested that this drug acts on two enzymes critical to cancer proliferation. It also demonstrates the ability to overcome both p-glycoprotein and topoisomerase II related drug resistance, which is observed in leading chemotherapeutic agents, including doxorubicin and etoposide. This drug is currently in clinical trials in the United Kingdom and Xenova is in planning stages for phase II and III clinical trials in both the UK and the US.

THE WAR ON CANCER
CHANGES STRATEGIES

Two decades ago we were given a presidential promise for a cancer cure and federal dollars were put into the cancer war chest. The research then was based on the belief that the disease arises from external agents that can be identified and either attacked or eliminated. Now defective genes are the targets of research and yet only about 5% of women's breast cancer is traceable to inherited gene defects.

Several key questions remain unanswered:

1. What causes the remaining 95% of women, who apparently inherit non-defective genes, to develop breast cancer?

2. What can be done to reduce the incidence of breast cancer in all segments of society?

In spite of the fact that technology for identifying cancer has advanced and this country spends about five times more per patient on chemotherapy than the UK does, survival for most types of cancer is similar in both countries. A decade ago, John Cairns of Harvard showed the folly of spending hundreds of millions of dollars every year on giving the growing number of patients chemotherapy, with little proven benefit, while doing almost nothing to protect the population from the single most influential cause of cancer, cigarette smoking. If one looks at the great strides in reducing the most prevalent diseases of the 19th century, infectious diseases, the great improvements came, not from medicines and treatment, but from public health programs that kept the diseases from occurring in the first place: improvements in housing, water supplies, sanitation, and working conditions.

One of today's disastrous diseases, cancer, is more likely to be controlled by implementing known preventive measures than by concentrating all our efforts on the side of cure. The authors of this article state, "No matter how efficient we may become at delivering health care, we must also seek to reduce the need for treatment...We need to identify avoidable causes of cancer in addition to smoking and to develop effective interventions that keep people from developing the disease altogether. To this sensible charge, we now wish to add that it is time to turn attention to confirming other avoidable causes of cancer." (PT)


TWO BREAST CANCER MYSTERIES

Cancer statistics are published annually by the American Cancer Society. The estimated number of new cases and the estimated mortality from each kind of cancer is given nationally and by the state. Beside the estimated number of new cases of breast cancer there is an asterisk which, at the bottom of the page and in very fine print, states that 25,000 cases of breast cancer in situ, annually, are not included in the listing of estimated number of new cases.

For 1994, if the number of cases of breast cancer in situ were included it would bring the total number of estimated new cases of breast cancer to 207,000 rather than the number 182,000 used in media reports. The treatment for breast cancer ranges from "Let's watch it" to mastectomy.

Calls to local physicians elicits surprise at this exclusion but no answers. Calls to ACS, NCI and tumor registries are equally unproductive.


VBCF BOOTH AT ORANGE STREET FESTIVAL

VBCF member Lisa Romberg and Beverly Tanner sponsored a booth at the Orange Street Festival in September. They distributed VBCF information about breast cancer and sponsored a raffle and sale to raise money for breast cancer research.
BRCA1 (continued from page 11)

take the risks others will not. The circumstances surrounding this discovery will boost our efforts to get new researchers funded. The Department of Defense breast cancer research money, for instance, is more often targeted to new and creative researchers sometimes removed from traditional breast cancer research units.

Dr. Wiseman and Dr. Futreal explained the gene and its large and complicated sequence. The most important thing learned was that genetics is not simple. Genetic research in breast cancer offers much promise. It will require years more research and much more funding before clinically useful information will become available. Dr. Karl Barret, Head of the Molecular Carcinogenesis Laboratory at NIEHS, said, “If there was anything in nature that we thought was simple, it was just an indication we did not know very much about it yet.” The more we learn about genetics, the more there is to know.

Some of the important information I was able to gather from this visit was:

1. BRCA1 is not the gene that we hoped it would be. It does not appear to be responsible for many of the sporadic cases of breast cancer, that is, those cases where there is not a strong family history. It will probably be present in less than 4% of breast cancer cases.

2. Researchers now believe a gene on Chromosome 13 is a better candidate for the breast cancer susceptibility gene that also occurs in sporadic breast cancer cases.

3. So far ten different mutations have been found that cause breast cancer on BRCA1 but there may be many more.

4. A test for those mutations will be difficult to develop and will be very limited in what it can tell us. At least two years will be necessary before a test can be developed. The test will only be able to identify those people that have one of the previously identified mutations. If a person has a different mutation from those already identified, the test will be negative but it may very well be a false negative.

5. Those particular scientists feel they are limited in what future research they can do without risking the participants' health insurance coverage. They are very sensitive to the risks being greater than the benefits for women who would want to participate in research on BRCA1 at this time.

standing of carcinogens and other triggers for breast cancer.

Michelle Bennett, Ph.D., another of the NIEHS scientists who worked on finding BRCA1, visited Richmond on October 19 to address the Breast Cancer Awareness Forum sponsored by First Lady of Virginia, Susan Allen. Ms. Bennett did a wonderful job of making very difficult science understandable.

The VBCF is anxious to continue to develop a dialogue with the basic scientists working on breast cancer research. We have shown in the past that a partnership with our physicians in planning our health care and a partnership with clinical researchers in planning clinical trials has great benefit. We expect that there is much we can learn from each other that will result in expediting the research necessary to eradicate this disease.

Addendum:

When the announcement of BRCA1 was made, the National Breast Cancer Coalition objected to the gene sequence not being made available to the public. Myriad Laboratories was filing for a patent on BRCA1 that week. Since that time, the gene sequence has been filed in the Genbank (and is therefore available to other researchers) but the issue of who has exclusive patent rights to this gene is still in contention. NIH and Myriad Laboratories are holding discussions as to whether the patent should be held jointly because of the major contribution made by the NIEHS scientists. The National Breast Cancer Coalition is continuing to question the ethical issues related to gene patents in general. The last four years of intensive effort to locate BRCA1 cost taxpayers many millions of dollars. Now private industry is claiming all profits related to developing a test or treatments associated with this gene. Industry is also demanding that there be no federally imposed price controls on such products. The VBCF will continue to study this situation and will develop a position paper on gene ownership in the near future.

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If you wish to read first hand about BRCA1, the discovery is to be published in Science Magazine, a publication of the National Academy for the Advancement of Science. You can receive a fax of this one article or be mailed the entire journal for $6.00. You can reach their communications department at 202-326-6417. Copies can also be found in the VBCF office.

RENEE NOWELL HAS BEEN WITH VBCF FOR ONE YEAR!! LET'S ALL REMEMBER TO SAY THANKS TO HER - HOW DID WE EVER MANAGE BEFORE SHE CAME TO US??
PENDINSA CHAPTER NEWS
Submitted by Ann H. Wilson

Sudie Stultz, Effie Terry and Ann Wilson were pleased to represent our chapter at the news conference held by Governor and Mrs. Allen on September 29th in Richmond. Governor Allen signed a Declaration which declared October as Breast Cancer Awareness, Prevention and Early Detection Month. We enjoyed a tea held at the Governor’s Mansion following the press conference.

SOUTHSIDE CHAPTER NEWS
Submitted by Mary Huff

Mary Huff, Executive Coordinator, gave a presentation on Breast Cancer Incidence, Risk Factors and Self-Exam on Saturday October 1 at the Virginia Beach Central Library. The presentation was open to the public and free of charge.

Katie Byrnes, Public Education Coordinator, arranged for mall displays throughout the October. Sites were Lynnhaven Mall (Oct. 8 and 9) and Pembroke Mall (Oct. 15 and 16).

Thanks to the Junior League of Norfolk-Virginia Beach, Inc., we will distribute laminated shower cards with instructions on breast self-exam. Their generous gift allowed us to purchase over 3500 cards for our community.

The VBCF will sponsor a special performance of Amazons in August on November 9, 1994 at the Generic Theatre in Norfolk. (Editor’s note: We hope that you receive this newsletter before then.) The playwright, Ernest Thompson, was inspired by a family member who battled breast cancer.

The Executive Committee of the Southside Chapter meets on an “as needed” basis. In addition to chapter officers, any member who expresses an interest in participating in Chapter projects and decision-making is welcomed.

The Peninsula Chapter hosted a Captain’s Choice Golf Tournament at the Smithfield Downs Golf Tournament on November 6, 1994.

Effie Terrie, Renee Nowell, Ann Wilson, and Sudie Stultz hold Declaration signed by Governor Allen on September 29

Several of our members participated in staffing the VBCF booth at the State Fair September 23 - October 2nd.

October was a busy month for our chapter. We staffed breast cancer awareness display booths and passed out pink ribbons in the following locations:

- October 1  Newmarket South Shopping Center
- October 3  Williamsburg Regional Library
- October 8  Coliseum Mall Shopping Center
- October 15  Oyster Point Industrial Park

In addition to these public awareness events, we will be placing pink ribbons in beauty salons in Hampton, Newport News and York County. The beauty operators are wearing pink ribbons and are encouraging their patrons to take one and wear it throughout October. I would like to personally thank each member who participated in all of the above events. Without you giving your time, it would not have been possible. Thanks!!!

Virginia State Fair
COOLING DOWN CAPSAICIN

Capsaicin is the active ingredient in chile peppers and cayenne pepper and used to ease the pain of mouth sores caused by chemotherapy. Ouch! Good news has arrived through a first year medical student has created a butterscotch brittle with several layers of capsaicin, now available in taffy form. Sugar in the candy inhibits the burn of the capsaicin.

ONE MORE REASON TO EXERCISE

For many years, experts have given men and women of all ages plenty of reasons to exercise regularly. Now we have another good reason. A researcher at the University of Southern California School of Medicine, Leslie Bernstein, has found that women who exercise an average of four hours a week over their childbearing years lower their risk of breast cancer by almost 60%. Even one to three hours a week is beneficial, but to a lesser extent. Dr. Susan Love, Director of the UCLA Breast Center, was enthusiastic about the finding, especially since exercise also reduces risk of osteoporosis and heart disease.

Several explanations for the benefit were proposed. Possibly the production of ovarian hormones may be altered so that the woman’s overall exposure to estrogen is reduced. Dr. Love suggested that exercise increases muscle mass and decreases body fat, but Dr. Bernstein found no association between breast cancer risk and body mass or body fat in her study. She did express concern about the need to develop lifelong habits of vigorous physical activity among American girls.

(FPT)

AP Online via Prodigy Service, 9/27/94.

FIRST ANNUAL DANCE FOR THE CAUSE A SUCCESS!!

Submitted by Wanda Bruce

The Jazzercise-a-Thon held on Saturday, October 15, 1994 was great fun and a great success. About 50 Jazzercise participants had collected sponsors, and they really danced up a storm!

The total amount collected from sponsors will be announced in about two weeks, and we hope to make this event even bigger and better next year. Our thanks again to Gloria Barnes and to the other instructors and Jazzercise students who gave their time to the VBCF.
MEMBER PROFILE: WANDA BRUCE

Exercise and nutrition have always been a strong part of Wanda Bruce's life, and play an even more important role since her breast cancer was discovered in 1991. She has traded running for walking every day, continues to eat mostly fruits and vegetables, and takes vitamins and antioxidants. Although she hopes that these measures will prevent metastasis or recurrence in the other breast, Wanda believes that the cause of breast cancer is environmental. She says "the contamination of food, soils, and water" must play an important role in the development of this disease, for "it is too widespread to be able to pinpoint any other cause."

Wanda and Bobby Bruce

Wanda Bruce feels strongly about her responsibility to help people become aware of breast cancer and to promote research. She is an extremely active member of the VBCF, and recently organized both Race for the Cause and Dance for the Cause (the Jazzercise-a-Thon). She, her husband Bobby, and Renee Nowell also worked many, many hours at the State Fair.

 Probably the most visible sign of Wanda's dedication and enthusiasm is her involvement in the pink ribbon campaign. This was started to awaken the public and the policy makers on Capitol Hill about the need for breast cancer research and has continued through Wanda's efforts. She found out that Estee Lauder was no longer a part of the campaign, so she purchased pink ribbon and began making and distributing the pink ribbons herself. She feels that this display of ribbons demonstrates how much the public attitude toward breast cancer has changed in the past five years. "Now I don't mind telling anyone, even total strangers, that I am a breast cancer survivor. Years ago, I wouldn't have."

Working for cancer awareness is an important part of her life, but crocheting, travelling, and work with other volunteer organizations also fill the hours since her retirement from C&P Telephone in 1993. She and Bobby, her husband of 35 years, have three children and six grandchildren, all of whom live close enough to spoil.

SUGGESTED READING:


Examining Myself, by Musa Mayer; Faber and Faber, 1993. ISBN 0-571-19828-7. (Editor's note: Linda Ellerbee calls this "the best book anybody has ever written about what it's like to have breast cancer. Also, Faber and Faber is donating a portion of the proceeds to the National Breast Coalition.)

BOOK REVIEW

by Patti Goodall

Winning Life's Toughest Battles: Roots of Human Resilience by Dr. Julius Segal, 1986, 150 pages.

I recently visited the Patient-Family Resource Library of the Massey Cancer Center at Medical College of Virginia after my oncology check-up. It seems that I don't read much anymore that is not related to breast cancer, so I like to check in and see if they have anything new. Although this is not a recent book, nor one that deals solely with cancer, it caught my eye. I was pleased that the book offered more than platitudes and puts the back to people facing difficult crises in their lives.

The author, Dr. Segal, is a psychologist who studied ordinary people surviving extraordinary stress, ranging from hostages and POWs to losing a child to diagnosis of life-threatening disease. While we may sometimes think and feel that our situation is unique, it clearly is not. What is unique is the way that certain individuals not only survive such challenges, but are able to adapt and prevail. Dr. Segal discusses the common traits and activities of people who faced overwhelming pain and loss, yet were able to find meaning in their suffering and in their lives. The five "keys" described by Dr. Segal include communication, control, conviction, clear conscience, and compassion. Using dramatic case histories, Dr. Segal encourages readers facing terrible experiences in their lives to activate the potential for healing and growth. Ultimately, Dr. Segal hopes that we may enjoy life more, become more productive, and increase our capacity for loving and accepting love. Not a bad goal for a book that can be read in an afternoon!
VBCF ANNUAL MEMBERSHIP MEETING TO BE HELD JANUARY 14, 1995

Mark your calendars now for Saturday, January 14, 1995 from 10:00 a.m. until 4:00 p.m. at the Virginia Museum in Richmond. Susan Allen, wife of Governor George Allen, has been invited to address our group. Workshop session include the following:

* Research update: has there been any progress in breast cancer diagnosis and treatment?
* Coping with grief and loss for women with breast cancer and their family members.
* Should you participate in clinical trials in breast cancer treatment?
* Discovery of the breast cancer gene: What are the implications?
* Briefing on VBCF’s national and state legislative activities.

Lunch will be provided. We hope to see you at the meeting -- and bring a friend! Look for registration materials to be mailed in November. Call (804) 285-1200 for more information.

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