Women Helping Women
VBCF Receives Donation from the Board for Women’s Health

The Board for Women’s Health has again generously donated funds for the Virginia Breast Cancer Foundation, funding the VBCF Newsletter for one year, a donation of over $12,500. In 1995 the Board contributed $15,000 to the Primary Care Perspectives Conference, making the Board for Women’s Health the largest single contributor.

The Board for Women’s Health began in the 1930s as an auxiliary for the Retreat Hospital in Richmond on Grove Avenue. Auxiliary volunteers raised money for special projects benefiting the hospital. In the 1980s, they opened the Gift Shop in the lobby of Retreat Hospital, solely operated by volunteer auxiliary buyers and clerks.

In 1995 the small nonprofit Retreat Hospital was sold to Columbia/HCA, a large corporation that owns many hospitals throughout the United States. The company allows the group to continue to operate the Gift Shop, but due to its change in status, the women formed The Board for Women’s Health from the auxiliary to benefit women’s health issues in the community.

The Virginia Breast Cancer Foundation was one of the first organizations brought to the Board’s attention through VBCF member and former newsletter editor Barbara Parker. Mary Jo Kahn was one of the first speakers for the new group, describing VBCF and its goals. In February, VBCF President Margaret Borwhat spoke to the Board and presented them with a glass sculpture acknowledging their contributions. The award is on display at the Gift Shop.

The Board for Women’s Health has also funded many other worthy projects for women in the Richmond area and in the state. Other recipients of the Board’s generosity include Dr. Harry Bear and the Massey Cancer Center for Breast Cancer Research. The Board for Women’s Health is planning a dinner dance in the spring for the sole benefit of breast cancer research at the Massey Cancer Center. Another plan is to establish a scholarship for radiologic technologists who plan to do breast imaging as their career.

The Virginia Breast Cancer Foundation gratefully acknowledges the Board for Women’s Health for financing our primary means of communication with VBCF members. Much can be accomplished through awareness of and education about breast cancer.
After nearly four years working with VBCF, I have decided to spend more time working with women undergoing treatment for breast cancer. It is their strength and courage that inspired me to fight for all of us who are or may be affected by this disease. After many long hours, I came to the conclusion that there were not enough hours in the day to accomplish everything that I would like. As a result, I have relinquished my position as President of VBCF and by doing so I will be relieved of the administrative duties and travel required of President.

I will continue to actively serve as a member of the VBCF Board and to support VBCF's mission. As President, I was able to meet and work with many of the members and I am thankful for all of your help, advice, and support. The strength of VBCF is its membership and their commitment to eradicate breast cancer. We demonstrated that when we worked together and got behind an issue we could make a difference.

During the General Assembly sessions we made our positions known and helped produce significant legislation that provided for increased insurance coverage for the treatment of breast cancer, including high dose chemotherapy with bone marrow or stem cell transplant. We worked hard to push for legislation concerning the genetic information privacy act.

We have been able to establish good relationships with our federal and state legislators. Meeting with them and their aides to share information was both a valuable and rewarding experience. Serving as VBCF’s representative on the National Breast Cancer Coalition Board and as its state coordinator for Virginia have been a part of my job that I particularly enjoyed.

It has been a pleasure to work with Mrs. Susan Allen, the first lady of Virginia, who was always willing to help VBCF and who served as honorary chairperson for Primary Care Perspectives. We have continued to build partnerships with organizations with the same goal of helping women fight breast cancer, such as the Board for Women’s Health, the Junior Women’s Club of Williamsburg, and presently, the Home 2000 project, which have provided us with additional forums to spread our message. The Virginia Nurses Association, oncology nurses’ associations, and numerous support groups with whom I have been in contact are powerful allies in the battle against breast cancer. We were fortunate to be able to work with the professionals at the Virginia Department of Health’s Breast and Cervical Cancer Early Detection Program. VBCF was asked to be part of the team that developed the Coalition for Every Woman’s Life.

I have many warm memories of my year as President of VBCF and it has been an honor and privilege to serve in this capacity.

With warmest wishes,
Margaret Borwhat

Phyllis Tyzenhouse was named Volunteer of the Year at the Membership Meeting June 1. She has contributed hours and hours of time researching and writing articles for the VBCF Newsletter. Her career as a nurse, nurse educator and Doctor of Public Health, as well as her roles as wife and mother, prepared her well to serve as a health advocate during her retirement. In addition to her efforts for VBCF, she is also extremely active in AARP.

As is probably true for most of us, Phyllis’ desire to fight breast cancer came from a personal experience. One of her four daughters, Joanne, underwent lumpectomy, chemotherapy and radiation eight years ago. “She had a rotten time of it,” says Phyllis. “But so far, so good.”

Right after joining VBCF, Phyllis was referred to a surgeon for follow-up of a suspicious area on a mammogram. While attempting a needle localization, her breast was placed under compression, but the surgeon was unable to visualize the lump. When the technologist informed the doctor that Phyllis was still under compression while he decided what to do. “Well, just leave her there,” she overheard him say. “It made me so angry,” said Phyllis. “I was uncomfortable and he couldn’t care less. I think it’s important that we as an organization put a face on breast cancer and make others know how we feel.”

As we become better informed as breast cancer advocates, the more our credibility increases.

We all owe Phyllis a debt of thanks for her efforts to educate us about the scientific and medical aspects of breast cancer.
Tidewater District Peninsula

The Peninsula Chapter held its third annual Fashion Show and Luncheon in March. Fashions were furnished for the show by Paige Harrell of Nags Head, North Carolina, raising over $5,000 for the VBCF. Thanks to contributors, volunteers and guests for the huge success.

Two hundred people browsed through several jewelry and fashion displays before lunch. VBCF Foundation Peninsula Chapter members Betsy Bishop, Carol Sandidge, Effie Terry, Sadie Stultz and Judy Weatherly received enthusiastic applause for their professional performances as models.

In addition to the show, Ann Wilson organized a silent auction. Nearly 50 Peninsula businesses and residents contributed to it, while nearly 40 local merchants, restaurants and businesses contributed to the door prizes. The Chapter is grateful to all of them for their support.

Jean Minor organized relatives and friends from the Suffolk Quilters Guild to create a special quilt as a prize for the show. Jean Basnight of Virginia Beach was the recipient of the much admired quilt.

Betsy Bishop, Judy Weatherly and Carol Sandidge walked through the night at the American Cancer Society’s Relay for Life. Over $82,000 was raised at that site for cancer research.

Tidewater District Southside

Patsy Monk has organized the Tidewater Mammogram Quilters for the third year to create a quilt for the benefit of the indigent women unable to pay for mammograms.

The design of the quilt shows a center medallion with the picture of a woman and a tree on the side. Local businesses, residents, survivors and those left behind by the victims of breast cancer are invited to sign individual leaves for the tree. Donations collected from those that sign will be given to the Beach Clinic, a free clinic for the indigent. The donations are earmarked to pay for mammograms for Beach Clinic clients who otherwise have no way to pay for them. For more information, contact Patsy Monk at 804-430-0747 or Susan Clark at 804-468-9425.

Shenandoah

About 25 people attended a Fashion Show with a Caribbean theme that was held as a fund raising event. Mary Jo Kahn spoke to the group during the Fashion Show.

A group of breast survivors from the Northwest District participated in the American Cancer Society’s Relay for Life as the Breast Cancer Eradicators team. They are continuing to meet monthly to support each other.

Charlottesville

Margaret Borwhat organized and helped staff a tabling event for two days outside the main Charlottesville Post Office in honor of the new Breast Cancer Awareness Stamp. Proceeds from the sale of tee shirts and pins with the image of the new stamp on them will go to the Virginia Breast Cancer Foundation.

Home 2000

"A Woman's Perspective"

Wanda Bruce reports that the Ukrop’s Golden Gift Certificate program raised over $1,500 for VBCF this year. Many thanks to those who participated.

Wanda set up a table at the ceremony for the unveiling of the Breast Cancer Awareness Stamp on June 17 in Richmond at Capitol Square near the Bell Tower. VBCF member Beblon Parks spoke at the presentation. Richmond Mayor Leonidas Young also spoke at the presentation.

Editor’s Note: If you have an active VBCF group in your community or if you individually are working in the fight against breast cancer and would like to submit a report, call Mary Huff at 804-973-0763. Let us hear from you!
The American College of Radiology, the American Cancer Society, the Y-ME National Breast Cancer Organization, the National Alliance of Breast Cancer Organizations, the American Medical Association, the Komen Foundation, and the American College of Obstetricians and Gynecologists have held fast to their recommendation that women in their 40s should have mammography screening. Now a Swedish report, based on combined data from studies in seven Swedish cities, one from Scotland, and one from New York City, showed a 24% decrease in deaths from breast cancer among women aged 40–49, who had screening mammograms, compared with women who did not. National health objectives for the year 2000 are to increase to 80% the number of women aged 40 or older who have ever had a mammogram, and to increase to 60% the number of women aged 50 or older who have a mammogram every two years.

Representative Barbara E. Vucanovich, R-Nev., is sponsoring a bill that would force the FDA to allow women to buy a controversial pad, the Sensor Pad, without a prescription. The Sensor Pad is two layers of plastic with a silicone filling that its inventor says increases the sensitivity of breast self-exam. The FDA recently approved the device after a ten-year battle but restricted its access by requiring a physician’s prescription. (See VBCF Newsletter, Jan/Feb 1996, In Brief). If the Sensor Pad legislation passes, it would be the first time Congress ordered the FDA to approve a medical device.

Nominations are needed for the 1996 Sharon H. Kohlenberg Healthcare service Award. The award was established in 1995 by the VBCF Board of Directors to recognize and honor a healthcare worker who “exhibits a deep and abiding commitment to the fight against breast cancer.” The award is named for Sherry Kohlenberg, a healthcare administrator and co-founder of VBCF who died in 1993 from breast cancer. The inaugural co-recipients of the award were Harry Bear, MD, PhD, and Tom Smith, MD, of the Massey Cancer Center at the Medical College of Virginia. Nominations must be submitted by September 1, 1996. Recipients will be honored at a reception to be held during Breast Cancer Awareness Month in October. Contact Patti Goodall at the VBCF office, 800-345-VBCF, for more information.

A multi-center study in the Boston area published their findings on the sequencing of chemotherapy and radiation therapy after breast conservation surgery in the New England Journal of Medicine on May 23, 1996. They concluded that it is preferable to give a 12 week course of chemotherapy followed by radiation therapy for women at risk of metastases.

Seren Cohen, a Ph.D. candidate in clinical psychology at Howard University, is looking for breast cancer patients and their partners to participate in a survey. The surveys will identify factors which improve resilience and reduce depression among patients and their partners following a diagnosis of breast cancer. To be eligible, volunteers must have learned of a breast cancer diagnosis within, approximately, the last one to 24 months. Partners need to be married or in an exclusive relationship. Couples from all cultural backgrounds are needed. Volunteer couples will receive $25 per couple which can be paid directly to the couple or donated to nonprofit programs benefiting breast cancer patients. For more information call: the Rese archful Partner Study at 202-363-0354 or send your name and address to: jimsen@earth.ers.com.

The Food and Drug Administration has approved the High-Definition Imaging ultrasound as another diagnostic procedure to determine whether lumps in women’s breasts are cancerous. (See VBCF Newsletter, Jan/Feb 1996, In Brief). The FDA approved an application by Advanced Technology Laboratories (ATL) to promote the ultrasound technique which was 99% accurate in trials diagnosing lumps as benign. Dick Tabbutt, director of outcomes research for ATL, said the high definition machines examine the border of the lump. If the margin is "irregular and angulated and looks like it's invading the surrounding tissue, that is an ominous sign" and should be followed by a biopsy. If the border of the lump appears smooth, the lump is almost certainly benign. Out of 700,000 surgical breast biopsies done each year, breast cancer is diagnosed in 180,000 cases. The new technique could save many women the expense, pain and emotional anxiety of biopsy.

Several VBCF members have reported unpleasant and painful experiences with stereotactic needle biopsies. We are investigating but in the meantime we have several suggestions. Prior to signing consent, ask the physician if local anesthesia will be given, how many "stabs" of the needle will be done, how long the procedure will take, and if anything can be given to reduce the discomfort of compression. According to a mammographer in the central Virginia area, local injection for pain relief can be given and the procedure should take about 20 to 30 minutes. Only one or two "stabs" of the needle should be necessary. Remember that you are in charge; if at any time you feel you can not continue, say so. If medical personnel do not release you from the equipment it could constitute assault and battery.
Breast Cancer Trials are Available at Massey Cancer Center Medical College of Virginia in Richmond

During the recent VBCF Annual Meeting, it was reported that several breast cancer trials are currently underway at the Medical College of Virginia Massey Cancer Center in Richmond. Women who are interested in these trials, or who may qualify for inclusion, are welcome to contact the center at 804-828-0450.

PREVENTION
NSABP P-1: Tamoxifen vs. Placebo

ADJUVANT
NSABP B-27: Trial of Pre-Operative Adriamycin/Cytoxan vs. Pre-operative AC + Taxotere vs. Pre-Operative AC + Post-Operative Taxotere. (To be eligible, patients must be diagnosed by needle biopsy and cannot have had a surgical or stereotactic biopsy.)

NSABP B-28: For node positive patients after surgery - Adriamycin/Cytoxan vs. AC followed by Taxol.

NSABP B-23: For node negative patients with estrogen receptor negative tumors - Adriamycin/Cytoxan vs. CMF +/- Tamoxifen.

NSABP B-21: For patients with tumors less than or equal to 1 cm. and negative nodes - Lumpectomy + Radiation Therapy vs. Lumpectomy + Tamoxifen vs. Lumpectomy + RT + Tamoxifen.

CALGB 9082: For patients with ten or more positive nodes - Chemotherapy vs. High Dose Chemotherapy with autologous stem cell rescue.

LOCALLY ADVANCED BREAST CANCER
NSABP B-26: Taxol as either a three hour or a 23 hour infusion.

METASTATIC BREAST CANCER
NSABP B-26: Taxol as either a three hour or 23 hour infusion. CALGB 9342: Taxol - low vs. moderate vs. high dose.

Pfizer DRI-301: Drolnoxifene vs. Tamoxifen

PHASE I TRIALS
Adoptive Cellular Therapy by Bryostatin-1-activated tumor-draining lymph node lymphocytes + Interleukin-2

Bryostatin-1 infusion

Lomotrexol, weekly IV infusion with oral folic acid

SUPPORTIVE MEASURES
URCC 2994: Pentoxifylline vs. Placebo for cachexia
URCC 1190M: Clonidine for hot flashes

INFORMATION
Cancer Information Service - 800-422-6237
Linen-Powell Resource Library at the Massey Cancer Center 804-828-8709

Physicians' Data Query (PDQ) from the National Cancer Institute
by phone: 800-345-3300
by fax: 800-380-1575
by e-mail: pdqsearch@icc.nci.nih.gov

CancerFax for Information Associates from NCI 800-NCI-7890

Women may Qualify for Genetic Counseling Program at Georgetown University

The CARE (Cancer Assessment and Risk Evaluation) Program is a genetic counseling and testing program offered by the Lombardi Cancer Center at Georgetown University Medical Center.

Through the CARE Program, women receive information and counseling about their risk for breast and ovarian cancer—two cancers shown to be related to genes that are inherited, or passed down, in families. This free program is supported by research grants from NIH, DOD and the Susan G. Komen Foundation.

If you had breast or ovarian cancer, you may be eligible for CARE if...

- you have a first degree relative who had breast cancer at age 30 or younger, or
- you have two first degree relatives who had early onset breast cancer (age 30 or younger) and/or ovarian cancer (any age), or
- you have three relatives on the same side of the family with early onset breast cancer and/or ovarian cancer.

For more information about CARE please call Jennifer Rocca at 202-687-1750.

Breast Cancer Clinical Trials - June 1996
Annual Meeting Held in Richmond

President Margaret Borwhat Highlights VBCF Accomplishments and Praises Volunteers

The Virginia Breast Cancer Foundation held its annual Membership Meeting at the Virginia Museum of Fine Arts in Richmond on June 1. VBCF President Margaret Borwhat reviewed VBCF's accomplishments for the past year, which included 1995's Primary Care Perspectives Conference, which was rated as "exceptional" and "well done" by 98% of the health care professionals who attended. Volunteers who worked on the conference have confirmed their willingness to sponsor and work on another in the future. The generous contributions from the Board for Women's Health and the Williamsburg Junior Women's Club were acknowledged, as well as the Jazercise program and Ukrop's Golden Gift certificate program.

VBCF is participating as a United Way charity, reported Margaret, and will be included on the pledge forms for the Combined Virginia Campaign in 1996, and VBCF has been chosen to benefit from HOME 2000, part of this year's Parade of Homes in the Richmond area. Other projects include participation in the National Breast Cancer Coalition's petition drive through May of 1997 and the Face of Breast Cancer exhibit in September in Richmond (story on page 11). The Pink Badge of Courage Reception will be held in October to honor the second Kohlberg Healthcare Service Award winner.

Margaret then introduced VBCF treasurer Nancy Golden who gave a financial report. The audit is complete and a financial statement will be available from the VBCF office. She thanked Mary Jo Kahn and Cindy Barnett for their contributions in the hours of work planning and completing the audit.

Keynote speaker Dr. Janette Sherman described cancer as a social disease that is not randomly distributed throughout the United States. Her presentation gave many examples of environmental carcinogens in and around our homes and stressed the need for primary prevention. Dr. Sherman believes the medical and scientific communities have a duty to explore and discern the cause of disease as well as treat illness.

During the luncheon, Margaret spoke of the importance and

Volunteer of the Year

Phyllis Tyzenhouse,
for time and expertise in medical review for the VBCF Newsletter

District Volunteers of the Year

Karen Board, Southwest,
for perseverance in securing ABMT coverage for state employees

Jean Hoshall, Northern,
for time and expertise in design, editing and typesetting for many VBCF projects, including the PCP Conference, the VBCF brochure and the VBCF Newsletter

Mary Huff, Northwest,
for time and efforts as editor of the VBCF Newsletter

Katie Byrnes, Tidewater,
for efforts in coordinating tabling events throughout southside Tidewater

Gloria Barnes, Central,
for efforts in organizing and leading the Jazercise Dance for the Cure

Ann T. Wilson, Southeast,
for efforts in coordinating outreach programs
Honorees from the Primary Care Perspectives Conference

Vivian Phillips,
for her work as recording secretary
Ann Wilson,
for her work on registration and spouse activities
Jennie Davies,
for her work on facilities coordination and spouse activities
Pam Cappetta, EdD, LPC,
for her work on program development
Les Dubnick, EdD, ABPP,
for his work on program development
Miltford Maloney, MD, FACP,
for his work on program development
Bert Aaron,
for his work as chair of the conference

Dr. Lerman, associate professor of medicine and psychiatry and director of bio-behavioral research at the Lombardi Cancer Center at Georgetown University Medical Center, presented the current findings on her study of the psychosocial implications of genetic testing for breast cancer.

Dr. Bear, who is chair of the division of surgical oncology for the Massey Cancer Center at the Medical College of Virginia, gave a brief review of how clinical trials are established, what safeguards are in place for participants and what trials are underway at MCV.

The final session was run by Dr. Cappetta, a licensed professional counselor from Williamsburg, who discussed ways to promote wellness in our lives and conducted a relaxation activity.

Many thanks to Patti Goodall, vice president of VBCF, for her efforts in coordinating the meeting and to Wanda Bruce for her tireless assistance.
Better Breast Cancer Treatment Lies Ahead

By Phyllis Tyzenhouse

As recently as three decades ago, there were few choices for women diagnosed with early breast cancer: the standard treatment was the radical mastectomy, developed by William S. Halsted at Johns Hopkins University. This procedure was universally accepted, based on Halsted's leadership in surgery and on his premise that breast cancer was a local-regional disease that required radical surgery to remove the tumor along with underlying muscles and regional lymph nodes. He believed that any cancer cells left behind could cause recurrence or metastasis. After operating, surgeons often remarked to patients and families, "I hope we got it all." The drastic Halsted procedure left women bereft of a breast, disfigured, restricted in arm movement and psychologically devastated. Sometimes they had painful swelling in the arm on the operative side due to disruption of lymphatic drainage. Dreading these effects and knowing that they had no choices, many women avoided or declined the operation or even postponed consulting a physician. The Halsted operation continued to be the standard therapy until clinical trials of less drastic procedures began in the early 1970s and newer treatments were introduced.

Around 1950, surgeon George Crile, Jr. from Cleveland observed that during World War II, breast surgery was often performed by general surgeons who had not been trained to perform the Halsted radical. They used less extensive surgery. At that time many of the highly trained, board-certified surgeons were in military service and were not available for civilian surgery. Dr. Crile noticed that women who had non-radical breast surgery survived longer than those who had radical surgery. He reasoned that an intact lymphatic system was needed to scavenge stray cancer cells and protect against metastasis; lymph nodes should not be removed unless cancerous. This was a departure from the current thinking of the day, but being convinced, he adopted less extensive surgery for the majority of his patients. Fame about his success spread among women who agreed with his thinking. Rose Campion, a journalist who heard of his work while awaiting her own radical mastectomy, signed out of a hospital in New York City and traveled to Cleveland to have Dr. Crile operate on her breast cancer. Her book, The Worm in the Rose, drew the attention of women everywhere who began to demand breast-sparing surgery. Campion's work, and that of others who publicized their experiences with conservative surgery, opened a new era for women to participate in decisions about their treatment. A colleague of Dr. Crile, Dr. Bernard Fisher of Pittsburgh, dissociation, and later chemotherapy, was that radical local-regional surgery fails to cure approximately 70% of patients presenting with early breast cancer because subclinical metastases are often well established before clinical detection. Excising the primary tumor fails to treat these early metastases. The clinical trials showed that systemic adjuvant therapy is needed to protect against local and distant recurrence to improve survival.

Breast conservation treatment is now well accepted after two decades or more of research, and the Halsted radical is no longer the treatment of choice for early breast cancer.

Conservative Surgical Therapy

Breast conservation is definitively the excision of the primary tumor and adjacent tissue (i.e., lumpectomy, segmental mastectomy, or partial mastectomy) followed by radiation and/or systemic chemotherapy or chemohormonal therapy. This procedure is appropriate primary treatment for the majority of women with stage I and II (early) breast cancer and is preferred because it provides survival rates equivalent to those of total mastectomy and axillary dissection, while preserving the breast. (Dr. Fisher uses the term "total" mastectomy in place of the more common "simple" mastectomy because he believes there is no such thing as a "simple" mastectomy.) This procedure removes the entire breast and sometimes the axillary (underarm) lymph nodes as well. Not all breast cancer patients are eligible for conservative breast surgery; those with gross multifocal disease, diffuse...
microcalcifications, or large tumors, for example, would require extensive tissue removal, leading to a poor cosmetic effect. Women with axillary or other lymph node involvement require more extensive treatment as well. Harvard researchers report a study that showed breast-conserving surgery (lumpectomy) alone was not as effective as lumpectomy combined with radiation therapy in patients with early breast cancer. There was a 16% local recurrence rate among the patients who had lumpectomy without radiation in their study.

**Adjuvant Therapy**

The primary therapy for breast cancer is usually surgery, as described above. Adjuvant (secondary) therapy, administered at some time after surgery, destroys cancer cells that may remain in the breast tissue, adjacent areas and any cancer cells that have spread throughout the body. Adjuvant therapy may be either local-regional or systemic. Local-regional therapy consists of radiation to the breast and nearby areas. It does not destroy cancer cells that have found their way to other parts of the body. Adjuvant systemic therapy includes chemotherapy and hormone (or endocrine) therapy. In chemotherapy, a combination of anticancer drugs, usually CMF (cyclophosphamide, methotrexate, and fluorouracil), CAF (cyclophosphamide, Adriamycin, and fluorouracil), or CA (cyclophosphamide and Adriamycin) are given intravenously in cycles over a period of time.

Adjuvant hormone therapy can be used if the patient’s breast cancer cells have estrogen receptors (“estrogen receptor positive” or ER+) in order to deprive the cancer cells of estrogen, which promotes the growth of breast cancer. For most patients, tamoxifen, often called an “anti-estrogen,” is used to interfere with the activity of estrogen on breast tissue. Many call the administration of tamoxifen “hormone therapy” because it interferes with the action of the hormone estrogen. It also acts like estrogen in other body systems, which led to the hope of beneficial effects in postmenopausal women, such as prevention of osteoporosis and heart disease. However, data released in a closed-door meeting at the National Cancer Institute, October 1993, revealed that so far the tamoxifen prevention trial has not shown that tamoxifen prevents heart disease in breast cancer patients. If this proves to be true, healthy women over 60 may not benefit from tamoxifen and may even be harmed. Testing of this finding has been hampered because not enough women at increased risk of heart disease have been recruited into the study. The NSABP (National Surgical Adjuvant Breast Project) reports that recruitment of all women has been disappointingly slow and about 20% of the 11,000 women initially enrolled dropped out of the study when they learned that tamoxifen could cause endometrial cancer.

**Neoadjuvant Therapy**

A newer approach to breast cancer treatment is neoadjuvant therapy. This consists of chemotherapy or radiation therapy given before breast surgery rather than afterwards. Its purpose is to kill local and distant cancer cells and shrink the tumor before surgery is performed, thus limiting the need for more extensive surgery. In a French study of 126 cases of operable breast cancer treated with neoadjuvant chemotherapy, 83% of the patients’ tumors shrank by more than 50%; these patients were treated successfully with conservative surgery rather than the modified radical mastectomies that they would otherwise have undergone.

The Massey Cancer Center at the Medical College of Virginia is participating in a new pre-operative chemotherapy trial under the direction of Harry D. Bear, MD, PhD, Chairman of the Division of Surgical Oncology. Eligible women for the trial must have an operable breast tumor diagnosed by needle aspiration. They will be randomized into one of three treatment groups: 1) standard chemotherapy followed by surgery, 2) standard chemotherapy followed by Taxotere and then surgery, and 3) standard chemotherapy followed by surgery and then Taxotere. Taxotere is a semi-synthetic drug, similar to Taxol, that is made from the European variety of yew. Since it is made from twigs and leaves, bark does not have to be stripped from the trees, causing them to die, as happens in the manufacture of Taxol from the bark of the Pacific yew. MCV is one of the 200 sites in the US and Canada participating in the project and they hope to enroll 40 to 50 women at MCV for the study. National Cancer Institutes sponsors the study, which is under the overall administration of the National Surgical Adjuvant Breast Cancer Project and the study is designated NSABP B-18.

**Primary Medical Therapy for Operable Breast Cancer**

Primary medical therapy is an innovative expansion of neoadjuvant chemotherapy. It has been shown to eliminate or reduce the need for mastectomy in certain patients with operable breast cancer and promises to control the disease without surgery for many women. Imagine treating early breast cancer medically, without any surgery! This approach is being studied in clinical trials in the US and the UK and the results bear watching.

Trials, carried out in Japan, France, and the UK, have included patients whose tumors have been relatively large, one to 12 centimeters in diameter, with a median of six cm. These are fairly large tumors, but in one small study, 84% of the patients treated with FEC intravenously responded to the treatment and 58% had complete remissions, no local relapses, and no patient had required mastectomy. The researchers plan to compare primary medical therapy with conventional mastectomy followed by adjuvant therapy. A Japanese study found that intra-arterial pre-operative treatment was more effective than the same drugs given by intravenous infusion in achieving local-regional control, with fewer side effects.

Since more and more women are being screened due to awareness of the high prevalence of breast cancer, breast cancers are being detected earlier than in the past. This makes it possible for them to be treated more conservatively with better outcomes than women diagnosed thirty or more years ago. Mortality decreased by five percent during the years from 1989 to 1992. Although the mortality reduction is more pronounced in younger women, it’s the first time mortality rates have changed in over 30 years and should give hope to all women that breast cancer will eventually be eradicated.
Cancer Patients Follow Chinese Health Practice

In Byrd Park on Tuesday mornings and in Deep Run Park on any morning, you may see people slowly walking and swaying. They are practicing Qi Gong (pronounced “chee gong”).

Qi Gong is an ancient Chinese form of exercise and breathing designed to stimulate and balance the flow of body energy (Qi) and blood in order to improve immune system function. Qi Gong mobilizes the body’s resources to maintain health or to assist in healing. Many people were introduced to Qi Gong and other traditional Chinese medicine in the Bill Moyers PBS program, “Healing and the Mind.”

Richmond area residents have been studying Qi Gong for the past year with Coach Xu (pronounced “shoo”). He learned Qi Gong in China 20 years ago and taught at the Shanghai Qi Gong Institute and at the Shanghai Rehabilitation Club for Cancer Patients. He teaches a specially developed Qi Gong for cancer patients that more than 10,000 people practice in China. The discipline is widely accepted in China as an adjunct to the Western medicine treatments. Regular Qi Gong practitioners report improved sleep, increased appetite and strength, improved immune functioning, better quality of life and prolonged survival. Many patients with very advanced cancer have survived long past their doctor’s expectations.

Coach Xu teaches several basic Qi Gong classes. Recently he started a cancer rehabilitation group on Tuesdays at 11:00 am with VBCF cofounder and member Phoebe Antrim as group assistant. “I have seen one woman taking chemotherapy for a lung metastasis go from completely demoralized and exhausted to an exuberant and energetic cheerleader for others. She is tolerating aggressive chemotherapy very well; her strength has steadily increased over a nine month period,” said Phoebe. “There are ten of us currently in the group. One member said she was so relieved to feel she was actively doing something for her recovery. And she’s right. An important part of our health and recovery is in our own hands.”

The class is excited about the autumn visit of three longtime experts in Qi Gong for cancer patients. One is the founder of the Shanghai Cancer Recovery Club, which now numbers over 4,500 members. They have lectured and taught throughout China and in Japan, organized cancer “Olympics”, produced theater plays, TV programs and written numerous articles and books.

Anyone interested is welcome to visit or join one of the classes. Call Phoebe Antrim at 804-358-1772 or Coach Xu at 804-780-6005 for more information.

Editor’s note: If you have tried non-conventional therapies to combat the effects of cancer or cancer treatments, let us know.

National Cancer Institute Initiates Cancer Genetics Network

The first meeting of the National Cancer Institutes Genetic Working Group was held on April 5 to plan a nationwide network for research and education related to all types of cancer genetics. It is the first national attempt to gather data that will be used to answer important research questions.

NCI recognizes that cancer genetics is an important area for clinical and epidemiological studies. Many patients will have to be recruited from around the country in order to provide statistically significant findings. A computerized network linking research investigators from all parts of the country and perhaps internationally to NCI is planned. Local investigators will build communication links in their own communities with those physicians offering genetic testing. One of the advantages to physician participation in the network will be access to current information about cancer genetic syndromes.

The Virginia Breast Cancer Foundation applauds the efforts of NCI to make access to cancer genetics clinical trials available to everyone. From the beginning of our advocacy efforts, broader geographical distribution of high quality clinical trials has been one of our goals.

One of the greatest problems to this initiative is the continued risk of genetic discrimination. It is a problem which must be solved if this research effort is to go forward. Formation of a nationwide network makes discrimination legislation more urgent. Mary Jo Kahn, a VBCF member, is serving on the Cancer Genetics Working Group. Her focus will be achieving national legislative protection for those participating in the network.
Safety of Breast Implants Still in Question

by Phyllis Tyzenhouse

The FDA (Food and Drug Administration) reviewed the safety of silicone-filled breast implants used in breast reconstruction in 1992. At that time, an FDA panel of clinical and scientific experts discussed data submitted by the implant manufacturers and listened to reports of patients' physical complaints attributed to the implants. Discussions became heated when the panel claimed that the implants were safe and the patients maintained that their injuries were due to the implants.

Although saline filled implants were also in use then, they did not receive FDA scrutiny because of a technicality: the saline implants were on the market before the Medical Device Amendments Act of 1976 became law.

Under the law, the saline implants can be marketed pending FDA's determination that they are safe, based on data supplied by the manufacturers. So far, there has been no ruling. Since 1992, silicone-filled implants have been available only for women who cannot use the saline-filled implants, providing that they consent to participate in clinical studies to track any complications.

As a result of the class-action lawsuit against the manufacturers of silicone-filled implants, Dow Corning, Bristol-Myers-Squibb, 3M, and Baxter International are required to pay $4.2 billion over 30 years to women who claim to have been injured. Among the major diagnoses reported by the patients are arthritis, autoimmune disease, Raynaud's disease, lupus erythematosus and connective tissue disorders. However, decisions about compensating the claimants are unsettled, following a report in the New England Journal of Medicine that there is no link between implants and the diseases blamed on them. Researchers at Harvard analyzed the cases of 516 women in the Nurses' Health Study, who had confirmed connective tissue disease, and 1,183 women who had breast implants. They did not find an association between silicone breast implants and connective tissue diseases.

In another study, Mayo Clinic doctors reviewed many years of records for 750 women with implants and 1,500 women without them. Both groups had nearly equal rates of rheumatoid arthritis, connective tissue disease, Hashimoto's thyroiditis, and cancers other than breast cancer. Similar studies that reached the same conclusion were done at New York University Medical Center Clinics and Case Western Reserve University.

Patient advocates protest that researchers who find no harm in silicone implants represent the manufacturers and have a financial stake in the outcome of their studies. The issue may never be settled: both sides assert that the other side profits financially and that they bias the evidence in their favor. In the meantime, patients have not been compensated.

The Face of Breast Cancer to be Displayed at Regency Square in Richmond

VBCF Founder Sherry Kohlenberg Featured as one of Four Virginia Women Honored in Exhibit

The Face of Breast Cancer, a photographic essay that personalizes the breast cancer epidemic, will be on display from September 16 — 25 at Regency Square in Richmond. The exhibit features photographs of 84 women who died of breast cancer from every state in the union. Keritha McCarthy, immediate past president for VBCF, served as editor and completion coordinator for the project.

Four Virginia women are featured. In the original exhibit are Kyong Ja Kim Pearce from Herndon and Lorraine Smusz from Buchanan. Marianne Thatcher from Arlington and Sharon Helen "Sherry" Kohlenberg from Richmond were added to the exhibit in December 1995 in "The Legacy Continues," the newest section which represents women who died from 1993 to 1995.

Sherry Kohlenberg was a founder of the Virginia Breast Cancer Foundation. The following quote is an excerpt from her speech at the National Breast Cancer Coalition rally at the US Capitol in Washington, DC, May 2, 1993, "We are told we are overreacting to statistics. We're told we have no business demanding a say in how research is conducted. But we keep going to funerals. Enough is enough! We must demand whatever it takes. We cannot pass this legacy on to our daughters. I will not go silently. I will go shouting into that dark night!"

In 1996, 4500 new cases of breast cancer will be diagnosed in Virginia and 1100 women will die of breast cancer in Virginia.

Mrs. Susan Allen will host a "Kick-Off" Event the first day of the exhibit, September 16, at which Senator John Warner, a determined and long-time supporter of breast cancer funding at the federal level, will speak. The Virginia Breast Cancer Foundation will participate and volunteers may be needed to staff tables. Tens of thousands of men and women who have seen these photographs have been moved to become advocates in the fight against breast cancer; VBCF representatives can tell them what we've done in the past, what we plan to do in the future and how they can help.

For more information, call the VBCF office at 1-800-345-8223 or NBCC at 202-973-0588.

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Membership Form
The Virginia Breast Cancer Foundation appreciates your support. We are a 501(c)(3) non-profit organization. Consult your tax advisor concerning tax deductibility.

Name
Family Membership Name
Address (include apt #, PO Box, etc)
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This newsletter is published by the Virginia Breast Cancer Foundation six times per year. The newsletter focuses on breast cancer issues and the activities of VBCF members. Should you wish to join VBCF, or have any editorial comments, please call 1-800-345-VBCF or write to: Virginia Breast Cancer Foundation PO Box 17884 Richmond, VA 23226

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Calendar
July
20 VBCF Board Meeting and Retreat
August
17 VBCF Board Meeting
September
21 VBCF Board Meeting
19-22 2nd National Lymphadema Network Conference San Francisco, 1-800-541-3259
16-25 Faces of Breast Cancer Regency Square Richmond
October
TBA Pink Badge of Courage Reception
4-6 3rd World Congress of Psycho-Oncology New York, 1-404-751-7332
19 VBCF Board Meeting

It is time we found a cure!

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