Please join us as we celebrate 10 years in the fight against breast cancer at The Ribbons & Roses Ball, Friday, October 5 at the elegant Jefferson Hotel in Richmond. The evening will include a reception, silent auction, dinner, dancing and announcement of the Sherry H. Kohlenberg Award. Tickets now available: $100 per person, Visa and MasterCard accepted. There are a limited number of tickets so please call 285-1200 or 1-800-345-8223. See you there!

**LEGISLATIVE PRIORITY:**
Here are VBCF/NBCC legislative priorities for the 107th Congress:

* Maintain level funding in the Department of Defense Breast Cancer Research Program for Fiscal Year 2002 so it can continue its enormous success.

* Enact legislation that would increase the number of uninsured and underserved women who would be eligible for access to breast cancer health care.

* Pass the Breast Cancer and Environment Research Act which makes grants for multi-institutional, multi-disciplinary research centers to study the potential links between the environment and breast cancer. These centers would award grants based on a competitive, peer reviewed process that involves consumer advocates.

* Enact the Genetic Information Nondiscrimination in Health Insurance and Employment Act to prohibit health insurers and employers from discriminating based on genetic information.


Patti Goodall is congratulated by Senator John Watkins for receiving a Virginia Senate Joint Resolution recognizing Patti for co-founding the Virginia Breast Cancer Foundation and for her decade long commitment to the fight against breast cancer.
VICTORY! VICTORY! VICTORY! VBCF members successfully advocated for the passage of the following breast cancer bills: 1. Mandated insurance for reconstructive breast surgery following a mastectomy to re-establishing the breast; 2. insurance coverage for a minimum of 40 hours hospitalization after a mastectomy and no less than 24 hours after endoscopic surgery; 3. Bill the two-year sunset clause of the Genetic Information Nondiscrimination Act; 4. Certain health care providers from discontinuing or canceling insurance coverage based on any genetic information obtained from a person's family history.

VBCF Member Beth Williams, nine weeks pregnant when she was diagnosed with breast cancer, shares her story on an April episode of CBS' "48 Hours." VBCF hosts a panel discussion on the aspects of "Sexuality and Breast Cancer."
When we started VBCF and asked for more money for research, we didn't anticipate that there would be... 

"We're not going quietly anymore. We're not going to suffer and die without a fuss."  
Patti Goodall

Angered by the lack of research and progress in breast cancer treatment and inspired by a growing breast cancer activists network, 5 women from a Medical College of Virginia support group hold a Mother's Day Rally (the Saturday before Mother's Day) at Virginia's State Capitol. About 50 people attend the rally - one of 3 rallies held nationally.

**VBCF joins the Massey Cancer Center and the Junior League of Richmond in sponsoring a Public Forum on Breast Cancer. VBCF speaks on the need to support more research funding.**

**VBCF delivers 25,000 letters from Virginians as part of NABC's "Do the Write Thing Campaign," urging Virginia Representatives and President Bush to increase federal funding for breast cancer research. VBCF meets with Senator Robb who offers his support.**

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**The National Breast Cancer Coalition's Annual Advocacy Training Conference is scheduled for April 27 – May 1, 2002 in Washington, DC. VBCF has a limited number of scholarships for the conference and lodging. If you are interested, call us at 1-800-345-8223.**

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Karin Noss, VBCF member, serves on 2 review panels with the Dept. of Defense Cancer Peer Review Program thus realizing VBCF's dream of activist's participation on policy-making committees.

**VBCF members join NABC for Rally Day, a culmination of "Campaign 26" calling on the President and Congress to increase funding for breast cancer research by $2.6 billion. VBCF delivers 8,000 Virginia signatures to the U.S. Capitol.**

**VBCF members testify before the Virginia Commission on Mandated Health Benefits supporting the bill mandating insurance coverage for breast reconstruction after surgery for the treatment of breast cancer.**

**VBCF also supports Virginia legislation mandating coverage for a minimum 48 hour stay after a mastectomy. The Commission recommends that both bills be reintroduced before the General Assembly in 1998.**

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**The White House taps co-founder, Mary Jo Kahn, to introduce President Clinton at a press conference where he pledges to send legislation to Congress banning all health plans, group and individuals from denying coverage or raising premiums on the basis of genetic tests.**

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**VICTORY!!! The 1992 budget passes with a $42 million increase for breast cancer research. (Throughout the 80's, the Breast Cancer Research budget had remained static at $80 - $87 million.)**

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The VICTCers are also busy advocating for early detection symptomatic mammography, mandating mastectomy lymph node removal for breast cancer patients, and prohibiting sex discrimination in health care. With ten Jewish women's organization, sponsors and present at "Understanding the Genetics of Breast Cancer." VBCF volunteers launch first Pink Ribbon Camp. Thousands of pink ribbons are distributed in Richmon and Norfolk, raising awareness of breast cancer epidemic.

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**VBCF hosts an educational seminar featuring prominent physicians and community activists on breast reconstruction, new treatments, and coping with diagnosis. And community activists share strategies for making change happen on a local level.**

**VBCF members in Virginia Beach, Newport and Richmond work with the Susan G. Komen Foundation and BMW for the first nationwide "Drive for the Cure." VBCF works with Komen and BMW for the following three annual events in Virginia.**

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"It's time we found a cure for breast cancer." VBCF original motto 
"Educate. Advocate. Eradicate." VBCF current motto
I recently returned home from a full day of VBCF events just in time to see Lance Armstrong don the yellow jersey for the 1st time this year’s Tour de France. Lance won the race for the 3rd time in a row, a week later. Lance was diagnosed with advanced testicular cancer five years ago. By the time he was initially diagnosed, his cancer had metastasized to his lungs and brain. His autobiography discusses the chemotherapy treatment he received in vivid detail. While I am thrilled for Lance and his family that his treatment appears to be successful, I am frustrated that there is not yet the same for those who have been diagnosed with breast cancer. I do not know a single individual whose breast cancer had metastasized to their lungs and brain who is still alive five years later — much less able to win the Tour de France three times in a row. While many advances have been made in the treatment of breast cancer, a cure has yet to be found. To this effort, VBCF has dedicated itself over the past ten years.

The lack of a cure has recently hit home with me personally more than ever before. The day before I watched Lance don the yellow jersey, I had my first post-chemotherapy meeting with my oncologist. As background, six years ago I was first diagnosed with ductal carcinoma in situ (DCIS) or pre-cancer as it is sometimes called. Following a lumpectomy and radiation, I deemed myself “lucky” that I had been diagnosed early. I was mistaken. Last January, a biopsy following my annual mammogram indicated the DCIS had returned. I elected to have a mastectomy with immediate reconstruction. All indications prior to surgery were that this is all the treatment I would need. Unfortunately, during the post-mastectomy tissue analysis, a small tumor was discovered necessitating further adjuvant therapy. The discovery of the tumor was a surprise to all — and again shows the limitations of our current forms of detection. Prior to my surgery, I had numerous mammograms and clinical exams and in all cases, the presence of the tumor was not detected.

During my post-chemotherapy meeting with my oncologist, I wanted more than he could give me. I know that many reading this have been in the exact same position. What we want to hear are 25 year survival numbers. What we also want is a test — such as the PSA test for prostate cancer — which tells us whether or not the chemotherapy has been successful. But what we ultimately want is no less than a cure. These same feelings of frustration led to the founding of VBCF ten years ago by five women who met in a support group. We owe these women, and many others like them, a debt of gratitude. Because of them, the "volume" has been turned up on breast cancer. This higher volume has led to an increase in overall awareness of breast cancer which in turn has led to higher levels of research funding. Only through these higher funding levels will a cure be found. This newsletter highlights the successes of VBCF over the past 10 years.

As with any organization, VBCF has undergone numerous changes since inception. However, 2 of the greatest changes occurred over the past 3 months. Our first Executive Director Teresa Dayrit left the organization and moved to California (Beverly Hills no less). Her commitment to the organization will be greatly missed and I speak for the entire Board of Directors when I thank her for her tireless devotion to the mission of VBCF. Chris Clarke has been hired as our new Executive Director and, if the first two months are any indication, VBCF will continue to thrive and grow under her directorship.

The second major change is the receipt of a sizable grant from a national settlement in a lawsuit against the Nine West Shoe Company. VBCF was selected by the Virginia Attorney General to receive this grant. The grant will allow VBCF to expand educational efforts, which were previously limited due to funding constraints.

To celebrate the successes of the first ten years, please join us at our Ribbons and Roses Gala Ball to be held in Richmond on October 5th. This will be a wonderful opportunity to enjoy an evening of good fun with many whose lives have been impacted by breast cancer.

For obvious reasons, my commitment to the mission of VBCF has greatly increased over the past six months. I am proud to be part of an organization that is so committed to the overall goal of finding a cure for breast cancer. I look forward to seeing many of you in October.

Barbara Dittmeier

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10 YEARS WITH THE VBCF

Interview with Patti Goodall, VBCF Co-founder

What are you most proud of with VBCF? That we’re still here and that we’ve gained recognition and respect in Virginia and nationally for our leadership in breast cancer advocacy.

What’s been your best time? When we got legislation passed in Virginia for insurance to cover a minimum stay of 48 hours in the hospital after a mastectomy and the delegate who was sponsoring the legislation, Philip Hamilton, said “This was passed because of you, because of VBCF.” Also, the fact that VBCF members have been invited to the White House and that women have been taken seriously in respect to this disease. Personally, for me, it was receiving the Senate Resolution.

What was your worst time personally? When Sherry died. We were in the same clinical trial. We were the same age. Why her and not me? That’s the question we haven’t answered yet. It just shows how little we still know.

Why don’t you call yourself a breast cancer survivor? I feel uncomfortable calling myself a breast cancer survivor because the truth is, I do not know if I will be among the 50% who survive breast cancer or the 50% who die from it. For me, it’s a personal, political statement. I believe that to call myself a survivor is to imply, wrongly, that I am able to triumph over this disease through sheer determination and courage. I believe we must use the language surrounding breast cancer to assure that we do no euphemize or gloss over the devastation of the disease but that we consciously and continually call attention to the increasing toll on women and their families: the fact is 50% of us won’t survive. Until all women can survive breast cancer, I’ll use my words to express the anguish and anger of the thousands of women who have no chance.

You’re the only founder and originating member who’s still on the Board. Why do you have such endurance? Because I have a daughter. We’ve made advances in treatment. We’ve probably increased survival time but we have had no significant impact on mortality issues.

What’s your vision for VBCF now? Our goal is to eradicate breast cancer. I’d like to know that we’re having an effect in the level of research being done, making sure the research is relevant and effective, that it’s having an impact on survival time and rates. Personally, I’d like us to look more carefully at environmental links.

What’s the most important thing someone reading this newsletter can do in the fight against breast cancer? Become an activist and an advocate. Find out more about how to do that by calling VBCF. We have a place for everyone; we have lots of activities and we always need help.

What would Sherry say to you today, watching you look through the archives? She’d want to be here with me. I thin’ she’d be amazed at far we’ve come but I also think she’d say she knew we could get to this point and we can’t give up.
A Canadian study shows there is no benefit to regular mammograms under the age of 50.

The sentinel lymph node technique is first tried. Clinical trials accrued beginning in 1996. With practice, doctors are demonstrating a 95-98 percent accuracy rate. *One in 8 women will develop breast cancer.*

Scientists at the National Institute of Environmental Health announce discovery of the breast cancer gene mutation BRCA1. The gene, if damaged, can predispose women to a greater risk of developing breast or ovarian cancer. This led to later discovery of the BRCA2 gene mutation and the availability of genetic testing for those concerned about a family history.

Dr. Susan Love receives funding to follow up on Dr. Papanicolaou’s (1958) ‘breast pap smear.’ Her ductal lavage procedure for early detection of breast cancer in high-risk women shows promise in clinical trials now being conducted.

NCI convenes a consensus conference to answer the question: Should younger women undergo routine screening mammograms? The answer is no. Screening advocates pressure the US Senate and NCI to reject the consensus decision. In March, NCI’s Advisory Board recommends annual mammograms for women during their forties.

Mayo Clinic publishes retrospective study stating prophylactic mastectomies are 90% effective. *The National Surgical Adjuvant Breast and Bowel Project* F-1 trial is halted after only 4 years because the results of the trial seem promising for the prevention of breast cancer. The trial reported a 48% reduction in breast cancer for women taking tamoxifen versus placebo. (Tamoxifen is not without its side effects however, and women are urged to discuss their risks with their doctors.)

The American Society of Clinical Oncologists reported the results of the clinical trial of Taxol in the adjuvant setting. After 2 years of the trial, there was a 4 percent increase in disease-free survival and a 2 percent increase in overall survival. Ongoing studies of Taxol have not demonstrated this same survival improvement.

Two new drugs, Angiostatin and Endostatin, have cured mice by cutting off the blood supply to tumors (angiogenesis). These drugs had not been tested in humans, but these drugs as well as other anti-angiogenesis drugs may become another form of cancer therapy.

Herceptin is the first monoclonal antibody approved for use in humans and does not have the debilitating side effects of traditional chemotherapy. VBCF with NBCCD had spent years advocating for funding research of Herceptin.

October 1998 - The FDA approves Tamoxifen for women at high risk for breast cancer.

Several studies find that bone marrow transplantation has no survival advantage over chemotherapy alone.

The Study of Tamoxifen and Raloxifene (STAR) clinical trial begins accruing patients. Raloxifene, originally developed to combat osteoporosis, may also decrease the risk of getting breast cancer. While this trial is ongoing, other scientists are developing new compounds like tamoxifen and raloxifene to test in clinical trials as the search for the perfect selective estrogen receptor modulator continues.

Many doctors are now using sentinel lymph node technique to help stage breast cancer, thereby decreasing a woman’s risk of lymphedema after breast cancer surgeries and treatment. Definitive study currently underway by American College of Surgeons. Reports at the San Antonio Breast Cancer Symposium focus on the promising results of trials of aromatase inhibitors (such as Arimidex and Femara). These hormonal agents are proving effective when women become resistant to tamoxifen and may ultimately prove more effective than tamoxifen in the adjuvant setting.

The Human Genome – wherein scientists sequenced the entire human genetic code – is completed. This offers the opportunity for ongoing research on the complex interaction of genetic makeup at birth and genetic changes during lifetime that result in cancer.

Scientists at the National Human Genome Research Institute develop a new genetic test that can easily distinguish between hereditary and sporadic forms of breast cancer. This new approach might make it possible for physicians to quickly and accurately diagnose the cause of an individual woman’s disease and may ultimately guide decisions about the most effective treatment.

At the National Breast Cancer Coalition (NBCC) Annual Advocacy Training Conference, NCI Director Richard Klausner, MD, tells advocates that thanks to the Human Genome Project - scientists will be able within the next 5-10 years to identify exactly what type breast cancer you have and what specific treatment will work. NBCC - marking its 10th year - announces that it hopes it will not need to be in existence in another 10 years.
VBCF sponsors "Primary Care Perspectives" a first of its kind conference providing state of the art breast cancer diagnosis and management information to primary care professionals.

"We need to continue to look forward. We're a long way from finishing." — Mary Jo Kahn, VBCF co-founder

VBCF launches participation in the National Breast Cancer Coalition's Campaign 2.6 calling on President Clinton and the U.S. Congress to re-commit to eradicating breast cancer by allocating $2.6 billion in federal dollars in breast cancer research between 1996 and 2000.

Working with U.S. Senator John Warner, Virginia's First Lady Susan Allen, NBCC and Regency Square, VBCF brings the "Face of Breast Cancer", a memorial photographic exhibit of women who have died from breast cancer across the nation, to Richmond.

Mary Jo Ellis Kahn receives the AVON Breast Cancer Leadership Award for her work in the area of genetic testing for hereditary susceptibility to breast cancer. AVON donates $100,000 to VBCF in honor of Mary Jo.

VBCF VP Ann Wilson attends a ceremony at the White House and President Bill Clinton announces that $30 million intended for general breast cancer and biomedical research will be used specifically for genetic research at hospitals, universities and laboratories across the country.

February

Sherry Kohlenberg, co-founder of VBCF, who died in July 1993, is added to "Faces of Breast Cancer: The Legacy Continues."

VBCF works with Senator Janet Howell to get the Genetic Information Privacy Act passed, making the results of genetic testing unavailable to health insurers for a two-year period and prohibiting health insurance companies from discriminating based upon family history.

March

SHARON H. KOHLENBERG HEALTHCARE SERVICE AWARDS
Presented to individuals in the healthcare field who have exhibited a deep and abiding commitment to fighting breast cancer.

NANCY G. DOPP VOLUNTEER OF THE YEAR AWARD
Presented to those who have selflessly given their time and talents to benefit the Virginia Breast Cancer Foundation and the fight against breast cancer.

April

VBCF hosts a ten-year anniversary party for the members. Fran Visco, NBCC President, speaks on the decade of breast cancer advocacy and its impact on breast cancer research funding and protection of individuals affected by the disease. In the last 10 years, funding for breast cancer has increased 6 times. Breast cancer activists have raised over $1 billion for research.

Collaborating with the American Cancer Society, Virginia Primary Care Association and others, VBCF works successfully to get the General Assembly to pass the Virginia Breast and Cervical Cancer Treatment Act.

With financial support from the Komen Greater Richmond Race for the Cure, Richmond Gay Community Foundation and the American Cancer Society, VBCF launches a new outreach program to educate lesbians about breast cancer. Lesbians are 3 times more likely to develop breast cancer than their heterosexual peers.

May

VBCF joins NBCC and other breast cancer activists to introduce the year's legislative priorities on Capitol Hill (see article on priorities). NBCC dedicates their Advocacy Conference in memory of VBCF originator member Kendra McCarthy

"I'm In The Pink Day," an awareness campaign and fundraiser started by the Chester Tri-Cities chapter goes statewide. The Friday before Mother's Day, participants wear a pink ribbon, contribute to VBCF, and remind women everywhere to be diligent about breast cancer issues.

June

VBCF commemorates its 10 year anniversary with a Ribbons and Roses Ball.

July

The Virginia Breast and Cervical Cancer Treatment Act becomes law.

"It's not just a cycle of deaths and funerals but a cycle of strength and transformation." — Stuart Self, VBCF board member

"We cannot allow the fight against breast cancer to be a one-day event. It is an ongoing battle." — Susan Allen, First Lady of Virginia

"We need to continue to look forward. We're a long way from finishing." — Mary Jo Kahn, VBCF co-founder

VBCF exists because of the generosity of others. We thank all the people who have financially supported us in our fight against breast cancer. While we cannot acknowledge everyone, we do want to especially thank the following individuals who every year give their time, energy and hearts to VBCF: Sharon Talarico for hosting the Annual Women's Golf Tournament which raised over $21,000 this year, Gloria Barnes for hosting the annual Jazzercise and the members of the Tidewater Chapter for their Annual Fashion Show. Thank you.
VBCF joins with NBCC to develop “Faces of Breast Cancer” national exhibit.

Governor Allen proclaims Breast Cancer Awareness Month at a press conference where VBCF member Kendra McCarthy speaks.

Governor Allen proclaims Breast Cancer Awareness Month at a press conference where VBCF member Kendra McCarthy speaks.

VBCF co-sponsors “Breast Cancer: In Search of Prevention.”

VBCF presents “Current Trends in Breast Cancer Research, Treatment and Advocacy” seminar which was partly filmed by a Japanese crew making a documentary to help Japanese women become more effective advocates.

When co-founder Sherry Kohlberg died, Patti wrote, “We are riding together on a bus that no one wants to be on. This is how it ended.”

“On the grounds of the State Capitol, VBCF hosts “Lighting The Way: Dark Night”, a candle lighting service. The message – lighting the way in partnership with the Motorcyclists Against Cancer – kicked off the ceremony with a feeling of hope and unity.”

“VICTORY! Thanks to the hard work of breast cancer activists in Virginia and across the nation, the Cervical Cancer Treatment Act passed becomes a law, guaranteeing treatment to low and uninsured women diagnosed through a screening program.”

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VBCF hosts “Breast Cancer: How You Can Make a Difference” with workshops on the different levels of breast cancer advocacy: self-advocacy, advocating for a loved one, and grassroots advocacy.

Thanks to a grant from the Mary Welford Foundation, VBCF expands its “Pink Ribbon Campaign” and distributes over 30,000 pink ribbons and information about early detection.

Order yours now. Call 1-800-345-8223

VBCF members meet in Virginia with Congressman Tom Bliley to discuss the need for the Breast and Cervical Cancer Treatment Program and he pledges support. A major turning point in passage of this bill.
Contribution

A contribution of $__________ is enclosed.

In Memory Of

or In Honor Of (If you would like an acknowledgment card sent, please include name and address of recipient.)

NAME

ADDRESS (INCLUDE APT.#, RO. BOX, ETC.)

CITY STATE ZIP

☐ Please send me information on Planned Giving

Yes, we accept MasterCard and Visa.

☐ Please contact me about becoming a VBCF volunteer.

Annual Dues Information

☐ Basic $20 ☐ Sponsor $250 ☐ Courtesy (available if unable to pay membership fee)

☐ Family $25 ☐ Patron $500

☐ Friend $100 ☐ Benefactor $1000

NAME OR FAMILY MEMBERSHIP NAME

ADDRESS (INCLUDE APT.#, P.O. BOX, ETC.)

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This newsletter, published by the Virginia Breast Cancer Foundation, focuses on breast cancer issues and the activities of VBCF members. If you wish to join VBCF, or have any editorial comments, please call 1-800-345-VBCF or write to: Virginia Breast Cancer Foundation, 5001 W. Broad St., Suite 201, Richmond, VA 23230

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