Virginia Breast Cancer Foundation: The Early Years  Written by Mary Jo Kahn, VBCF Co-Founder

Virginia Breast Cancer Foundation began with nothing, really nothing, but a handful of angry women. That may sound harsh, but there are things you should know about breast cancer 20 years, even 40 years, ago.

When my mother was diagnosed in the 60’s, the words breast and cancer were almost never said in public and people whispered them in private. Twenty some years later, some things had changed. Cancer could be discussed in the open, even breasts could be, but breast cancer was still whispered, as if it were something embarrassing to have. Meanwhile, the lifetime risk of having the disease had risen steadily from 1 in 20 when my mother was diagnosed to 1 in 9 when my sister and I were diagnosed in 1989. Yet even with this startling rise in incidence, there was no special outlay of research money to combat this disease. Breast cancer was a silent epidemic.

The founders of VBCF met in a breast cancer support group at MCV after our diagnoses. It was a time in America when women were shaking their heads and were wondering what was going on here. We felt like women were dropping like flies, yet no one seemed concerned about helping us. Then we got angry!

In the spring of 1991, Patti Goodall, because of a chemo complication, was in the hospital watching the Today Show. That day they were interviewing Elenor Pred who was organizing a Mother’s Day Rally in San Francisco to raise awareness about the breast cancer epidemic. Patti picked up the phone and called 411 San Francisco and asked for Elenor Pred. Lo and behold, there was only one, and she and Elenor had a long conversation.

When Patti came back to support group she was fired up as was her good friend, partner in breast cancer, and another member of our little support group, Sherry Kohlenberg. It really did not take much persuasion to talk the rest of us and a few members of the autologous bone marrow transplant support group into following...
VBCF is here today because of a vision that five women shared in 1991. Their vision continues to remain the mission of VBCF — the ERADICATION of BREAST CANCER through EDUCATION and ADVOCACY. On November 5, 2011, we held Our Ribbons & Roses Reception to commemorate our 20th anniversary. Four of our five co-founders were able to attend: Phoebe Antrim, Judi Ellis, Patti Goodall, & Mary Jo Kahn. Unfortunately, our fifth co-founder, Sherry Kohlenberg, lost her battle to this disease in 1993. The evening was dedicated to our Immediate Past President, Becky Morris, who lost her battle in December, 2010.

Congratulations to our award winners, Mary Saunders and Leotha “Candy” Wilkins. During our reception, Judi Ellis presented the Nancy G. Dopp Volunteer of the Year Award to Mary Saunders. Dr. Harry Bear presented the Sharon H. Kohlenberg Healthcare Service Award to Leotha Wilkins. Dr. Bear and Dr. Tom Smith were the first recipients of the Kohlenberg award that recognizes a medical professional who goes above and beyond in making a difference in the lives of folks diagnosed with breast cancer.

And, a big shout-out to all our reception committee members, particularly our co-chairs, Lisa Branner and Samantha Reed. It was such a wonderful event.

I am so proud to have been associated with these and so many other wonderful women and men during my term as president of the Board. My term will end on 12/31, but I will continue to serve for two years as Immediate Past President and as VBCF’s representative on the Board of the National Breast Cancer Coalition. It has been an honor representing you and the organization. I am truly thankful for all the support that I received from our Staff, VBCF Board, Chapters, and YOU.

Watch for our January e-news and the first One Voice in 2012 where you will meet our new officers and our new Board of Directors members.

In this edition, you will see lots of articles about our great chapters and how they are making a difference in their community and throughout the state. They also had fund-raising events, which help us pay the bills each month. October was so busy for everyone associated with VBCF. We had so many requests for literature tables and speakers that we were unable to staff all of them. If you are interested in helping at these types of events, contact Jaime at our office (jaime@vbcf.org).

When I share my story publicly, I often say that while I do not wish breast cancer on anyone, my life has truly been blessed and enhanced by my journey. It may sound corny, but its true and much of that is because of the wonderful women and men that I have met.

So, I will end with Happy Holidays and a wish that your 2012 be filled with love, laughter, joy, hope and Good Health.

Please contact me if you have any questions or comments about VBCF. I can be reached via email at president@vbcf.org (until 12/31) or gorudis@verizon.net or call the office at 804-285-1200 and leave a message.
Sharon H. Kohlenberg Healthcare Service Award

This award recognizes individuals employed in the healthcare field who exhibit a deep and abiding commitment to the fight against breast cancer. The award honors the memory and reflects the spirit of Sherry Kohlenberg, a co-founder of VBCF, who was a vibrant, competent healthcare worker and a dynamic breast cancer activist. Sherry died from breast cancer in 1993.

Presented to: Leotha Wilkins, RN and the Hope Wellness Center

Mrs. Leotha ‘Candy’ Wilkins, RN, is President and CEO of the non-profit Sisters of Hope, Inc. She is a dedicated healthcare provider who has placed her life on hold to help those with financial limitations who are battling breast cancer. She lost her sister, Melanie, to breast cancer several years ago. It was her sister’s battle that led her to create the Hope Wellness Center in Woodbridge, a non-profit organization dedicated to helping the uninsured and underinsured who are suffering with breast and prostate cancers and HIV/AIDS.

In her professional life, Mary has been a registered nurse for 30 years, with the second half of her career devoted to oncology practices with a focus on caring for women with breast cancer. She has her master’s degree in nursing and certification in oncology nursing. For over 10 years, she worked at Virginia Commonwealth University Medical Center on a multidisciplinary oncology team associated with Massey Cancer Center. She currently works at the Ellen Shaw de Paredes Institute for Women’s Imaging.

She currently lives in Charlottesville with her husband of 30 years, Sam Saunders and has two grown sons. Mary Saunders is an amazing volunteer, always giving of herself, and doing so with a smile and positive attitude. VBCF is proud to present this award to Mary Saunders.

Want to receive the VBCF Connection, our monthly e-newsletter? Visit www.vbcf.org to sign up!
Volunteer Spotlight: Marilyn Lewis

Marilyn Lewis is a native of Virginia and a 1975 Business Administration graduate of Norfolk State University. In her early work career she worked in the Portsmouth School system, but decided to transition into the federal government. She now has 24 years of government service.

Marilyn was invited by Eunice McMillan, founder of the Hampton Roads Chapter, to join the chapter. Eunice asked if she wanted to be a part of an advocacy group for breast cancer. Little did she know that joining would bring so much meaning to her life. Marilyn has never had breast cancer, but the first hand experience of losing friends and family members to this disease constantly motivates her to be an active volunteer and advocate. Marilyn is currently the treasurer of the chapter.

Her greatest enjoyment comes from working on the committees for special projects such as Victory Walk, Rolling for Life Motorcycle ride and the chapter’s annual luncheon. The annual luncheon is her pet project. The luncheon is the chapter’s major fundraiser. Marilyn’s family and friends come from all parts of Virginia and Washington, D.C. to lend a hand and fellowship with the chapter as they work to raise the money needed to eradicate this disease.

In addition to her fulltime job, she has assumed the responsibility and care for a sick and aging friend. Those of you who are caretakers understand what this entails. Also, in her spare time she has adopted by love, a nephew, affectionately called Lil’ Darryl, although he is over six feet tall. Marilyn has never been a mother, but her desire to make a difference in this young man’s life has caused Marilyn to extend herself to him.

She enjoys watching football and basketball, listening to jazz, and attending plays. She also enjoys getaway trips with her two sisters and girl friends when they all need time to refresh and have fun.

Marilyn’s calling in life can best be summarized by two Maasai tribal sayings: □ One hand cannot clap on its own but it needs the other hand to make a clap. □ Many hands make light work. □

VBCF Library Outreach Program

The VBCF Library Outreach Program began at the local level in the Central Virginia Chapter of VBCF. The purpose of the program is to provide education on breast cancer topics to the public by donating money for breast cancer books and periodicals to be purchased by public libraries. VBCF took this program to the state level in 2007, donating money for breast cancer books and periodicals to public library systems in areas of the state that do not necessarily have an active VBCF Chapter, allowing us to provide educational resources to residents in those areas. VBCF set up a Library Outreach Grant Program in 2010, with funding cycles occurring in July and December of each year. Priority is given to libraries in underserved communities. Applications can be found online at www.vbcf.org.

Libraries receiving funds in the July 2011 cycle were: Wythe-Grayson Regional Library, Waynesboro Public Library, Bedford Public Library System, Pittsylvania County Public Library, Staunton Public Library, Arlington Public Library, Pulaski County Library System, and Craig County Public Library, Inc.

Two of VBCF’s chapters, Blue Ridge and Central Virginia, have also made library donations this summer and fall. The chapters make donations to library systems in their surrounding area to purchase breast cancer books, periodicals, and other media.

The Central Virginia Chapter donated to Appomattox Regional Library System, Fort Lee Community Library, and Pamunkey Regional Library.

The Blue Ridge Chapter donated to Jefferson-Madison Regional Library.

Thank You Chapter Members & Volunteers!

Thanks to your hardwork & dedication, VBCF was able to:

- Staff over 50 literature tables & health fairs
- Provide speakers for more than 20 engagements
- Distribute over 86,000 pink ribbons and literature with information about breast health and free screenings through the Every Woman’s Life Program for the uninsured and underinsured.

Educate. Advocate. Eradicate.
Photos (l-r): Photo 1 and 2: Diners enjoy a meal at The Brickhouse Run in historic Old Towne Petersburg during the 15th Annual Breast Cancer Awareness Dinner. The Central Virginia Chapter hosts the event with The Brickhouse Run and receives a portion of the proceeds from dinner and all tips earned by the celebrity waitstaff. Photo 3: The Hampton Roads Chapter presented the Overton Award, Chapter Volunteer of the Year Award, and the Twining Award at their annual luncheon on November 12. Photo 4: Volunteers help set up for the Peninsula Chapter’s 13th Annual Golf Tournament. This year’s tournament raised over $6,500 for VBCF. Photo 5: The Prince William Chapter participated in a number of health fairs during breast cancer awareness month, including the 6th Annual American University Breastival. Photo 6: The Prince William Chapter participated in the Role Models Fashion Show at Potomac Mills. The event included a runway fashion show, food, music and several door prizes. Lydia Stewart and Brenda Bryant represented the VBCF-PWC Chapter and received awards for their work with VBCF. The event raised almost $900 for VBCF.
Virginia Breast Cancer Foundation: The Early Years - Continued from Cover.

Elenor into action, even if we did not have any idea what that meant. We started planning our own Mother’s Day Rally. Footnote: it was exactly 4 weeks until Mother’s Day, not exactly a reasonable time frame for pulling off a statewide rally.

Undeterred, on Mother’s Day, 1991, on the Capitol grounds by the Bell Tower, we had our first Mother’s Day Rally. The support group and some family members got together at my house and made posters. We had our first T-shirts made. We had speakers. Dr. Harry Bear was one of those speakers, if my memory is correct. Most importantly, we got press coverage! Our children had made some really sweet posters that were on the front page of the next day’s newspaper. As a result of the rally, The Richmond Times Dispatch did a whole story on the current state of breast cancer and our nascent organization’s efforts to eradicate it. We had met our first goal: to raise awareness.

After the rally was over, the five founding members of the Virginia Breast Cancer Foundation, Patti Goodall, Sherry Kohlenberg, Phoebe Antrim, my sister, Judith Ellis, and me, knew we had another goal yet to meet. We needed to make sure enough research money was available not just to make progress on breast cancer, but enough to actually eradicate the disease. Most of us had young children. What we were fighting for was prevention.

Patti continued her conversations with Elenor and soon learned of a meeting Elenor was planning in Washington, D.C. Patti had to work and could not go. She called me and I was able to rearrange my schedule. The next day, my 12-year-old daughter, Michelle, and I took the train to Washington and began an unbelievable journey.

Our first meeting was with organizations that had been communicating with Elenor Pred after her TV appearance. Besides Richmond and San Francisco, there were groups there from Arizona, Boston, Vermont, San Diego and three or four other locations. At some point in the meeting, I took a step back and studied the people around the table. Separately, but simultaneously, there were strong, intelligent, articulate women from all over America saying enough is enough. It was a true grassroots movement, not led from the top down, but by the unified determination of many. At that moment, I realized we were an unstoppable force and we would succeed.

Our little band of Elenor’s groups headed for the National Cancer Institute and met with the Director there and many of his heads of departments. We were totally stonewalled. Although Elenor kept interrupting to say they should be listening rather than talking, the director insisted $30 million was more than enough money, and we should be satisfied with the progress they were making. Later that year, Bernadine Healy, the first woman Director of the National Institutes of Health, betrayed all women by telling Congress that it would be dangerous to allocate any more money to breast cancer research.

The next day, there was a meeting of approximately 100 other breast cancer groups, to explore joining together in some sort of coalition with a unified goal of securing more funds for breast cancer research. I remember introducing myself that day as being from Richmond, Virginia representing a group to be named later. We may not have settled on a name yet, but we knew we would be part of this coalition. To eradicate breast cancer it was going to take Virginia and 49 other states.

Next, we invited every person who might possibly be interested to an organizational meeting in my living room. Maybe 20 people came. That night, we named ourselves, decided to be a statewide organization, decided to incorporate, and to explore becoming a non-profit. I was made president, possibly by default; I was the only one who had time to do it.

We immediately volunteered to be on the working group that later became the Board of Directors of the National Breast Cancer Coalition. We were the first Chairs of the Grassroots Taskforce for NBCC. There we took what we had just learned about organizing breast cancer advocates in Virginia to the other states. We helped them to put on Mother’s Day Rallies, to form legislative telephone trees, and to recruit membership. Holding a seat on the Board of NBCC for twenty years has meant twenty years of hard, time consuming, financially challenging work. Few organizations in the country have contributed as much as VBCF has to the national, as well as the state, efforts against breast cancer.

I was recently reminded of our first trip to Washington to meet with our Congressmen. Twenty years ago, we were relatively young women, some of us not yet forty and we were scheduled to meet with Senator John Warner’s health aide. The aide made the mistake of saying to us, “Well, everyone has to die of something.” Continued on Page 8.
Dr. Susan Love Foundation’s Army of Women
Recruiting for The Milk Study

Researchers at the University of Massachusetts at Amherst are studying the breast cells normally found in breast milk to see if there are any epigenetic differences between women whose biopsies turn out to be healthy and those whose biopsies show a problem, such as cancer. Learning more about these epigenetic differences may eventually help researchers develop a way to provide women with information about their breast cancer risk.

The researchers have already enrolled more than 250 women, but mostly Caucasian women. Since breast cancer risk factors differ among ethnic groups, the researchers are particularly interested in enrolling African-American women, Latinas, Asian women, and other ethnic minorities.

Who Can Participate? You can join the Milk Study if you match ALL of these categories:

• You are a breastfeeding mom
• You have had a breast biopsy at any time in the past OR you are going to have a breast biopsy to diagnose a lump in your breast
• You live in the United States

What Does Participation Involve? You will be asked to donate two fresh milk samples (one from each breast). After the research team receives your breast milk samples, they will contact you to ask if you have had a breast biopsy. If you have had a biopsy, you will be asked to provide a copy of the biopsy report. Approximately one year after sending your breast milk sample, the research team will contact you to ask about any breast problems you have had in the last year. The information you provide is confidential and will be kept private. For complete details visit www.armyofwomen.org/current/view?grant_id=375.

Not a match for this study? Join the Army of Women and visit www.armyofwomen.org/current to view other studies that are currently recruiting.

ALTTO Breast Cancer Clinical Trial: Targeted Therapy for HER2 Breast Cancer

ALTTO is an international, phase III clinical trial of two targeted therapies for HER2-positive breast cancer. HER2 is a protein found in high levels in about 25 percent of all breast cancers. Tumors that overproduce HER2 tend to be more aggressive and are more likely to recur than those that do not.

The drugs that are being tested in ALTTO, lapatinib and trastuzumab, target the HER2 in different ways. Researchers want to find out whether one drug will prove better than the other at helping women live longer without a recurrence of their disease, or if the two drugs will work better together.

The ALTTO study has enrolled more than 8,000 participants in 50 countries on six continents. Women with HER2-positive breast cancer who have had their tumors completely removed by surgery were eligible to join.

Beyond improving treatment for women with this type of breast cancer, the ALTTO trial represents a new level of international cooperation in the advancement of cancer care. ALTTO is one of the first global initiatives in which two large, academic breast cancer research networks covering different parts of the world have jointly developed a study in which all care and data collection are standardized, regardless of where patients are treated.

On September 9, 2011, the leadership of ALTTO announced that it will discontinue Arm 2 of the trial. The Independent Data Monitoring Committee review of efficacy in the trial was triggered after a pre-specified number of events was reached. Stay tuned for the results of this trial.
Virginia Breast Cancer Foundation: The Early Years - Continued from Page 6.

We had a reporter with us that day and the aide ended up being quoted in the paper. Despite his aide’s faux pas, Senator Warner became our biggest advocate in Congress and the following year became crucial in securing research funds through the Department of Defense.

As Grass Roots Chairs for NBCC we were key in organizing the Do the Write Thing Campaign. Each state was asked to send letters to each Congressperson and the President equal to the number of new cases of breast cancer in their state that year. Our number was around 4200, we sent 10’s of 1000’s. Nationally, we needed 43,000 letters; over 2 million were collected from around the country. The overwhelming success of the Do the Write Thing Campaign proved we were a force with which Congress must reckon.

The votes in Congress for the breast cancer research money that year went down to the wire. There were a few Senators who were in tough races for re-election in 1992 and were courting the women’s vote. At the last moment, these Senators reversed their no votes. The Senators who had voted no rushed to change their votes to yes when they realized the bill was going to pass. The vote was now overwhelmingly in our favor! We won our fight for $300 million more!

Breast cancer research monies have continued to increase because you are still persistent and still a force to be reckoned with. There is so much history that the Virginia Breast Cancer Foundation has made and so many more accomplishments for which you are responsible. I am so very proud of you. Many times pioneers, who start organizations, are the organization and when they leave, the organization folds. That is not what happened to the Virginia Breast Cancer Foundation. Since the founding members and a tough band of early volunteers laid the groundwork, you have matured, thrived, and grown into a more powerful force against breast cancer each year. I had to leave after my second bout with breast cancer around 1999. Others retired for other reasons. Many have died.

I know you have all felt the pain of losing a friend or loved one to breast cancer. It is in their memory, it is for yours and my future, and it is for our collective children that you continue to fight. The eradication of breast cancer is going to happen. Trust me, you are still an unstoppable force and you will succeed.

Help Us Succeed in Putting an End to Breast Cancer by January 1, 2020

State Lobby Day
Save the date for VBCF’s State Lobby Day • Tuesday, February 7, 2012 • in Richmond, VA. Advocates will break into teams to visit our Delegates and Senators and lobby for important legislative issues related to breast cancer. Your voice matters!

If there is enough interest we will charter a bus to bring participants from the Tidewater and Western Virginia areas. Contact VBCF at 800-345-8223 or www.vbcf.org to sign up today.

National Lobby Day
Save the date for VBCF’s National Lobby Day • Tuesday, May 8, 2012 • in Washington, D.C. VBCF will charter a bus from Hampton Roads to Yorktown to Richmond to Washington, D.C. where advocates will break into teams to visit our Representatives and Senators and lobby for important national legislative issues related to breast cancer. If there is enough interest transportation will also be coordinated from the Blue Ridge area. Last year VBCF brought close to 100 advocates to Washington for National Lobby Day, and this year we’re aiming to bring even more! Your participation matters! Contact VBCF at 800-345-8223 or visit www.vbcf.org to sign up today.

Make a Contribution:

• Your donation of $20 will pay for one advocate to attend State Lobby Day.

• Your donation of $40 will pay for one advocate to attend National Lobby Day.

Visit www.vbcf.org to donate online or make checks payable to VBCF and mail to: 5004 Monument Avenue, Suite 102, Henrico, VA 23230. Donations are tax deductible.

Like us on Facebook!
www.facebook.com/virginiabreastcancerfoundation
Thank You!

A special thank you to the following organizations and individuals who partnered with VBCF to raise awareness and funds this fall:

- A New Length Salon & Day Spa, Mechanicsville
- Alpha Kappa Alpha Breast Cancer Walk, University of Richmond
- Books-A-Million, Virginia Stores
- Brighton Collectibles, Williamsburg Outlet
- Brighton Collectibles, Stony Point Fashion Park
- Brooke Point High School, Stafford
- Calypso Studios, Inc.
- Carpenter Co.
- Castlewood High School SADD Club, Castlewood
- Central Virginia Sporting Clays - Shoot for a Cure
- Emilio’s Restaurant, Richmond
- Hunter Holmes McGuire VA Medical Center, Richmond
- Grafton High School, York County
- James River Air Conditioning, Richmond
- K & B Tattooing, Richmond
- Monkees of Richmond
- PC Recycler
- Pink Ribbon Polo Committee - Crush for a Cause
- Project Yoga Richmond Inc.
- Prince Edward County High School, Farmville
- PUMP Custom Fitness, Richmond
- Red Nail Salon, Richmond
- Skipwith Academy
- Thairapy Salon, Richmond
- Transatlantic Brides & Parents Association, Shenandoah Valley Branch
- Warrenton Auto Service, Warrenton
This holiday season, give a gift that:

• says you care
• provides help and hope for others
  • provides education
• saves packaging and shipping
• you don’t have to shop for
  • will keep on giving
• is tax deductible

Make a donation to Virginia Breast Cancer Foundation (VBCF) in honor or memory of a loved one. VBCF will send a gift acknowledgment within one week directly to the name and address provided. Donate online at www.vbcf.org or mail a check to: VBCF, 5004 Monument Avenue, Ste. 102, Henrico, VA, 23230.