Mary Jo Ellis Kahn Introduces President Clinton at White House

On July 14, VBCF co-founder Mary Jo Ellis Kahn introduced the President at a White House event later aired by C-Span. The event was called to announce the release of Health and Human Services Secretary Donna Shalala’s report on genetic testing and proposed legislation protecting privacy issues.

In her remarks, Mary Jo referred to her own family’s struggle with breast cancer and genetic testing. As one of four daughters of a mother who died of breast cancer, Mary Jo and her sisters have had to face both the reality of breast cancer and the difficult choice of prophylactic mastectomies. Pointing to her daughters and her niece, Mary Jo said, “Breast cancer is always a family disease, but when more than one generation is affected, it can become a way of life…we have struggled with whether or not to learn our genetic status”…knowing…”we may risk losing the health insurance for the next generation of Ellis.”

As Mary Jo concluded, she stated, “Let us hope that as our country learns more about our inheritance of DNA, both that which is good, as well as that which is imperfect, that we use this knowledge to bind us closer together, not separate us from one another.”

President Clinton referred to the “era of discovery…We are literally unlocking the mysteries of the human body…” He went on to state that it is “clear that it is wrong for insurance companies to use genetic information to deny coverage…It’s wrong when someone avoids taking a test that could save a life just because they’re so afraid that the genetic information will be used against them…Now, this kind of discrimination is—really it’s more than wrong, it’s a life-threatening abuse of a potentially life-saving discovery.”

Sighting the need for protection against genetic discrimination, the President pledged to send legislation to Congress that will ban all health plans, group and individual, from denying coverage or from raising premiums on the basis of genetic tests.

In attendance at the press conference, in addition to Secretary Shalala, were Dr. Francis Collins, head of the Human Genome Project, Susan Blumenthal, head of Women’s Health Office at HHS, and Congresswoman Louise Slaughter (D-NY), sponsor of HR 306, The Genetic Information Nondiscrimination in Health Insurance Act of 1997, one of several bills already filed during the 105th Congress. President Clinton specifically mentioned Senator Olympia Snowe’s (R-ME) bill (S 89) and support for legislation by Senators William Frist (R-TN) and James Jeffords (R-VT). Comprehensive reports on federal and state legislative issues affecting our members start on page 6 of this issue.
Close to Home
by Patti Goodall

When I learned the news of Princess Diana’s death, and then Mother Theresa’s, I thought about breast cancer. Breast cancer had nothing to do with their deaths, but for many of us, death and breast cancer are inexorably entwined. Breast cancer kills 46,000 Americans every year; over 1,100 women in Virginia. It’s hard to ignore; you live with it every day. You may forget about the diagnosis of breast cancer for moments, perhaps even days. But then someone has a recurrence, or dies, and the thought flies into your head, “Will I be next?” I think about the circumstances of my own death. It could be from breast cancer, or a car crash (like Princess Diana), or a heart attack (like Mother Theresa). While many people might have similar thoughts, I think that once you’ve been diagnosed with a chronic, killer disease like breast cancer, even if you are in remission (some say “cured”), the fear remains. It could come back, and it often does, with a stunning vengeance. This is a war, and you wonder, “Why am I the one still standing?”

Several of our members died recently. One was a very active member, whom I last saw at the hearing this summer on insurance benefits for breast reconstructive surgery. She was there with her two beautiful daughters, hugging them tightly and smiling as they posed for a jubilant post-hearing picture. It was a wonderful moment. I hope that the memory of all the wonderful moments she shared with her husband, daughters, family members, and friends will sustain them. I hope that we, the living, focus on making lots of wonderful moments in our lives to leave behind for those we love, no matter who we are or how we take our last breath.

I’m pleased that VBCF is bringing one of the leaders in the battle against breast cancer to Richmond on October 7. We look forward to hosting an evening with Dr. Susan Love, who will give a short lecture and then take questions from the audience. A reception follows the lecture where Dr. Love will sign her books. You may purchase Dr. Susan Love’s Breast Book or Dr. Susan Love’s Hormone Book at the reception, with a portion of the proceeds benefiting VBCF. Capacity is limited, so please purchase tickets now!

October is Breast Cancer Awareness Month, always a very busy time for VBCF. Keep an eye out for VBCF baskets full of pink ribbons in Tidewater, Richmond, and Northern Virginia. Would you like to help distribute baskets in your community? Give us a call! If you are interested in participating in awareness activities, we have shower cards, brochures, and educational materials available for dissemination at your work or in your community. We are truly warriors with pink ribbons, so let us proclaim loudly our battle cry in October, “Nothing less than a cure and prevention!”

Profile

Sharon Talarico

Sharon Talarico moved from Connecticut to attend the Medical College of Virginia, receiving a degree in occupational therapy and a masters in pediatric occupational therapy. After nine years, she found her career veering away from patient care. Drawing on childhood memories of always being the number one Girl Scout cookie sales girl, Sharon now runs a successful financial consulting business.

Anybody who knows Sharon Talarico knows why her friends call her “The General.” The diminutive dynamo is a “get it done” kind of gal who divides her time between golf, a thriving financial services business and community service.

later she passed away, a victim of breast cancer, leaving two small children.

By that time the golf tournament had grown. Sharon looked for an organization that not only promoted education and awareness of breast cancer, but one that would be an advocate for the women who were its victims. The annual golf tournament, held in honor of Stephanie Steiger and other women with breast cancer, continues to support VBCF; this year raising over $80,100.

Sharon was honored as a VBCF Volunteer of the Year. She currently serves as a member of the finance committee, helping it direct funds into socially responsible investments. She may appear short in stature but her accomplishments are towering.
Central Virginia District

Libby Gatewood sponsored another Big Girls Dress Up Tea Party at the South Bend Clubhouse in Enon on Saturday, July 26, inviting friends, family and business associates to share delicious food and tea. Everyone had a great time creating their “special hat.” Prizes were awarded for: the most beautiful hat—VBCF member Annette Thomas; the most creative hat—Shirley Snider; and best overall look—Carol Messina. The Big Girls Dress Up Tea Party promoted breast cancer awareness among the women who attended by having a program on breast self exam. Libby donated $640 contributed by the “Big Girls” to VBCF for outreach and education in the Tri-Cities area. Many thanks to Libby, who works tirelessly for breast cancer education in this region.

Central & Tidewater Districts

On August 4-6, VBCF joined with the Susan G. Komen Foundation and BMW in its Drive For The Cure, with a goal of raising $1,000,000 for cancer research. BMW donated $1 for each mile test driven at BMW dealers across the nation. Richmond had the highest number of test drives on the East Coast! A fleet of cars was driven from city to city with volunteers at the wheel of luxury BMW cars. VBCF helped by furnishing volunteer drivers and getting folks out to the dealerships to drive the cars. The event started in Tidewater, where Ann Wilson coordinated the activities. In Richmond, Wanda Bruce and Beblon Parks helped to coordinate volunteers and were among those driving in the white BMW caravan on to the next city, Chapel Hill, NC. The caravan included a signature car which will bear the names of all drivers. In each sponsoring city a local “hero” was chosen and honored for her part in fighting breast cancer. Virginia’s “heroes” were: Betty Busciglio, Virginia Beach; VBCF member Nancy Greenport-Ennis, Newport News; and VBCF President Patti Goodall in Richmond. Not only was it a lot of fun in driving the cars, but also a tremendous opportunity for the VBCF to share information about breast cancer and help raise money for cancer research. Thanks to everyone who helped coordinate and all who participated in the event.

See Page 9 for further Chapter News

Editor’s Note: If you have an active VBCF group in your community, or if you are working individually 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!

For the 4th annual Jazzercise/VBCF “Dance for the Cause.”

We are organizing this as a state-wide event this year.

We need your help in Tidewater, Roanoke, Charlottesville, Staunton/Harrisonburg, Poquoson, Fredericksburg & Northern Virginia.

Your help is needed to staff a breast cancer awareness table at the events.

Richmond Class
DATE: Sun. October 5
PLACE: Jewish Community Ctr.
TIME: 1:30—3:30 P.M.

Contact Becky Morris 804-672-0061 or VBCF 804-285-1200. Call your local Jazzercise instructor 1-800-FIT-IS IT and be sure they have committed to this event.
As fall approaches, schools, corporate offices and government installations all over the state and country are gearing up for United Way campaigns. How can your annual giving to the United Way benefit the Virginia Breast Cancer Foundation? Easy! Direct your employer to designate VBCF as the recipient of your contributions. Most organizations will provide you with a list of eligible organizations that should include VBCF. If VBCF is not listed, write it in the space provided for “other.” In 1995, VBCF received a little over $1,000 in United Way designated contributions. In 1996, these gifts exceeded $10,000 and 1997 looks to be a good year as well. Name the Virginia Breast Cancer Foundation as your United Way designated recipient and help us to make 1998 even bigger.

In the July issue of the Journal of Pain and Symptom Management, a survey of doctors-in-training conducted in St. Louis showed a poor understanding of pain management based on guidelines published by the World Health Organization. The doctors in the study were internal medical residents, radiation oncology residents or hematolgy-oncology fellows. The 81 physicians essentially flunked an 18 question section on the pain management of a hypothetical 55 year-old patient with advanced lung cancer. Less than half recognized that the risk of cancer patients becoming addicted to narcotics is less than 1%. Only four of the 81 correctly converted an intravenous dose of morphine to its oral form; three out of four of the physicians calculated a dose that was less than one third the correct amount.

The CIONA HealthCare Lady Killer Tour ’97 is a statewide motorcycle tour to chase a killer, breast cancer. The tour raises money for the breast cancer research program at MCV’s Massey Cancer Center. Virginia’s First Lady Susan Allen is the Honorary Chair. The statewide motorcycle tour took place September 27 and 28 to kick off Breast Cancer Awareness Month. In addition to CIONA HealthCare, corporate sponsors of the Lady Killer Tour include Care Advantage, Haynes Jeep & Eagle, Marriott, McDonald’s and Ukrop’s.

As an advocacy organization, we believe that knowledge is power. Share knowledge with others through a gift of books or other materials—and be sure to use an attractive VBCF bookplate to mark the occasion! We have designed three attractive bookplates to meet your gift-giving needs. The bookplates are burgundy print on a white background with the VBCF logo. Bookplates may be purchased at $1.50 each or $3.00 for a set of three different bookplates. It’s a great way to donate books to libraries, support groups, hospitals, or to present a special gift to a friend. Proceeds benefit VBCF. Choose from ‘to—from,’ ‘In Honor Of,’ or ‘In Memory Of.’ Contact VBCF at 804-285-1200.

Hunter Homes McGuire Veterans Administration Medical Center celebrates the Third Annual Breast Cancer Awareness Week, October 6-10, with a series of events at the Center. The public is welcome to attend the events, which include a play, “The Pack,” on the 6th; a lecture, “Diagnosing Breast Cancer” on the 7th; a panel discussion of breast cancer survivors on the 8th; a Women’s Health Fair on the 9th; and, on the 10th, the week will conclude with the “Walk for Awareness.” A donation for T-shirts will be asked. And a contribution will be made on behalf of the Medical Center to VBCF. For information on all the events, or to sign up for the walk, call Beverly E. Ross, Women Veterans Coordinator, 804-675-5389.

In Memoriam

The Virginia Breast Cancer Foundation extends its deepest sympathies to the families and friends of the following members who died recently.

Tina Forkin

Annette Thomas

Annette Thomas’ sudden death had an especially painful impact on the VBCF board of directors. She had been very active in VBCF activities in the last year. Look for her beautiful, vibrant face in many of the photos included in this issue.

May we all continue to remember the dead and fight for the living.
Noted Breast Surgeon and Best-Selling Author Dr. Susan Love In Richmond

VBCF to host lecture, reception, and book-signing on October 7

The Virginia Breast Cancer Foundation is proud to present evening with nationally acclaimed surgeon and breast cancer advocate Dr. Susan Love on Tuesday, October 7, 1997, at The Cornerstone in Richmond. Dr. Love will give a lecture beginning at 6:00 pm, followed by a reception with hors d’oeuvres and a cash bar.

Also that evening, the winner of the 1997 Sharon H. Kohlenberg Healthcare Service Award will be honored. The award is named in memory of Sherry Kohlenberg, a healthcare administrator and cofounder of VBCF. VBCF gives the Kohlenberg Award each year during Breast Cancer Awareness Month to a healthcare provider who shows a deep and abiding commitment to the fight against breast cancer.

Susan M. Love, MD, is an author, teacher, surgeon, researcher and activist. She graduated from the Downstate Medical School cum laude in 1974. She did her surgical residency at Boston’s Beth Israel Hospital and was chief resident in 1979. She opened a private practice in general surgery in 1980 as the first woman surgeon on the staff of Boston’s Beth Israel Hospital. In 1982, she joined the staff of the Dana Farber Breast Evaluation Clinic, the first comprehensive multidisciplinary center for breast care. In 1988, in the private sector, she founded the Faulkner Breast Center in Boston, the first facility in the country to include a multidisciplinary, all female staff with five surgeons, two clinical nurse specialists, a plastic surgeon, radiation therapist and medical oncologist. This program has received national recognition and continues to this day combining patient care with a research program and fellowship in breast surgery.

In 1992, Susan Love was recruited by UCLA to found a multidisciplinary, comprehensive program addressing all aspects of breast care. In the fall of 1994, a generous gift from Revlon led to the establishment of the Revlon/UCLA Breast Center. The Center, under Dr. Love’s direction, developed the first comprehensive practice guidelines on breast disease, published in The Cancer Journal from Scientific American in January 1996. Within four years the Center was treating over 4,000 women a year in a cost effective, yet empowering way, leading McCall’s magazine to designate the UCLA Medical Center as one of the top ten hospitals for women because of its expertise in breast cancer.

In 1996, after twenty years of direct patient care, Dr. Love left clinical practice to devote more time to her basic research and her growing interest in women’s health to become an adjunct professor in clinical surgery at UCLA. She has a $500,000 grant from the Department of Defense to develop an intraductal approach to breast cancer. In addition, she is attending business school and intends to start an independent think tank on women’s health issues and ways to improve the health care of women in the managed care environment.

Dr. Love has been a leader in innovative approaches to the treatment of breast cancer, authoring many journal articles and coauthoring an Atlas of Surgical Techniques in Breast Surgery. In addition to her role in educating medical students and other health care providers at Harvard Medical School and then UCLA, she has always felt a mission to educate the public. As a result she lectures extensively, appears in magazine interviews, and on radio and television. Her book, Dr. Susan Love’s Breast Book, has been called “one of the most important books in women’s health in the last decade.” The second, fully revised edition, was released in June of 1995. Her book on menopause and the hormone dilemma, Dr. Susan Love’s Hormone Book, was released in February of 1997 and was on The New York Times best seller list. Susan Love has never been satisfied with the status quo. In her frustration at the lack of progress in breast cancer research, she helped found the National Breast Cancer Coalition, a coalition of breast cancer advocacy groups formed to involve breast cancer patients and their supporters as advocates for action, advances and change. Through political action, this group has increased research funding for breast cancer from $90 million to $410 million in two years. Their 1993 petition drive led to the White House, where Susan Love helped to deliver two million signatures to President Clinton demanding a National Action Plan for Breast Cancer. Susan Love now is one of the cochairs of that plan, bringing together women scientists, business people and politicians in an unprecedented effort to stop this disease.

For more information on the October 7 event, contact VBCF office at 800-345-8223.
Bills Introduced in 105th Congress To Have Impact on Women Living with Breast Cancer

by Jean Hoshall

Several important pieces of legislation were introduced early in 1997, dealing with issues directly impacting women living with breast cancer and their families and friends. The bills dealing with mastectomy/lymph surgery protection and reconstructive surgery (including symmetry) languish without public hearings. In the Senate, the first hearing relating to genetic discrimination was held on September 10. And the National Breast Cancer Coalition warns that Congress may reduce or eliminate DOD breast cancer funding.

Mastectomies/Lymph Surgery Protection and Reconstructive Surgery Initiatives

The Breast Cancer Protection Act of 1997 (HR 135), was introduced by Representative Rosa DeLauro (D-CT) in January. It would prohibit group health plans, group health insurance issuers and issuers of health insurance in the individual market from covering less than 48 hours of hospitalization following mastectomies or less than 24 hours following lymph node dissections.

On the same day, Representative Anna Eshoo (D-CA) introduced HR 164, The Breast Surgery Benefits Act of 1997, which requires group and individual health insurance plans and group health plans to provide coverage for reconstructive breast surgery (including symmetry surgery) if they cover mastectomies.

In February, Susan Molinari (then a Republican Representative from New York) introduced her version, HR 616, the Women's Health and Cancer Rights Act of 1997. This legislation would cover medically appropriate minimum hospital stays for mastectomies, lumpectomies and lymph node dissections (at the physician/patient's discretion) and coverage for reconstructive surgery (including symmetry), as well as other coverages. Similar to, but not as explicit in its language as Eshoo and DeLauro's bills, the legislation received strong bipartisan support, including cosponsorship by Rick Boucher, Democrat of Virginia's 9th District, and Republicans Tom Davis (11th) and Frank Wolf (10th). However, with the unexpected resignation of Ms. Molinari this summer, HR 616 seems to have been orphaned. In July, HR 616 had 92 cosponsors, but has added none since Congress returned after Labor Day from its long summer vacation. The Eshoo and DeLauro bills have continued to build support among House members, with additional cosponsors signing on to the bills. DeLauro's bill has nearly 190 cosponsors, five of whom signed on as cosponsors in September. Five of Virginia's House delegation are cosponsors. Eshoo's bill has 123 cosponsors (two from Virginia), 28 of whom signed on in September.

The bills were referred to the House Committee of Commerce, chaired by Virginia's 7th District Representative Thomas Bliley and to the Committee on Education and the Workforce, chaired by William Goodling (R-PA), with HR 616 to House Ways and Means as well. All three bills languish without public hearings. Representative Marge Roukema (R-NJ), a chief cosponsor of both DeLauro's HR 135 and Molinari's HR 616, urged Speaker Newt Gingrich to "fast track" hearings. Speaker Gingrich, however, has yet to schedule any hearings. Similar legislation was introduced in the Senate, including bills by Senators Tom Daschle (D-SD) and Alfonse D'Amato (R-NY).

In an effort to move HR 135 and HR 164 forward and get hearings scheduled, DeLauro and Eshoo have launched a petition drive on the internet. The petition drive, accessed though the Sapiens Health Network (http://breastcare.sbn.com) is using October's Breast Cancer Awareness Month to urge the House Committees-Commerce; Education and Workforce-to hold hearings. Other breast cancer organizations providing links include Y-ME, the Breast Cancer Fund, Community Health Project, American Medical Women's Association, National Lymphedema Network, American Society of Plastic and Reconstructive Surgeons, and the Breast Reconstruction Advocacy Project.

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Genetic Discrimination

Numerous bills dealing with genetic discrimination were introduced in the 105th Congress. Some are directed to employment practices; others at medical privacy and insurance discrimination. On the House side, Representative Louise Slaughter (D-NY) sponsored HR 306, The Genetic Information Nondiscrimination in Health Insurance Act of 1997. On the Senate side, two bills are particularly relevant; Senator Olympia Snowe's (R-VT) S. 89, titled identically to the House version and Senator Pete Domenici's (R-NM) S. 422, the Genetic Confidentiality and Non-discrimination Act of 1997. With the release of HHS's Report in July (see cover story), it appears that the bills dealing with medical genetic discrimination may be folded into a Medical Privacy omnibus bill. On the House side,
no hearings have been scheduled, again, with the Commerce Committee (Biley of Virginia), House Ways and Means, House Education and the Workforce, nor their subcommittees.

In the Senate, the Labor Committee’s first hearing was held September 10, 1997, where Secretary of HHS Donna Shalala submitted legislative proposals to the committee. The testimony created national news, particularly concerning the rights of law enforcement to breach confidentiality of medical information. The second hearing is scheduled on September 25. Of importance to VBCF members will be assurances that any omnibus legislation has strong provisions concerning genetic testing, disclosure, confidentiality and discrimination provisions.

DOD Funding

As the appropriations process continues, the Department of Defense’s $175 million dollar breast cancer research program may be in jeopardy. The peer-reviewed research program, IDEA—Innovation Developmental and Exploratory Awards—launched in 1992 under the Department of the Army, has been unusually successful in driving cost-effective, results-oriented research. Among the promising research funded has been the potential of DNA in reducing or immunizing against tumors, ways to block the potentially bad effects of estrogen without losing the benefits, discovery of genes that appear to ‘jump start’ breast cancer and some that do the opposite.

Persuading members of Congress of the importance of retaining these important research dollars under the umbrella of the Department of Defense is a major effort of the National Breast Cancer Coalition, and they are launching a major effort as a follow-up to Campaign 2.6 in May.

If you want more details about these important federal legislative initiatives, you may contact the VBCF office (800-345-8223). If you’re on the internet, or have access to it through your library or perhaps a friend, you will find a wealth of information, including full text of bills, listings of cosponsors, history and status, as well as addresses, phone numbers, e-mail addresses: http://thomas.loc.gov. And don’t forget the Sapient list-up: http://breastcare.shm.com, to express your opinions on the Breast Cancer Protection and the Breast Surgery Benefits bills. Those who wish to write or call will find phone numbers and addresses in the cosponsor box below. Make sure you identify yourself (name, address, phone numbers, Congressional District, and, if you wish, your affiliation with VBCF). Please copy VBCF or cc by e-mail: VBCF at 104775.3233@compuserve.com.

The chairman of the House Commerce Committee is also the Congressional representative from our 7th District. VBCF is sure Representative Biley would appreciate hearing from his 7th District constituents, as well as other Virginians, voicing our opinions on these issues. He must schedule hearings before these bills can move forward. VBCF encourages you to voice your opinions on legislation of importance to women living with breast cancer.

(Editor’s Note: I e-mailed my representative, Tom Davis, to express my opinion on HR 135. He responded within a few days. He said he is a full supporter and cosponsor of HR 616, but “…will support HR 135 if it came before the full House for a vote…” I plan to contact Representative Biley and Speaker Gingrich.)

Tally of Cosponsorship by Virginia Congressional Delegation (as of 9/20/97)

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All phone #s (202) area code. House of Representatives: R=Rayburn Bldg, Washington, DC 20515; L=Longworth Bldg, DC 20515; C=Cannon, DC 20515. Senate: SR=Russell Bldg, DC 10510. E-Mail to Senators and Representatives: http://thomas.loc.gov
Virginia Legislative Agenda

Commission Recommends Re-Introducing Two Key Bills

Delegate Phillip Hamilson’s (R-Newport News) bill, HB 2020 (1997), mandated not less than a minimum 48-hour hospitalization after mastectomy and not less than 24 hours after lymph node dissection surgery. Nothing in the legislation would have required such a hospitalization, just that insurance companies issuing individual or group health plans must include such provisions in policies sold in Virginia. The bill was “left,” or tabled in 1997. Delegate Hamilton intends to re-introduce the legislation in January. Between now and January, getting state senators, delegates and candidates on board for this legislation will ensure a better chance of passage during the session.

S 948 (1997), mandating insurance coverage for reconstructive breast surgery (including surgery to reestablish symmetry) was introduced by Senator Roscoe Reynolds and “left” in the same manner as HB 2020, and was referred to the Special Advisory Commission on Mandated Health Insurance Benefits. The Commission, which heard testimony at a July 29 hearing, recommended re-introduction of this legislation in the 1998 session.

A study conducted by the American Society of Plastic & Reconstructive Surgeons indicated that fear of losing a breast is a leading reason many women do not participate in early breast cancer detection programs. It is imperative that this bill pass in 1998 to help eliminate this fear for all women and to ensure that women diagnosed with breast cancer have the option of physical and emotional renewal with breast reconstruction.

There are currently 21 states that mandate coverage for reconstructive surgery. Of those 21, 15 include language requiring coverage to restore symmetry. With the support of our membership, VBCF will work for passage of this bill.

It is critical that our General Assembly senators and delegates, as well as this year’s candidates, understand our individual concern about these issues. If each of the 100 members of the House of Delegates and the 40 members of the State Senate could be persuaded to sign on to this legislation before the session begins in January, passage would be assured. At this time, both candidates for governor of Virginia have indicated they would support legislation concerning 48/24-hour breast surgery protection. VBCF members, friends and family who wish to work for this legislation should contact the VBCF office at 804-285-1200 or 800-345-8223. E-mail to: 104775.3233@compuserve.com. VBCF has proven that it “can get the job done.”

Research provided by Lauren Ellis, Becky Morris and Teresa Dayrit.

Getting Things Done

by Lauren Ellis and Becky Morris

Heeding the call for support for S 948 in the summer newsletter, VBCF members wrote letters, called and visited members of the Mandated Health Insurance Commission and Appeared at its Hearing on July 29

Members of the Virginia Breast Cancer Foundation wrote 50 letters to the Mandated Health Insurance Commission relating their experiences. Members also contacted and met with the various members of the commission personally asking for their support.

Over 40 VBCF members and women from the MCV Stony Point support group attended the hearing on July 29, many wearing their bright fuschia tee-shirts, creating a visual impact when VBCF President Patti Goodall asked for a show of support from the audience. Several members bravely spoke before the Commission telling in very personal ways why they felt strongly that insurance companies should be required to pay for reconstructive surgery.

Dr. Harry Bear, director of the division of Surgical Oncology at MCV and 1995 recipient of VBCF Sherry Kohlenberg Award, spoke on behalf of the American Cancer Society. Dr. Carol Shapiro, a plastic surgeon from Northern Virginia and president elect of the Medical Society of Virginia, spoke as a representative of that organization. Both explained the difficulty in being able to predict at the time of initial surgery what reconstruction will be required to provide symmetry between the affected and non-affected breast. Both answered questions from the committee. Dr. Shapiro explained that since the breast does not function, some insurance companies see this surgery as cosmetic or optional.
Patti Goodall said it is critical to cancer patients to know that breast reconstruction will be covered when clinically recommended by a physician and the desire of the patient. VBCF member Becky Ris spoke of the emotional duress she suffered submitting nude photos of herself to the insurance company three times before approval was finally obtained with the help of her corporate benefits office. “No one should have to be humiliated and treated like this. Is this what you would want for your wife or mother or daughter? Women with breast cancer are fighting for their lives. Don’t make reconstruction another battle we have to fight!”

Mauri Whitehurst, another VBCF member and thirty-four-year-old mother of two young children, was denied coverage for reconstruction of the opposing breast because it was considered cosmetic under the regulations governing the HMO’s. Surgery had to be postponed twice until she received insurance approval. Mauri stated, “Reconstruction has made a wonderful difference in my life. Reconstruction has helped me put my cancer experience behind me. I am no longer consumed with thoughts of cancer; I get up in the morning and get dressed and do not give it another thought. I feel that I am healthy again and that I can go on with my life.” She asked that the commission recommend passage “so that no other woman will have to fight the dual battles of cancer and a mutilating surgery burdened with the fear of financial hardship.”

Eastern shore resident Janet Hickman testified that her insurance company deemed the two-year post mastectomy surgery to be cosmetic. She stated that each woman’s life has a different set of circumstances which determine the timing of events. In her case, the cancer recurred eighteen months after the original mastectomy on the scar incision. Had she had immediate reconstruction, this may not have been discovered, resulting in a more severe prognosis. And Gail Smith, who is responsible for contacting Senator Roscoe Reynolds to introduce this bill, told the committee how she wished others would be able to focus on getting well as she had been able to do. Each woman’s powerful, courageous testimony made an impact.

Reggie Jones, representing the HMO Insurance Association of Virginia, said that his group does not oppose Virginia Senate Bill 948, but wants clarification on how many surgeries will need to be covered. He wanted the committee to consider questions such as: how long after the initial surgery will reconstruction be allowed? What will happen when the consumer changes companies?

The Commission reviewed the testimony and at their meeting on August 27, voted to recommend the bill for legislation in the 1998 General Assembly.

Many thanks to all who worked to insure the Mandated Health Insurance Commission was well informed on the importance of this issue. Thanks to Senators Reynolds, Couric, Houck, Howell, Lucas, Y.B. Miller and Whipple and Delegate Rhoads, sponsors for the bill. Special thanks to Nancy Golden, Teresa Dayrit and Becky Morris who coordinated this effort to educate our policy makers on the importance of this bill; and to VBCF members and interested parties from across the state who traveled to the hearing: Ewelce Wheeler and Bosom Buddies from Waynesboro and Staunton; B.J. Kreider and friends from Northern Virginia; Jenny Pearsons and friends from Tidewater area; Norma McLaughlin from the Southwest District; MCV Stony Point Breast Cancer Support Group; and VBCF board members Barbara Regan, Mary Moniz and Bev Soble.

Central Virginia — Richmond

July 19, Richmond’s Highland Springs Golf Course was the scene of the 11th Annual Memorial Golf Tournament. Women from the area—120 golfers, together with caddies and cheering sections, teed off to play golf and join in the fight against breast cancer. The tournament was started in 1987 by Sharon Talarico as the Barbara Edwards Memorial Golf Tournament. The tournament honored the Varina golf coach and Greater Richmond Golf Association champion who had been killed in an automobile accident. In recent years, honorees included Stephanie Steiger, Sherry Kohlenberg and Jean Lahet, all victims of breast cancer. Sharon sees this tournament as “an opportunity to give back to the community, hopefully help save lives and have a bunch of fun doing it.” While many talented golfers were recognized, there were loads of prizes for other skills. VBCF member Diane Horvath’s team won as the Best Dressed Team with hand painted shirts and pink ribboned hats. Cindy Barnett and her prize committee did a tremendous job in securing merchandise for prizes and cash contributions which totaled more than $8,100. While these generous sponsors are too numerous to name, two corporate partners deserve special notice—Central Fidelity Bank which gave $1,000 and women’s shoe manufacturer RYKA, represented in Richmond by Teresa Holloway. Said Holloway, “It’s fun, with friends and for a good cause. RYKA has been involved in women’s issues since it was founded in 1987 and is proud to join the fight against breast cancer.” It was a day of fun, fun and golf, but it was also a day for remembering those who were there in spirit. Sue Lahet remembered her mother, a victim of breast cancer. Sue had fulfilled her mother’s wish to have her ashes spread on the water that she loved. She also remembered the blue heron that had flown over then as silent witness. As she and her team reached the golf hole that had been dedicated to her mother beside the many lakes at Highland Springs, she looked up to see a large bird fly by, a blue heron.
from the editor

Mary Huff

Phyllis Tyzenhouse recently resigned as medical review writer for the Virginia Breast Cancer Foundation Newsletter. I can’t begin to thank Phyllis enough for her years of service. She has done an outstanding job in searching the medical literature for articles pertaining to breast cancer and writing her own articles in terms easily understood by non-medical readers. Barbara Parker, the previous editor, repeatedly praised Phyllis for the hours she put in, the high quality of her work and her reliability. I wholeheartedly agree.

We will strive to maintain the quality and quantity of medical articles without Phyllis, but it’s going to be extremely difficult. VBCF owes a deep debt of gratitude to Phyllis for all her efforts on the newsletter and the Board of Directors. Many thanks and best wishes, Phyllis.

We need your input—about your activities as part of a VBCF chapter, your individual activities on behalf of the challenge of breast cancer, pictures of activities with VBCF members, articles you find in newspapers and magazines and, of course, letters to us. We also know that writing the story frequently becomes a chore that simply doesn’t get done. For the past two years I’ve been just a little sloppy in setting real deadlines. So, starting now, Jean Hoshall and I are going to try and get a little more organized at Newsletter Headquarters! We’re trying to turn around production and mailing to 21 days, but we really need your help on meeting deadlines in order to do this!

**Newsletter Deadlines:**
- Winter Issue (Jan-Feb-Mar) December 1, 1997
- Spring Issue (Apr-May-Jun) March 1, 1997

The Winter issue will feature breast cancer activities that occurred during the month of October. We’d like to know of any activities through hospitals, American Cancer Society, etc., that were related to Breast Cancer Awareness month and your participation in activities.

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**How To Get Your Stories, Your Letters & Your Pictures To Us**

**Hard Copy:** No computer? We’ll take envelopes, yellow pads, “post-it-notes.” Send it to: Mary Huff or Jean Hoshall. No time to write a story? List the activity, the participants, briefly what happened, VIPs, etc. We’ll write the story, turning your information in literary glory (or to fit the space). Good article? Send it, with the publication name and date. Found it on the internet? Call or send the URL.

**Computer Diskette:** (we don’t do MAC): Compose your story in your word processor (Word, WP or Works), “just the facts, Ma’am,” and we’ll do the rest. We need “The Who, The What, The Where, The When and the Why.” At the top of the story, please give your name, phone, internet and fax number, if you have them. Do Not Format. Just type it in regular, old-fashioned, straight block paragraphs. Please use upper and lower case on headlines. Do not underline, bold or italicize. We have set formatting for the newsletter and we will do that during publication. Indicate at the end of the story or article if pictures are enclosed. If you have ideas for pull quotes or special emphasis on part of the story, indicate what you want at the end of your copy.

First, ‘SAVE’ your document as usual. This is the ‘SAVE’ feature under ‘FILE’ on the ‘MENU BAR’ at the top of your screen. Then use the ‘SAVE AS’ under the same “FILE” to Save the document as a Word Perfect 5.x file onto a floppy diskette. Send the diskette and a copy along with the pictures. Do not forget the hard copy, because we may have a translation problem, or a damaged diskette. If you’ve retrieved an article from the internet into your word processor, make sure to attribute, with (URL) information included at the end of the article.

**Computer Internet:** If you want to e-mail your story, the best way is to compose your story in your word processor, ‘SAVE AS’ as indicated above on your hard disk. Then go to your mail service in your Internet provider and when you are in the ‘MESSAGE’ part of the memo section, type in your name and telephone # (very important) and then just use the “Attach” feature, find the file you wish to send and click on it. It will automatically attach the file to your electronic mail. This way we will receive it as a Word Perfect file. Again, if there are pictures, make sure to indicate on the bottom of your word processor file, or in the message section of the “Mail” and send them. In the Subject section, please type VBCF Newsletter, so we’ll know which messages to weed through and won’t accidently delete your story. We’ll always respond to your mail to let you know we’ve received it, so, if you don’t get a thank you on the Internet, you’ll know the transmission failed.

**Pictures:** We love pictures. We love pictures that do not have finger marks all over them. We love pictures in which the people are identified and we know what they are doing. We need your help! Please try to handle the pictures on the edges only and the best way to identify the people, the place, and the activity is to use a “Post-It-Note”—preferably, the 3”x5” one. Stick it on the back with enough showing on the bottom to write: the persons (left to right), the activity, the date and anything else relevant. If you want the picture back, please write your name, address and “Please return” at the bottom of the “Post-It-Note.” If you have multiple pictures to send, it is best to put a piece of tissue or even paper in between them, or slip them into separate envelopes. This helps protect them from scratches.

Keep those cards, those letters and those pictures coming in. That’s one of the reasons the VBCF newsletter gets rave reviews!

Mary Huff
505 Village Woods Lane
Ealessyville, VA 22936
804-973-0763
MHuff@virginia.edu

Jean Hoshall
9716 Water oak Drive
Fairfax, VA 22031-1020
703-281-2775 (Ph & Fax)
Jeanjph@AOL.com
The Impact of Mammography on Breast Cancer Rates
by Phyllis Tyzenhouse

Breast cancer is a worldwide disease with different rates of incidence and mortality in each country. Even within one country, the incidence rates can vary considerably due to population characteristics, age and racial distribution, diet, exposure to toxic substances, differences in childbearing patterns, and availability of health care, to name a few differences. Five months ago, the Associated Press released a statement from the Centers for Disease Control and Prevention (CDC) reporting that the breast cancer rate in the United States has risen sharply since the 1970s. This is not because more women are getting the disease, they said, but because they are getting early screening.

The report claimed that while the rate of breast cancer death has remained steady since 1973, the incidence increased by one-third among white women and by almost half among black women. The news release did not report that the death rate has declined markedly since the mid-1980s or that the incidence rates have leveled off, leaving the impression that the rates may still be increasing. There is no doubt that breast cancer is a major public health problem as well as a devastating problem to thousands of women and their families, but according to the CDC the data do not support the notion that it is epidemic. The disease is endemic in the United States. Breast cancer incidence increased rather dramatically in the 1980s, rising from 82.2 cases per 100,000 women in 1980 to 112.4 in 1987. Since 1987, incidence has leveled off.

An analysis by Chu and associates at the National Cancer Institute (NCI) paints a different picture from that of the CDC. This group studied the trends in breast cancer mortality, incidence and survival rates, according to the extent of disease at time of diagnosis. Only white females were studied, so the findings are not necessarily applicable to women of other races. According to the NCI, overall breast cancer mortality rates in the United States have dropped markedly since 1990. The age-adjusted breast cancer mortality rate for US white females fell 6.8% from 1989 through 1993, the last year for which data were available. Among women 40 to 79 years of age, there was a statistically significant decrease in the slope of the mortality trend, by approximately 2% per decade of age per year. This is an abrupt change from the slight increase in breast cancer mortality seen in the 1980s, but the age-adjusted mortality rate was lower in 1993 than at any time since 1950. According to Chu, there is no indication that this decrease will abate. The probable reason for the decrease is better medical intervention, such as early detection and successful treatment.

The breast cancer incidence rate, that is the number of new cases reported in one year in a defined population, rose rapidly between 1980 and 1987, from 85 cases per 100,000 US population to 112 per 100,000; an increase of 32.5% or 4% per year. One reason for this increase is that there may have been an increase in some of the risk factors prior to the increase in cases.

In each age group over 40, there was an increased incidence of localized breast cancer (confined to the breast), along with a declining incidence of regional disease, in which breast cancer has invaded regional lymph nodes. Since 1991, the incidence of localized breast cancer has shown an increase. At first glance, it may appear that the increased incidence in localized breast cancer is bad news, but rather it is evidence that mammography has played a major role in the detection of cancers before they progressed to higher stages, so now fewer cancers are being detected after the disease is regional. Mammography can detect smaller tumors and localized lesions that can usually be treated with breast-conserving surgery, and that is why the incidence of localized disease shows an increased rate, while the incidence of regional disease is lower. This trend should eventually lead to lower mortality since about 50% of breast cancer deaths occur in women diagnosed with regional disease. There has been little change in the incidence rates of localized disease among women under 40, because of the limited use of mammography in this age group. During the mid-1980s, the in-situ cancer rates increased in women 30-39, indicating some increase in the use of mammography by younger women, perhaps baseline mammography.

There has been considerable impact on breast cancer rates by mammography because it can find breast cancers at earlier stages when they are more readily treated. Although the data were collected on white women only, a future article will address the incidence and mortality of breast cancer in non-white populations.

"CDC: Breast Cancer Rate Risks," Associated Press via Prodigy Services, 10/5/96. NCI data via CancerNet.

Pregnancy Risks After Breast Cancer May Not be as Great as Thought

Women of childbearing age who have been treated for breast cancer are usually warned not to get pregnant. The assumption was that elevated levels of estrogen throughout the 40 weeks of gestation may trigger breast cancer cell reproduction. However, two studies suggest the risk may be smaller than previously thought. In 1993 at the NIH's conference on Breast Cancer in Younger Women, Karen Hassey Dow, RN, PhD, presented a small retrospective study of 27 women who had successful pregnancies after breast cancer treatment. When matched with women with similar tumor size, lymph node status and age who did not become pregnant after treatment, the mortality rate was slightly decreased. A new study in the journal The Lancet had the same results. Researchers were able to find 5,725 women of childbearing age in the Danish Cancer Registry and the National Birth and Induced Abortions Registers who had been treated for breast cancer. Eighty-four women who had full-term pregnancies had a slightly decreased mortality when compared to the others. These two studies are small samples with many variables; however, for women with a history of breast cancer who want to conceive, these results can be reassuring and may be more credible than the conventional warning based on an assumption of increased risk.
Membership in the Virginia Breast Cancer Foundation

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Calendar

October

5 Dance for the Cure—Jewish Community Center, Richmond
6-10 Awareness Week—Veterans Medical Center, call Beverly Ross, 804-675-5389
7 Dr. Susan Love—Lecture & Reception, The Cornerstone, Richmond
10 Walk for Awareness—VAMC, call Beverly Ross, 804-675-5389

November

8 VBCF board of directors meeting

December

1 Deadline for Winter Newsletter—Contact Mary Huff 1-804-973-0763
13 VBCF board of directors meeting

The 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
PO Box 17884
Richmond, VA 23226
Mary Huff, RN, Editor
Jean Hoshall of JPH Designs
Design and Typesetting
Patti Goodall
President

Contributors to this issue:
Becky Morris Nancy Golden
Lauren Ellis Teresa Dayrit
Mary Jo Kahn
Photos by:
Nancy Golden Ann Wilson
Wanda Bruce

It's time we found a cure!