Virginia Breast Cancer Foundation

takes the lead in fight against discrimination

Two Senate Subcommittees approve
Genetic Information Privacy Act

Bill Goes to Senate; Insurance Lobby plans to fight in House

Senate Bill 335, called the Genetic Information Privacy Act, would make the results of genetic testing for any disease unavailable to health insurers for a two year period. The Joint Subcommittee to Study the Ramifications of Breast Cancer Susceptibility Gene Research voted unanimously on January 18 to recommend legislation to the Senate Commerce and Labor Committee. On January 29, representatives from the health insurance industry requested that the full committee refer the bill to the Senate Financial Institutions and Insurance subcommittee.

During its meeting on February 2, that subcommittee unanimously voted to refer the bill back to the full committee. As this newsletter goes to print, it is anticipated that the legislation will go to the Senate before February 14. Senator Janet Howell (D-32nd District, Reston, McLean), is chief patron of Senate Bill 335 and was chairman of the subcommittee that studied the issues related to the consequences of genetic testing to individual citizens in the Commonwealth for the last year (see VBCF Newsletter, May/June 1995). Other patrons include Senators Yvonne Miller (D-5th District, Norfolk) and Richard Saslaw (D-35th District, Fairfax) and Delegates Jean Cunningham (D-71st District, Richmond), who will carry the bill in the House, Mary Christian (D-92nd District, Hampton), Richard Fisher (R-35th District, Vienna), Frank Hall (D-69th District, Richmond) and Robert McDonnell (R-84th District, Virginia Beach).
As we begin Virginia Breast Cancer Foundation's (VBCF) fifth year, I envision our organization improving the lives of women diagnosed with or at risk of breast cancer. There are many challenges: access to quality screening and treatment for all women, increasing and influencing research funding, and facilitating the application of research findings to clinical practice. VBCF is applying for funding to provide mobile mammography vans for screening of minority and underserved communities. There must be insurance reform that eliminates preexisting condition exclusions and provides portability. VBCF is working for 1996 state and federal legislation that would prohibit insurance discrimination based on genetic testing. We must work to reduce exposure to environmental carcinogens. We are forming a task force that will recommend policies and VBCF initiatives.

Virginia lags behind other regions' use of breast conservation surgery. We sponsored Primary Care Perspectives for professionals and our educational programs reach the general public. We will continue these efforts and work with professional medical organizations to expedite change.

Our members join VBCF because breast cancer has in some way touched our lives. VBCF members are knowledgeable, capable, and determined to eradicate breast cancer. We know from personal experience issues that affect those diagnosed with breast cancer. Those who have gone through the process can give so much to those in the initial acute phase of being diagnosed and far beyond. VBCF will work to match our members who are survivors with women newly diagnosed. VBCF is also planning a resource book for women diagnosed with breast cancer that will cover a broad range of information and services.

My first experience with VBCF was traveling to Washington to participate in a rally at the capitol. On the bus, I found myself frequently nodding my head in affirmation as I shared common experiences and emotions with others diagnosed with breast cancer. Once in Washington, I was surrounded by many women, their families, and friends sharing a common goal. These women served as role models who chose to create an effective and affirming experience in the face of a devastating and tragic disease. There was mutual support and a shared strength. My goals for VBCF in 1996 are challenging, but I know I am not alone. We travel on a journey together with collective resolve to do whatever we can to end the suffering caused by breast cancer.

Alice Johnson

Married with three grown children, Alice Johnson was an active volunteer in her Norfolk community, spending hours each week at local hospitals, schools and her church. Alice was devastated five years ago after a screening mammogram found a cancerous lump. But once she recovered from the ravages of chemotherapy and radiation, she began looking for ways to help others benefit from her experience. She was instrumental in establishing a biweekly support group for women with all kinds of cancer at Sentara Norfolk General Hospital and volunteers to accompany patients undergoing breast diagnostic studies at the hospital's Cancer Center. "They're scared to death," says Alice, "I think it really helps to have someone there who's been through the system, got bad news and survived. Just having someone to talk to while waiting is comforting."

In addition to all these activities, Alice has been an active volunteer for the Virginia Breast Cancer Foundation since she joined in 1992. She has served as legislative coordinator for the Tidewater District, executive coordinator for the Southside Chapter and is on the board of directors for VBCF. She has participated in almost all VBCF events on the Southside of the Tidewater District, many events in Richmond and some in Washington, D.C.

"Breast cancer is an epidemic today. There's a chance one in eight women will get it. That's too scary to do nothing," says Alice. "What you do today to touch other's lives can become extremely important. Having breast cancer certainly changed my priorities as well as my family's priorities."

One of Alice's priorities is promotion of regular mammograms combined with monthly self-examination and annual clinical examination. "I was 47 when I was diagnosed with breast cancer on a screening mammogram. No one was able to feel it. I get upset when I read articles questioning the value of screening mammograms for women between the ages of 40 and 50. I wouldn't be here today if I hadn't had a screening mammogram. Thankfully, they caught mine in a fairly early stage, although I did have lymph node involvement."

Unfortunately, for VBCF, one change in the Johnson family's priorities will take her away from the Commonwealth. She and her husband David have sold their home of twenty years in Norfolk in anticipation of a move to rural North Carolina in summer of 1996. David, currently the medical director of Children's Hospital of the King's Daughters, wants to return to community pediatric practice. We'd like to thank Alice for many contributions to the fight against breast cancer and wish her well in her new home. Knowing Alice, our loss is sure to be North Carolina's gain.
Central Virginia District

The Ukrop's Golden Gift Program ran through January 6, 1996. WE NEED YOUR HELP! Wanda Bruce will be helping the office staff to add the golden certificates for VBCF. Look for your February issue of the Ukrop's newsletter which arrives the first week of February. This golden certificate is attached inside the newsletter like a coupon that has to be cut out. If you missed or lost the certificate, Ukrop's will issue a duplicate upon request. ALL CERTIFICATES MUST BE TURNED IN BY MARCH 16, 1996. The VBCF office will be sending envelopes to those in the Central Virginia District addressed to the VBCF office. Place your golden certificate in the envelope and mail it back. If you have any questions, call Wanda Bruce at 672-1500 or 285-1200. In the past VBCF has received sizable donations from this campaign but we need your support to benefit.

Breast Cancer Awareness Initiative

Governor and Mrs. Allen hosted a reception at the Executive Mansion on November 4 to wrap up the Initiative for Breast Cancer Awareness for 1996. Advocates and cancer care providers from the state attended. Pictured with Governor and Mrs. Allen (center) are VBCF members Wanda Bruce, Audrey Childress, Gloria Barnes and Patti Goodall.

Tidewater District—Peninsula

The Peninsula Chapter elected new officers for 1996-97 at their November meeting. The program for the November meeting was “Massage Therapy for Cancer Patients” with emphasis on lymphedema and mastectomy. Sister Josandra, OSF, certified massage therapist from Mary Immaculate Hospital, Women in Focus, gave the presentation. In December we were joined by Drs. Bruce Booth, oncologist; and Cassieanne Booth, a psychologist. Dr. Booth presented a slide show on the history of breast cancer and recent treatment advances.

The Fashion Show Committee has begun planning the March 23, 1996 event. It will be held at the Ramada Inn in Newport News. Details on time and tickets will be in the next newsletter.

Editor's Note: If you have an active VBCF group in your community or if you individually are working in the fight against breast cancer and would like to submit a report, call Mary Huff at 804-973-0763. Let us hear from you!
The Virginia Breast Cancer Foundation is organizing a group to study the procedure used in stereotactic needle biopsy. We are interested in talking to women who have had the procedure. If you or someone you know has had the procedure, please call the VBCF office at 1-800-345-8223.

A FDA Advisory Committee unanimously urged the Food and Drug Administration to approve the High-Definition Imaging ultrasound as another test to study suspicious breast lumps before biopsy. Typical ultrasound testing is often performed after a lump is found on mammogram. It can usually differentiate whether a mass is a solid tumor or a fluid-filled cyst, which is not dangerous. The High-Definition Imaging (HDI) ultrasound provides a clearer picture. Out of 1,021 breast lumps studied, HDI ultrasound was 99% accurate in diagnosing lumps as benign. The manufacturer predicts that 40% of the 700,000 surgical breast biopsies done in the United States yearly will be eliminated by the new technology. The HDI ultrasound should only be used on breast lumps that measure one centimeter or more in diameter.

A 32-cent “Breast Cancer Awareness” commemorative stamp is scheduled to be released this summer. The stamp pictures the silhouette of a woman with a pink ribbon next to the words “Breast Cancer Awareness.”

On November 28, 1995, Virginia Breast Cancer Foundation volunteers met with first year medical students at the Medical College of Virginia for a discussion of testing for BRCA1 and its implications for the women and families involved. The discussions were part of the curriculum for the Medical Genetics course. Each discussion group consisted of 20 medical students with one or two VBCF members and one or two MCV faculty. VBCF Past President Mary Jo Kahn coordinated the session with the Genetics faculty. “We did it last year and it went so well, we were asked to participate again,” said Mary Jo. “VBCF volunteers are actually the med student’s first encounter with patients. It’s a great opportunity to humanize their didactic information. I expect we will do it every year.” If you have any interest in participating in the next session, please call the VBCF office, 1-800-345-8223, and leave a message for Mary Jo.

After ten years of running the FDA approval gauntlet, Inventive Products, Inc. has finally won approval of its Sensor Pad. The pad is two layers of plastic with a silicone filling. The pad’s inventor, Earl Wright, contends that the pad aids women doing breast self-examination by improving their sense of touch, although he admits it is equivalent to using soapy water. The FDA approval has significant restrictions; it will only be available through clinics and doctors’ offices. The Sensor Pad has been controversial since the 1980’s, as other critics joined the company in criticizing FDA standards for medical devices. Opponents to approval of the device voiced concern that women would place too much confidence in the device and forego mammograms and clinical exams.

On the front page of the Nov/Dec 1995 Newsletter, we incorrectly identified Judy Wood and Janet Mettler as members of the Williamsburg Junior Women’s League. They belong to the Junior Women’s Club, an international organization dedicated to improve the quality of life in their communities.

Members of the Williamsburg Junior Women’s Club raised over $12,500 for VBCF. We apologize for the error and express our appreciation for their work and generosity that will help us eradicate breast cancer...
Primary Care Perspectives, sponsored by the Virginia Breast Cancer Foundation (VBCF) was held November 10 through 12 at Colonial Williamsburg. In attendance were primary care professionals including family practitioners, internists, obstetricians and gynecologists, nurse practitioners, physician assistants, and pharmacists. The program attracted over 115 participants, some from as far away as California.

Breast cancer is the most misdiagnosed disease or condition in the United States. Failure to diagnose the disease early when it may be most successfully treated occurs in all age groups but happens more often in younger women. The primary care professional, usually the first to see the patient, must know when to refer to specialists. VBCF endeavored to provide primary care professionals with state-of-the-art information about breast cancer diagnosis and treatment.

Participants were welcomed to the conference Friday evening by Alan Nelson, executive vice president of the American Society of Internal Medicine, speaking of the enduring values in health care and by Joseph Heyman, deputy director of technology applications at NASA, speaking on the impact of technology on the medical profession.

The Saturday Sessions
Saturday morning, Conference Chair Bert Aaron gave the opening remarks, followed by Virginia's First Lady Susan Allen, honorary chair of Primary Care Perspectives. Mrs. Allen said she was there because of her desire to eradicate breast cancer. Her mother-in-law and grandmother were diagnosed with breast cancer and her great grandmother succumbed to breast cancer. She stated that despite educational efforts she still hears complaints from women that many of those in the medical profession don't have enough information. She encouraged and supported dialogue between professionals, stating she thinks the conference brings us "one step closer to ridding the planet of breast cancer."

Keynote Address
The keynote address was given by Dr. Stephen Edge, chief of breast surgery at Roswell Cancer Center Institute in New Mexico. Dr. Edge, formerly at the University of Virginia, forecast significant changes for the next generation of breast cancer therapies. While Dr. Edge acknowledged advances in screening and breast imaging techniques, many breast cancers are still missed. He listed short term challenges as 1) improving sensitivity and specificity of screening, 2) increasing the efficacy and reducing the morbidity of local and systemic therapies, and 3) breast preservation. He emphasized there is "absolutely no difference in survival between lumpectomy and mastectomy." According to Dr. Edge, primary university centers vary from 20% to 70% use of breast conserving surgery; differences which can only be accounted for by the quality of public and physician education.

Dr. Edge cited public policy challenges that include health care reform and access and reimbursement for clinical trials. He contends that solutions can come from new partnerships with informed advocates such as members of VBCF who demand research and access to trials.

Saturday Morning
Saturday morning's session speakers included Dr. Thomas J. Fahey, Jr., medical director of Memorial Sloan Kettering Breast Center, who stated people on the front line, the patients and physicians, should be aware of the problems and social issues and that he was pleased "to speak at a program like this." He stressed the need for people to be informed as much as possible about the risks and benefits of various treatments. He was followed by Dr. Daniel Kopans, associate professor of radiology at Harvard Medical School and director of breast imaging at Massachusetts General Hospital in Boston. Dr. Kopans discussed the controversy of mammography for women ages 40-49.

Saturday Afternoon
The afternoon sessions began with Sofia Merajver, M.D., Ph.D., director of the High Risk Breast Cancer Clinic at the University of Michigan Medical Center, who presented timely information on problems inherent in using the BRCA1. She stated that 10-12% of all breast cancer is attributable to breast cancer susceptibility genes, which is characterized by younger age at onset, higher prevalence of bilaterality, and presence of associated tumors (ovarian, prostate, colon, endometrial, sarcomas). She praised survivors and advocates who have demanded higher accuracy in clinical trials and questioned the usefulness of some research. She believes that insurance issues regarding genetic research will be settled thanks to groups like VBCF who apply pressure to make this happen. Genetic research and testing has created a need for risk assessment, genetic counseling, and close surveillance. Strategies to accomplish these tasks are being developed under approved protocols and Dr. Merajver advised that no one be tested unless it's under protocol.

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Physicians and Nurse Practitioners who attended the Primary Care Perspectives Conference had this to say...

..."VBCF staff and volunteers are to be commended and congratulated. Could not have been better."

..."I do believe the conference was very well organized and very well delivered. The messages delivered are directly applicable to Primary Care and delivered in a way which is easily acceptable to physicians."

..."Excellent choice of speakers"

..."Excellent conference... would like to see this meeting an annual event."

..."Where else would you find such speakers, the best in the world."
The Virginia Breast Cancer Foundation extends its appreciation to the following groups and individuals, for their generous contributions for the Primary Care Perspectives Conference

**Benefactor Level**

The Board of Women's Health

**Platinum Level**

Susan G. Komen Breast Cancer Foundation

**Gold Level**

Virginia Breast and Cervical Cancer Program

**Silver Level**

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Norfolk Southern Railroad
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From the conference: (Top Left) VBCF Past President Kendra McCarthy and Conference Chair Bert Aaron; (Above Right) Dr. Stephen Edge, keynote of the Conference; (Below Left) Participants of the Conference luncheon; (At Left) Exhibitor Virginia Breast Cancer Pain Initiative; and (At Left) VBCF Foundation President Margaret Borwhat with two conference speakers, Dr. Marcia Greenleaf of Sloan Kettering and Ronnie Kaye of UCLA.

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The Primary Care Perspectives Conference was made possible by the members of the committee, each of whom gave endless hours of time and boundless energy to the project.

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**Transportation**
Ed Wilson
Ronnie Kaye, marriage and family therapist, teaches a course on doctoring at the medical school at UCLA and is the author of *Spinning Straw into Gold*, a book based on her experience with breast cancer. Ms. Kaye described a diagnosis of breast cancer as a profound emotional and spiritual crisis. Doctors need to become healers, practitioners that treat the whole person and not just the disease. Healers need to become familiar with human reactions to crisis, recognize individual differences and accept people's feelings without judgment or criticism.

Saturday's session concluded with a critique of treatment modalities by five specialists. Dr. Mark Ellis, from Williamsburg Community Hospital, discussed hormonal and chemotherapy. Since breast cancer is a systemic disease, Dr. Ellis elaborated, there must be systemic control. While it may take years to develop a palpable one cm. tumor, metastasis can occur at any time during tumor growth. He discussed new chemotherapy agents such as Taxol and Navelbine as well as the promise of dose intensive chemotherapy with bone marrow or stem cell rescue. Dr. Jennifer Harvey, acting director of breast imaging at the University of Virginia, discussed mammography for non-radiologists and described characteristics of masses more typical of cancers. She stressed the need for physicians to refer women for mammograms, noting that women need to become more active in their own health care maintenance.

Dr. Harry Bear, chairman of the Division of Surgical Oncology at the Medical College of Virginia, discussed surgical decisions. He concurred with Dr. Edge that there is no difference in long term survival for those undergoing mastectomy versus breast conserving surgery. He said that a ten-year study conducted in 1993 and reevaluated in 1995, in addition to seven large prospective studies, provide incontrovertible evidence on the safety of breast conservation techniques. He disputed commonly claimed contraindications. He relayed information on tremendous regional differences. New England has a 42% breast conserving surgery rate, while Virginia has a 21.8% rate. "There is no medical reason," Bear asserted, "It reflects to a large degree the physician's preference. Elizabeth Snyderwine, Ph.D. and head of chemical carcinogenesis science at NCI, lectured on dietary factors and her research implicating ordinary cooking methods of meats and fish as a source of carcinogenic agents. She emphasized the complex mixture of carcinogenic and anticarcinogenic agents in peoples' diets and emphasized the need for further study.

Marcia Greenleaf, Ph.D., from the Department of Psychiatry at Memorial Sloan Kettering Cancer Center, characterized the power of the mind. Contrary to pop psychology, Dr. Greenleaf disputed the idea that the mind can create anything just by being positive. Determination to keep a positive attitude can ignore important emotional signals, be a detriment to healthy anger and may actually do physical damage. I think, I feel, I react; therefore I am, Dr. Greenleaf believes is an improved version of the old adage. Health care professionals need to recognize the psychological aspects of care and be willing to refer otherwise psychologically healthy patients undergoing acute and chronic changes in their life to mental health professionals.

**Sunday Sessions**

Sunday morning, Judith Robinson, MLS, from Eastern Virginia Medical College, demonstrated computer on-line access to medical databases. E. Haavi Moremel, Ph.D., from the Department of Human Values and Ethics at the University of Tennessee, discussed managed care. Thomas Hubbard, M.D., J.D., from the Marshall-Wythe School of Law at the College of William and Mary, lectured on liability and the primary care professional, when to refer, and how to talk to patients about suspected cancer. James Taylor, Ph.D., from the University of Southern California's Human Factors Department, discussed "Managing the Treatment Team."

The program concluded with remarks by Kendra McCarthy, past president of VBCF. Ms. McCarthy discussed the role of advocacy and the relationship with health care professionals.

During the conference, artist and VBCF member Barbara Hawley exhibited some of her works that depict her diagnosis and treatment of breast cancer. Sharon Cotner from Colonial Williamsburg offered a historical interpretation of breast cancer in the 18th century during Saturday's lunch. A spouse program provided the opportunity to tour Williamsburg and surrounding sites both Saturday and Sunday. There were receptions on Friday and Saturday evenings.

**Primary Care Perspectives** was overwhelmingly successful. Evaluations by the attendees resulted in very positive feedback and comments. Nearly 98% of attendees rated the conference in terms of professional content as excellent and well done. All attendees answered that they would incorporate the information into their patient care.

Bert Aaron, chairman of the conference, did a phenomenal job gathering resources and attracting volunteers. VBCF member Dr. Lester Dubnik and Dr. Milford Maloney, past president of the American Society of Internal Medicine, assembled a remarkable array of speakers of the highest caliber that drew many positive comments from the attendees. "Where else would you find such speakers, the best in the world," commented one physician. To our knowledge this conference has been the only program for primary care professionals focused solely on breast cancer sponsored by an advocacy group. VBCF hopes it serves as a model for other grass roots organizations and plans to offer another conference in 1997. Bert Aaron commented, "The conference was a success thanks to all the volunteers who worked so tirelessly." Thanks to all the donors, speakers, volunteers, exhibitors, and participants for a job well done!
Anti-Estrogens Show Promise for Postmenopausal Women

Although Hormone Replacement Therapy (HRT) using estrogen with or without progestin has been used for a number to years to prevent the dreaded osteoporosis and heart disease prevalent in postmenopausal women, only about 20 percent of the women who could benefit actually take these supplements.

Many women are wary of the serious potential hazards of HRT, uterine and breast cancer, and so do not take the hormones even though the benefits of reducing heart disease and preventing osteoporosis outweigh the risks of these cancers.

Research is going on to develop “Anti-Estrogens” that would offer the benefits of estrogen without its potential risks and may be available in a few years. The anti-estrogens are not hormones but synthetic chemicals that compete with estrogen for the same cell receptors, win the race, and block the promotion of new cancer cells that estrogen might cause. The drugs are able to fool the estrogen receptors and activate the receptors. At the same time, the synthetic drugs are able to lower LDL, the so-called “bad cholesterol,” associated with heart disease. The LDL is one of the total cholesterol fractions; HDL, or “good cholesterol,” is another fraction, that lowers risk to heart disease. The anti-estrogens do not raise HDL as natural estrogen does.

It is likely that a new name will be found for the “anti-estrogen” group because inclusion of “estrogen” in the name connotes “hormone” and the new drugs are not hormones. The first anti-estrogen, tamoxifen, is a successful drug used to treat breast cancer because it kills cancer cells and blocks estrogen’s promotion of new ones. Scientists studying tamoxifen discovered that patients who were using it had lower cholesterol and healthier bones than women who were not using it, and that is how the race to perfect this class of drugs got underway. While tamoxifen has been linked to uterine cancer, the new anti-estrogens do not seem to have this effect.

Since anti-estrogens stand to benefit 50 percent of the population some day, drug manufacturers have a potentially lucrative market awaiting them, and are already at work. Lilly is in the middle of a four-year trial of its Raloxifene, looking at its effect on osteoporosis. When the results are in next year, they expect to be able to file an FDA application. Pfizer is in the final stages of testing Droloxifene for breast cancer and will begin Phase 3 of its osteoporosis tests. SmithKline Beecham is in Phase 2 tests of Ixoflene for both breast cancer and osteoporosis.

So far, the anti-estrogens have not been tested for their ability to protect against colon cancer and Alzheimer’s disease, which estrogen has been shown to influence.

A drug, available since October, 1995, is alendronate sodium, offered by Merck as Fosamax (R) to treat osteoporosis in postmenopausal women. Now cleared by the FDA, this is the first drug to strengthen bones by increasing bone density and restoring some of the lost bone. Until now, estrogen replacement and calcium have been the main therapies for osteoporosis, but they can only slow bone loss, not strengthen bone as Fosamax can. Osteoporosis is one of the most prevalent diseases in postmenopausal women. It affects 25 million Americans, men as well as women. Bone loss can occur at any age, but it accelerates after menopause. Early bone loss is insidious and occurs without symptoms, so it is often not diagnosed until after fractures of the spine, hip, or wrist have occurred.

Merck estimates that the daily dose of Fosamax will be one mg tablet, costing consumers between $1.65 and $1.80 per day. However, the prices are set by pharmacies and by adding their markup, the price would be higher.

The side effects observed in clinical trial were generally mild and not severe enough to cause patients to stop taking it. The most commonly reported side effects were gastrointestinal and musculoskeletal pain. The side effects have been studied only for four years, so the long-term effects are not known at present.


Data Contradicts Conventional Wisdom

Women on immunosuppression drugs after organ transplant found to be protected against breast cancer

It has long been supposed that strengthening the immune system is protective against developing cancer, but a recent study of mice and a large study of women shows otherwise. A prospective European study of 25,914 women who were immunosuppressed by drugs after receiving heart or kidney transplantation were followed for one to 11 years. In 86 of the women, breast cancer was diagnosed during the first post-transplant year. The expected rate of incidence for de-novo breast cancer in this group was 113.8, calculated by the chi square method; this yields a relative risk (RR) of 0.49, which is half the normal risk. After the first year, the breast cancer RR increased to 0.84, but this still shows protection. These results indicate that the immunosuppressed women were protected only against breast cancer, but not against ten other major cancer types that were also observed. For these ten cancers, the immunosuppressed women had higher than expected incidence.

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Statement of the Virginia Breast Cancer Foundation, presented by Mary Jo Ellis Kahn to the Joint Subcommittee on January 18, 1996

1. Genetic diseases do not cost the health insurance industry any more money now than there are some tests for genetic susceptibility. Genetic diseases are already factored into the expected costs to health insurance providers.

2. Inheriting a predisposition to disease is beyond anyone's control.

3. Adverse selection due to genetic predisposition is not a factor in health insurance purchases. All American families are trying to obtain the best possible health insurance coverage that they can afford. No one would choose not to purchase health insurance just because they did not know they were at risk for a certain disease. For instance, one in eight women will develop breast cancer in their lifetime.

4. Inability to obtain health insurance will be a death sentence for those women who do develop the disease. Exorbitant rates and exclusionary policies will be profitable to insurance companies at the very real price of human life.

5. Genetic research is vital to learning the causes, preventions and cures for all cancers. We have in just a few short years made much progress in understanding the physiology of cancer. We have had limited success in treating tumors—cancer at its late stage. Now by studying the DNA of cells, the step-by-step process that turns a normal cell into a cancer cell, we can find solutions to this complicated disease that will eventually save the health industry much money.

6. The National Cancer Institute, the National Center Human Genome Research and various medical professional organizations are attempting to set up a national research protocol for genetic susceptibility. Researchers are so optimistic about what can be learned from those few people carrying a genetic predisposition to cancer that will affect all people with cancer that they have made this area of research a major priority. If people must fear losing their health insurance if they choose to enter a research study, those studies will not be possible.

7. Genetics research and what it will mean to medicine, patients and families and our society is very new. Members of the Virginia Breast Cancer Foundation are comfortable with a prohibition lasting two years with a sunset clause because we believe this prohibition will be adopted on the federal level and in all 50 states over the next few years. Writing a more permanent bill at that time will be easier and more effective.

The Virginia Breast Cancer Foundation supports this bill for the following reasons:

1. The definition of genetic information is broad enough to include those families who may experience discrimination even if only one member has had genetic testing or has had the disease. This definition is crucial if the bill is to have any effect in preventing health insurance discrimination.

2. Any bill should include all genetic susceptibility diseases because the issues are the same as for breast cancer.

3. Health insurance should be dealt with separately from other potential forms of genetic discrimination because it is the one most life threatening.

4. Myriad, the company which holds the BRCA1 patent, has stated they will market genetic testing for breast cancer later this year. OncorMed announced their intention to start marketing the test immediately. The need to prevent companies from using genetic susceptibility testing in underwriting for health insurance is urgent.

5. Five bills addressing genetic discrimination and health insurance have been introduced on the federal level. A two year prohibition will allow us to learn much about what a more permanent prohibition in Virginia needs to include.

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Mary Jo Ellis Kahn, past president of VBCF, represented the Virginia Breast Cancer Foundation and testified before both subcommittee and the full Senate committee, urging them to approve the resolution (see her statement on page 10). Kahn has been involved for several years in genetic issues and currently is cochair of the Hereditary Susceptibility Working Group, a part of the National Action Plan for Breast Cancer.

Of special note was the absence of health insurers' comment at the first subcommittee meeting. Although there had been statements that genetic testing information would be used in underwriting health insurance policies, there was no representation or opposing statements. There was a rumor that the health insurance industry has decided not to use genetic testing information and did not intend to contest the legislation. "Even though they say at this time they have no intention of using it, the bill would provide a level of confidence for women who decide to participate in genetic testing and research," stated Senator Howell.

Then on January 29, the Senate Commerce and Labor Committee voted to return the Genetic Privacy Bill (SB 335) to the Senate Financial Institutions and Insurance Subcommittee. Two organizations representing the insurance industry, the Health Insurance Association of America (HIAA) and the American Council of Life Insurance (ACL), questioned the definition of genetic information and stated that people would be able to increase their benefits. The subcommittee is chaired by Senator Richard Saslaw, a member of the original joint subcommittee, which was supportive of the Genetic Privacy Bill. When they met on February 2, the subcommittee voted unanimously to refer the bill back to the full Senate committee.

"Because of the many constituent calls from members of VBCF and others, there was strong support from the Senate subcommittee to pass the legislation with only minor changes," said Kahn, who has followed this legislation closely and is optimistic Senate Bill 335 will pass the full Senate. However, there is reason to believe the health insurance industry plans to launch a major campaign to defeat the bill if or when it crosses over to the House of Delegates later in February. "The only way we can impact the legislative process is through the personal commitment of our members and their willingness to call their individual representatives. The Health Insurance Association of America and other industry groups employ high-salaried lobbyists, while VBCF is an all-volunteer organization," Kahn added.

The bill is especially timely in that two companies, Myriad Genetics Inc. and OncorMed, Inc., have issued press releases stating that their laboratory tests designed to detect mutations on the BRCA1 gene will soon be on the market. The Oncor test is available under specific guidelines and with the recommendation of a physician. The expanded availability came after the company's institutional review board approved a clinical testing protocol designed to correctly identify high-risk patients and ensure they are appropriately counseled on the risks, benefits and limitations of their evaluation. Myriad expects to market tests for both BRCA1 and BRCA2 gene mutations later this year.

When the BRCA1 gene was finally localized and sequenced in 1994, breast cancer advocates and patients were hopeful that a blood test would be able to tell if a woman had an hereditary form of breast cancer or if it was nonhereditary, also known as sporadic. However, many scientists say that interpreting the data from the tests is still a murky science and that oversimplification of the tests and its benefits may harm a public unprepared for the difficult medical and ethical decisions as well as the possible discrimination in employment and insurance that would probably follow testing.

"To date there are over one hundred different documented mutations of the BRCA1 gene. Some of the mutations, such as the 185delAG mutation that is prevalent in the Ashkenazi Jewish population, have been definitely linked to a higher risk of breast cancer, but there are many other genetic mutations of the BRCA1 that are just being identified and followed. At this time it is unclear to most researchers what risk is associated with the less commonly occurring mutations. More research on larger groups of women is needed. Both the Virginia Breast Cancer Foundation and the National Breast Cancer Coalition recommend those women interested in being tested for hereditary breast cancer do so only as part of a research program. (For more information, call VBCF, 1-800-345-8223.)

The Virginia Breast Cancer Foundation recognized the need for genetic information privacy before large scale testing for BRCA1 mutations starts and urged Senator Howell to establish and lead the subcommittee. "Senator Howell quickly saw the need for legislation to ensure genetic information privacy and has done a wonderful job," says VBCF President Margaret Borwheat.

The National Action Plan on Breast Cancer has identified genetic discrimination in health insurance as a high priority. There is need for federal legislation prohibiting insurers from using genetic information, but questions regarding when and if it will evolve require the Virginia Breast Cancer Foundation and Virginia state legislators to protect the families of Virginia with state law now. Be prepared to assist us in this endeavor: find out who represents you in the state Senate and House of Delegates, if you don't know. "Your phone call to your Senator and your Delegate is all that will prevent health insurance coverage being denied to individuals with a family history of breast cancer," said Kahn. "You should call the VBCF office daily to get current information on this legislation and encourage others to contact their elected representatives as well."

Follow the news on General Assembly actions. Be ready to participate in a phone tree to inform VBCF members about this issue. Call your representatives and let them know you support the Genetic Privacy Act. Whether or not your family has a history of breast cancer, we all have DNA and we are all at risk of genetic discrimination.

Senate Bill 431—

Would require health insurers and HMOs to provide screening mammograms: one between ages 35-39; one every two years ages 40-49; and annually for ages over 50.

Benefits may be limited to $50 at ACR or Virginia approved facilities.

Patrons are Senators Stolle, Couric, Edwards, Quayle, Saslaw, Schrock, Stosch & Trumbo. Contact your representative if you support this legislation.
**Membership Form**

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

Name

Family Membership Name

Address (include apt #, PO Box, etc)

City  State  Zip

Phone  FAX

**Annual Membership**

- [ ] New
- [ ] Basic $15
- [ ] Family $20
- [ ] Supporter $25
- [ ] Friend $50
- [ ] Patron $100
- [ ] Sponsor—Greater than $100
- [ ] Courtesy (available if unable to pay membership fee)
- [ ] Memorial Contribution $_____

If you would like an acknowledgment card sent, please indicate name and address of recipient

Name of recipient of acknowledgment card

Address (include apt #, PO Box, etc)

City  State  Zip

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**Calendar**

**February**

17  VBCF Board Meeting

**March**

2  VBCF Board Meeting

23  Peninsula Chapter
Fashion Show
Ramada Inn, Newport News

**April**

11–14  Seventh National Mtg
State Cancer Pain Initiatives
Austin, TX (608/265/4013)

20  VBCF Board Meeting

23  General Membership Mtg
Location TBA

**May**

5–6  NBCC 4th Annual Conf.
Arlington, VA

18  VBCF Board Meeting

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This newsletter is published by the Virginia Breast Cancer Foundation six times per year. The newsletter focuses on breast cancer issues and the activities of VBCF members. Should you wish to join VBCF, or have any editorial comments, please call 1-800-345-VBCF or write to:

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**It is time we found a cure!**

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