National Health Insurance Reform Bill Passes House of Representatives

VBCF Requests Waiver for Genetic Information Protection

A flurry of activity recently brought about the passage of the first Republican initiative to reform health insurance. The purpose of the legislation is to limit pre-existing conditions and make health insurance more portable. These issues are of utmost concern to women with breast cancer and their families.

The Virginia Breast Cancer Foundation thanks Representative Thomas Billey for his prompt response to our request that "genetic information" be added to the wording of House Bill 3160, the health insurance reform bill. Even though there was reluctance to accept any amendments, Representative Billey acted quickly to insert wording that specifically states that genetic information for which no treatment has been previously sought will not be considered a preexisting condition. As chairman of the Commerce Committee which dealt with one of the original health insurance reform bills, his help was critical in making this change to the final bill that passed the House.

Information on the lengthy bill is sketchy and the ramifications are unclear. The bill does provide access to health insurance if a person is already a member of a group policy and wishes to change jobs where another group policy is offered. It apparently does not offer protection for people who need to apply for an individual policy for whatever reason. It provides no cost controls for those who must change policies.

Issues which are of major concern to advocacy groups, such as cost controls and portability to individual policies, are not addressed. There was little effort to launch lobbying efforts; at this time insurance reform must be accomplished in small steps.

On the Senate side, the Kassebaum/Kennedy bill is still being written. The National Breast Cancer Coalition is keeping us advised on both bills as they progress. We'll continue to follow their progress in the next newsletter.
Jennie Davies had only been in the United States for six weeks when she was told she had breast cancer in 1994. The family of four, including a nine-month old baby, had relocated from England so her husband could start a new business. “I was stunned. It came right out of the blue. Robert’s family had a history of cancer but not mine. Our families were supportive but they were physically thousands of miles away,” says Jennie.

Her new neighbors in Williamsburg proved to be kind, helpful and invaluable. “They hardly knew us but several women volunteered to watch my two sons when I had chemotherapy and radiation. They scheduled their lives around my medical treatment. They were absolutely wonderful. I was so fortunate.”

The support of her family and friends helped her; the family had medical insurance that relieved the financial worries that accompany a diagnosis of cancer. “Having young children dependent on you is a big influence while going through cancer therapy. I needed to do everything I could to be healthy for them and for me. I want to see them grow up.”

Knowledge that not all women in similar situations have the same financial and human resources makes Jennie angry. So when she saw an article in the Virginia Gazette about the Virginia Breast Cancer Foundation, she quickly called to volunteer. “I wasn’t looking for a support group. I didn’t need it. I needed to do something to help other women who aren’t as fortunate as I,” Jennie said.

VBCF members Bert Aaron and Vivian Phillips immediately recruited Jennie to help with the Primary Care Perspectives Conference. She took minutes, held meetings, organized spouse activities and coordinated arrangements with the facility. She began attending the Peninsula Chapter meetings on the second Tuesday of each month. “The Peninsula Chapter is an active and dynamic group. Last year they raised over $17,000 for VBCF in various ways,” commented Jennie. “When asked if I could take over a role in the leadership of the chapter, I was happy to do so.” She is the new Peninsula Chapter Chair and Tidewater District Representative, replacing Ann Wilson. When asked about her goals, she talked about public education in addition to continuing fund-raising and recruitment. “Several of us have taken the course to teach breast self exam. We want to reach more women in our community and increase breast cancer awareness.”

Juggling child care for her two-year-old and nine-year-old sons, Jennie also works outside the home for ARC as an advocate for the mentally retarded in addition to traveling to Richmond and Newport News regularly on VBCF business. “I’m busy but it’s rewarding. VBCF has been a great way for me to repay those who helped me by helping others and fighting breast cancer.”

New Officers, Board Members Elected at March Meeting

The board of directors of the Virginia Breast Cancer Foundation voted at their March 16 meeting to extend the terms of Margaret Borwhat as president, Patti Goodall as vice president and Vivian Phillips as secretary until January, 1997. Nancy Krause Golden was elected treasurer. Joining the board as new members filling vacancies are Mary Huff of Charlottesville, Becky Morris and Phyllis Tyzenhouse of Richmond, and Ann Wilson from Tidewater.

Jennie Davies of Tidewater and Caz Phelps of the Northwest District join the board as district representatives.
Around the Commonwealth

Northern Virginia

Members of the chapter are participating again this year in the 7th Annual Breast Cancer Awareness Workshop at Arlington Hospital on Saturday, June 1. Registration for the event, sponsored by Arlington Hospital and the American Cancer Society, begins at 8 a.m., with a buffet breakfast, with the presentation beginning at 8:30 a.m. The keynote speaker will be Jeff Struwing of the National Cancer Institute, who will be speaking about the newest information concerning gene research and genetic testing. Among the panel discussions planned for the five hour session will be ones particularly addressed to reconstruction surgery and insurance. The VBCF members Domicella Rieder and Suzanne Newman are members of the organizational committee. All members of VBCF are encouraged to attend. Please call Sherry Browlett, American Cancer Society @ 703/938/5550 to make reservations.

Northwest District
Shenandoah

Shenandoah VBCF members volunteered recently at an American Cancer Society telethon. In addition to answering phones, several members were interviewed and spoke about VBCF. The group is continuing to recruit new members and hopes to see a response to an article in a local newspaper. Plans for the spring include a fund raising event for VBCF in May.

Central Virginia District

Wanda Bruce reports that the golden certificates from the Ukrop's Golden Gift Program are coming into the VBCF office. It will be awhile before we know the final tally but Wanda sends her thanks to all in the Richmond area who participated.

The Virginia Breast Cancer Foundation received $638.24 from the Race for the Cause which was sponsored by the Colonial Heights Rotary Club and the Tri-Cities Road Runners in Richmond last October.

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!

Be An Angel!

You can help reduce VBCF's operating expenses by contributing toward our monthly rent of $350. The VBCF office has been a crucial factor in allowing us to centralize our activities and materials. Our office space is not luxurious, but it's home and we'd like to keep it!

Choose from among the following hierarchy:

| Cherub     | $87.50/$175.00/$262.50 (for 1, 2 or 3 weeks rent) |
| Angel      | $350.00 (1 month)                              |
| Archangel  | $700 and up (2 or more months)                |

Rent angels will receive a thank you card containing an angel pin and a written acknowledgment in VBCF’s newsletter. In addition, Rent Angels and Archangels will have their name and the month(s) sponsored on a plaque in the VBCF office. You can make a difference in the fight against breast cancer by becoming a VBCF Rent Angel!
◆ Nominations are being sought for the 1996 Sharon H. Kohlenberg Healthcare Service Award. The award was established in 1995 by the VBCF board of directors to recognize and honor a healthcare worker who "exhibits a deep and abiding commitment to the fight against breast cancer." The award is named for Sherry Kohlenberg, a healthcare administrator and founder of the VBCF, who died in 1993 from breast cancer. The inaugural co-recipients of the award were Harry Beat, M.D., Ph.D. and Tom Smith, M.D., of the Massey Cancer Center at the Medical College of Virginia. Nominations must be submitted by September 1, 1996.

Recipients will be honored at a reception during Breast Cancer Awareness Month in October. Please contact Patti Goodall at the VBCF office for additional information.

◆ The California state legislature has passed a law designating two cents on every pack of cigarettes sold in that state to pay for a variety of breast screening and diagnostic services for low-income, uninsured and under-insured women. Eligible women are those with incomes at or below 200% of the federal poverty level and who meet other criteria based on age and risk. The program, Breast Cancer Early Detection Program, is getting underway this year. There is some concern that if the rate of cigarette smoking drops drastically, the money going to breast cancer will diminish. Michigan has levied a tax of fifty cents per pack of cigarettes, which is earmarked for public health programs. Again, reduction in smoking could dry up this source of support.

◆ Thanks to member Nancy Davenport-Ennis, there's a new refrigerator in the VBCF office. If you have anything you think might be of use at the office and would like to donate it, call the VBCF office at 1-800-345-8223.

◆ The Jonsson Center at UCLA is recruiting women with metastatic disease and whose disease has been resistant to traditional chemo or hormonal therapies. A low fat diet regimen has been developed that will include soy and fish oil supplements. By changing the fat composition of the study participants, researchers hope to reduce or eliminate tumors. For more information about the trial call 1-310-794-1274.

◆ The Nordstrom's Department Store in Chicago has installed a breast cancer screening facility. When shoppers register for a mammogram, they are given beepers that will signal them for their appointments wherever they are in the store.
University of Richmond’s T. C. Williams School of Law Sponsors Legal Advocacy Institute in May

On May 9, 1996, the T. C. Williams School of Law at the University of Richmond will sponsor its second institute to train lawyers and patient advocates on the fundamentals of legal advocacy. Registration is open to all who are interested in assisting women with breast cancer and can be done directly with the law school. The one day intensive institute will focus on four topics:
1) employment discrimination
2) insurance coverage
3) planning for disability and death
4) Medicare and Medicaid benefits.
Two sessions will be offered concurrently in the morning and two concurrently in the afternoon. Each session will be three hours, including presentations by noted speakers followed by practical applications of the specific topic. Lawyers attending will be able to receive six hours of continuing legal education credits.

The number of women who are diagnosed with breast cancer is at an all-time high. Many of these women have limited resources to deal with the issues surrounding the nonmedical aspects of treatment. The purpose of the institute is to train volunteers to become legal advocates for women with breast cancer. The American Cancer Society and Virginia Breast Cancer Foundation will assist in referring women with breast cancer who need services to those trained through this institute.

Virginia Breast Cancer Foundation members and friends who are interested in obtaining information and training which will enable them to advocate for women with cancer and legal problems are encouraged to attend. Advocates need not be lawyers.

The registration fee is $30.00 per person. Lunch and all materials are included in the registration fee. To register, send your check to: Professor Ann Hodges, T. C. Williams School of Law, University of Richmond, Richmond, Virginia 23173. Registration and refreshments will begin on May 9 at 8:30 AM. For more information, call (804) 289-8192.

If you receive the newsletter after May 1 registration deadline, please call Ann Hodges to see if space may still be available.

Virginia Votes to Protect Women
VBCF members Help Inform Legislators of Vital Interests in Passage of Legislation

Thanks to a dramatic response on the part of our membership, Virginia Senate Bill 335, sponsored by Senator Janet Howell (D-32th), was passed unanimously with no changes by the 1996 General Assembly. The new law provides a two-year moratorium on the use of genetic information to limit or differentiate health insurance coverage for applicants or current participants based solely on genetic information. During this two-year time period, the legislature will continue to study genetic discrimination and the effectiveness of the law, as well as its consistency with national legislative initiatives.

Virginia is the first state to enact a law that prevents health insurance discrimination based on all forms of genetic information, including everything from DNA test results to family history. Without the specific inclusion of family history, it would have been possible for health insurance carriers to have eliminated coverage for any young woman whose mother had breast or ovarian cancer unless she provided verification she did not carry a BRCA1 or BRCA2 mutation. Both the Health Insurance Association of America and the American Council of Life Insurers opposed wording of the bill and wanted to introduce changes to limit its scope. It was your enthusiastic energy to educate your legislators about genetic discrimination that allowed this bill to become law with unqualified support.

The Virginia General Assembly, mindful of Thomas Jefferson’s ideal that all men (and women) are created equal, voted not to allow advances in the science of genetics to be used as a high-tech discrimination tool. Please thank your representatives and Senator Howell for their support of this important bill by writing to them at the General Assembly Building, Richmond, VA 23203.
What is BRCA1?
A Discussion of the "Breast Cancer Gene" and The Implications of Proposed Genetic Testing

Prepared by:
The National Breast Cancer Coalition
The National Center for Human Genome Research, NIH
The National Cancer Institute, NIH September 1995

Genes contain the hereditary information that is passed down from parent to child. They serve as the blueprint for many features. Everyone has two copies of a gene called BRCA1 in the cells of their body, one inherited from their mother and one from their father. In most people, both BRCA1 genes function normally. But in some individuals, one copy carries a misspelling. This change, or alteration, can occur at hundreds of different sites along the BRCA1 gene. Some of these changes make a person more at risk for developing breast or ovarian cancer, and may possibly be associated with cancers of the colon and prostate.

In a recent research study, one particular alteration in BRCA1 known as 185delAG, was found to occur more frequently in a group of Jews of Eastern European descent (Ashkenazi Jews) than among other ethnic groups in the study. Approximately one percent of Ashkenazi individuals were found to carry this alteration in this preliminary study. The National Cancer Institute and the National Center for Human Genome Research will soon begin another research study of the Ashkenazi Jewish population to determine exactly how common this alteration is and how often this alteration is related to the incidence of breast cancer and ovarian cancer.

Research on BRCA1 alterations will eventually help scientists better understand what goes wrong inside a cell when it becomes cancerous. This research is expected to lead to earlier methods of detection, more effective treatments, and more successful preventative strategies in the future. In the meantime, because of the uncertainties surrounding the interpretation of the tests results, testing is being offered in research protocols.

Anyone wishing to learn more about this research or who is interested in participating in this research, may contact the number at the end of this article for further information.

What we know and don’t know about BRCA1 alterations:

Known: Most people who develop breast cancer, including those in the Jewish population, have normal BRCA1 genes. In fact, only about five to ten percent of all breast cancer cases appear to be inherited and not all of these are related to BRCA1.

Unknown: Although certain to be fairly low, the exact percentage of inherited breast and ovarian cancers in the Jewish population is not known.

Known: Women with a strong family history of breast and/or ovarian cancer who have inherited an alteration in BRCA1 have a substantial risk of developing breast and/or ovarian cancer. This often occurs at an unusually early age, for instance, before menopause.

Unknown: The cancer risk for an individual without a strong family history who is found to carry the 185delAG alteration is not known. There are other factors such as life style, hormonal factors, environmental influences, and other inherited traits that affect cancer risks. As testing for alterations in the BRCA1 gene becomes available to researchers, the interaction of these factors can be studied.

Known: Not all women who carry the BRCA1 alteration will develop breast or ovarian cancer.

Unknown: The alteration is not the single cause of disease, only a contributing factor. There must be other factors, yet unknown, that affect the development of cancer in addition to having an altered BRCA1 gene. Therefore, people who carry the altered gene are said to have a susceptibility to breast and ovarian cancer.

Known: There is a risk that genetic information can be used to discriminate against those individuals found to be susceptible to disease. Researchers must keep the data they collect private and confidential. However, if results of the tests are given to the individual, insurance companies, employers, child adoption agencies and others may require that the person share the results of this test with them.

Unknown: The extent to which discrimination based on genetic information will become widespread is not clear. There are only a few states in which legislation has been enacted to prevent health insurance discrimination following genetic testing. Efforts are underway by consumer groups to limit discriminatory practices based on genetic information.

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Genes and More Genes

Knowledge about genetics and breast cancer has increased exponentially, but there are more questions now than ever before.

by Phyllis Tyzenhouse

The financial implications as well as treatment and prevention of systemic spread of the disease affect large numbers of people. However, not all are primarily concerned with eradicating breast cancer.

Ever since the news broke in September 1994 that a defective BRCA1 gene was associated with breast and ovarian cancer in some families, researchers have been busily searching for other genes, applying for patents on their discoveries, and working on vaccines and testing materials. Newly organized companies with patents in hand, some with university connections, are developing marketable products derived from the gene. The financial success of these ventures should warm the hearts of stockholders. (News about the first gene, BRCA1, has been printed in previous issues of this newsletter.)

BRCA1 gene

BRCA1 genes are thought to act as tumor-suppressor genes in normal conditions, and individuals inherit one gene from each of their parents. Both copies of the gene are normal in most individuals. If one gene is a mutant and the other is healthy, the woman would remain cancer free, unless the healthy gene becomes damaged by an environmental toxin or other agent. Scientists estimate that women from BRCA1 families who inherit a mutation in the gene have up to a 90% lifetime chance of developing breast cancer, and in many cases it occurs before age 45. The risk for ovarian cancer is about 84% in some families. Dr. Mary-Claire King, a molecular geneticist at the University of Washington, Seattle, whose research led to the isolation of BRCA1, believes that BRCA1 may be involved in breast and ovarian cancer even in the 90%-95% of women who do not inherit a defective gene, although the mechanism is not yet understood.

Financial Interests

Fifteen months after BRCA1 was announced, a second gene, BRCA2, came on the scene. This discovery was announced in the 21/28 December, 1995, issue of Nature. The discovery was made by an international team, led by researchers at the Institute of Cancer Research (IRC) in the UK and at the Duke University School of Medicine. The announcement touched off a controversy over patent rights: CRC Technology (Cancer Research Campaign), which funded the IRC effort in the UK, and Myriad Genetics Inc., an American biotech firm, a co-holder of the BRCA1 patent, have both filed for patents. Myriad claimed a right to the patent after reading about the discovery of BRCA2 in Nature. They believe that the gene is identical to the one they discovered. At stake is the exclusive right to produce commercial products derived from the gene, which should be lucrative indeed. A few weeks after announcing claim to the patent on BRCA1 in September 1994, Mark H. Skolnick of the University of Utah and founder of Myriad Genetics, Inc. of Salt Lake City, went public and sold stock at $18 per share. The value is now around $30 per share and the company is worth $22 million. Skolnick holds a 12% stake in Myriad. The company is hard at work developing products derived from the gene, such as a test for breast cancer. Other companies are racing to produce a test also. Because 80% to 90% of women carrying either BRCA1 or BRCA2 mutations could develop breast cancer, profits from the test, estimated at $850 per test, could be considerable. The Wall Street Journal and Business Week frequently publish articles on developments in the breast cancer gene arena, which should be of great interest to entrepreneurs.

In September, 1995, scientists added a new dimension to knowledge about BRCA1 when they reported that nearly one percent of over 850 blood samples taken from Eastern European (Ashkenazi) Jews contained a specific gene mutation that might continued on page 9
To Test or Not To Test

by Mary Huff

Whenever someone is diagnosed with cancer, they ask “Why? Why me?”

For those of us with female relatives, a diagnosis of breast cancer holds more questions for the future than just our own prognosis. Mothers, sisters and daughters of women with breast cancer have their personal risk double when that family member is diagnosed. Although the percentage of inherited breast cancer is thought to be no more than 10%, no one knows who falls in that category. Even when multiple cases of breast cancer affect relatives, it is possible that the family is the victim of bad luck and the cancer was not inherited.

In 1994 when the BRCA1 gene was sequenced, there was hope for a simple blood test to determine which women had inherited the tendency to develop breast cancer. Five years later, there are blood tests coming on the market but the answer to the question of testing is far from clear. There are over 100 mutations documented when the actual number of people tested is relatively small. The risk associated with the various mutations is still unknown to a large extent. And there is no easy answer to the question “What should I do now?” once the test results are known.

Compounding the dilemma is the shocking lack of privacy involving medical information. Some companies specialize in compiling large medical databases to sell to drug companies, insurance companies and other interested parties. Health maintenance organizations are establishing enormous computerized files of medical records. Every time you go to the doctor, every time you fill out information requests for life or health insurance, you have no way of knowing where the information goes.

The passage of the Genetic Information Nondiscrimination Act in the 1996 Virginia General Assembly was an important victory but the battle is far from over. In November 1995 the United States Senate held hearings related to a bill called the Medical Records Confidentiality Act. Opponents and supporters of the bill agree on one thing: if the public thinks their privacy is protected by current legislation, they are sadly mistaken.

The VBCF joins the American Society of Human Genetics, the National Breast Cancer Coalition and the Advisory Council of the National Center for Human Genome Research in urging every one interested in genetic testing to only do so in a research setting with a protocol approved by an institutional review board and full informed consent.

NIH Report on BRCA1

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Known: Not everyone will want to be tested for genetic susceptibility to disease. Whether or not to be tested is a personal choice that should be made only after thoughtful consideration of the benefits and risks associated with testing. Each person should be informed of the known risks and benefits of genetic testing and have a chance to discuss these issues with a knowledgeable health care provider before deciding whether or not to be tested.

Unknown: Much is still unknown about the psychological impact of genetic testing on individuals and families, as well as other issues that affect how one evaluates risks and benefits. All the risks and benefits of genetic testing have not yet been determined. An informed decision about genetic testing is often very difficult to make because all the risks and benefits have not yet been determined and will be constantly changing with time. Important considerations, such as the psychological impact of genetic testing, may vary greatly among individuals and families.

Known: If a woman tests negative for an alteration in BRCA1, she may still get breast cancer. On average, a woman has a one in eight lifetime risk of developing breast cancer.

Unknown: All the genes that may increase a woman’s risk of breast and ovarian cancer have not been identified and, therefore, cannot be tested for.

Known: Women who carry an alteration in BRCA1 should be monitored closely for breast and ovarian cancer.

Unknown: There is much research that needs to be done to help women who carry an altered BRCA1 gene make choices about their future medical care. Women should be aware that many things, such as, what age to begin mammography, what diagnostic test to have done for early diagnosis of ovarian cancer and the effectiveness of prophylactic mastectomies (removal of a woman’s healthy breast to reduce her risk of breast cancer) or ovariectomy (removal of the ovaries) have not been studied in people who have an alteration in the BRCA1 gene. While awaiting more scientific answers, women are encouraged to learn as much as they can about their options for medical care and to be actively involved in their health care decisions.

For additional information, please contact the Cancer Information Service (CIS), a program of the National Cancer Institute. The CIS provides a nationwide telephone service for cancer patients and their families, the public, and health care professionals. CIS information specialists have extensive training in providing up-to-date and understandable information about cancer and cancer research. They can answer questions in English and Spanish and can send free printed material. In addition, CIS offices serve specific geographic areas and have information about cancer-related services and resources in their region.

The toll-free number of the CIS is 1-800-4-CANCER (1-800-422-6237).
Volunteers Sought for BRCA1 Gene Research Study

The National Institutes of Health would like to recruit between 300 and 5,000 volunteers from the District of Columbia, Maryland and Virginia to participate in a study to see if an alteration in the gene identified with breast and ovarian cancer, BRCA1, is associated with increased risk of cancer among Jews of European descent (Ashkenazi Jews). A wide range of volunteers is needed for the study. Jewish men and women over the age of 21 with or without personal or family histories of cancer.

Recruitment began in February and will continue until recruitment is complete this summer. The recruits are expected to be available during the autumn months of 1996. They will go to one of several convenient locations to: 1) donate blood collected from a finger prick and 2) fill out a brief family medical history. The history will include questions about the types of cancers in siblings, children, parents, aunts, uncles and grandparents. A large number of volunteers is needed because the BRCA1 gene alteration is thought to be present in only one percent of the general population of Ashkenazi Jews.

For more information or to enroll as a volunteer, call 301-251-4272 between 9:00 AM and 8:00 PM Monday through Friday.

Genes

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predispose them to breast and ovarian cancer. The gene defect has been identified as a two-base deletion in the BRCA1 genes. This defect, known as 185delAG, is so named because the deletion of two subunits of DNA, A and G, occur at positions 185 and 186 on the gene. The entire BRCA1 gene is 5,592 subunits long. This gene alteration might possibly account for as much as 16% of breast and 39% of ovarian cancers in Ashkenazi women age 50 and under. In comparison, inherited BRCA1 alterations are estimated at 4% of breast and 12% of ovarian cancers among the general population. More studies are planned to validate the frequency of the genetic defect among a larger population of Ashkenazi men and women in order to lay the groundwork for studying intervention strategies.

The HER-2/neu Gene

Yet another gene involved in breast cancer has come on the scene. Researchers have found that tumors have the ability to produce extra copies of certain genes, and women whose early breast cancer tumors contain extra copies of HER-2/neu oncogene are more likely to relapse after initial therapy. This gene is believed to make a protein that causes cancer cells to grow more rapidly, so the more gene copies present, the more the cancer cells are stimulated to grow. Breast cancer patients whose tumors do not produce the extra copies have a better prognosis that those with the aggressive, rapidly multiplying form. If physicians could determine which women do not have extra HER-2/neu, they would not have to subject patients to adjuvant chemotherapy that is not needed. Oncor, Inc. has developed a test for hospital and commercial laboratories that would detect HER-2/neu, but they must await FDA approval before marketing the test material, called Inform. In October, 1995, a FDA advisory committee withheld approval because Oncor's study of 244 women was not large enough to determine if Inform yields valid results. They said many more women should be studied. On the basis of this rejection, Oncor's stock dropped 44 cents per share to $5.87, showing the sensitivity of the market to FDA's actions. Today the price is $5.25. Inform is already being sold in Europe, so the FDA's rejection was a great disappointment to Oncor.

Genes in Therapy

On the basis of the fact that normal BRAC1 genes secrete a protein that suppresses breast and ovarian cancer, researchers at Vanderbilt University, along with Mary-Claire King and others, have tested the material on mice with induced breast cancer. In two out of five mice, the tumor was completely eliminated, and the others survived longer than expected. Other mice, treated with mutant BRCA1 genes, were all dead of massive malignancies in just over a week. Although the research is very preliminary and has not been tested on humans, the concept holds promise of being used as a supplement to surgery for breast cancer, especially since the substance would not harm healthy tissues in the breast or elsewhere as current chemotherapeutic agents do. The substance, as yet unnamed, is thought to be a granin, a protein secreted by cells, broken into peptides by enzymes, that enters extracellular spaces. In test tube studies, the granins were found to be influenced by hormones. This fits with present knowledge that BRCA1 is highly responsive to estrogen. Now that early research on granin-BRCA1 has shown important implications for breast cancer therapy, there is no doubt that a new race to develop, test, and market products from granin is mounting among various companies in the gene business.

Estimated New Breast Cancer Cases in Women by Age in 1996

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*Estimates may not add to total because of rounding.
Have Mammography Services Improved since the New Quality Standards Became Law?

by Phyllis Tyzenhouse

Beginning October 1, 1994, all facilities providing mammograms had to be certified by the Food and Drug Administration, showing that they had met the Mammography Quality Standards Act (MQSA). Almost a year before the October 1 deadline, the FDA notified all facilities of the need to upgrade their practices and sent quarterly newsletters informing them about the requirements. By July 17, 1995, 93% of the 10,170 mammography facilities in the United States had achieved full certification by meeting all 18 of the FDA requirements.

Before the MQSA became law, mammography facilities could voluntarily obtain accreditation through the American College of Radiology, but only between 37 and 44 percent of the American mammography units were accredited as of July 1993. At that time, there were wide variations in oversight and only two states, Michigan and Texas, had enacted legislation specifying 18 requirements. Virginia required only four of the 18 points and ranked 19th from the bottom of list.

When the MQSA became law on October 1, 1994, only about half of the mammography facilities had completed the accreditation process in time to receive full certification. The two main reasons were that the facilities failed to submit the required materials on time, or that they did not meet the requirements. Facilities that were shut down were granted extensions or allowed to reapply for certification, depending on the reasons for loss of accreditation.

In order to study the impact of the closure of about 400 mammography facilities, the FDA hired an independent research firm, which found that 97% of the closed facilities were within 25 miles of a certified facility and 62% were within one mile. This meant that the closures did not have a negative effect on access to quality mammography in those areas, and most of those that closed, voluntarily or by request, were low-volume operations in independent physicians' offices. Previous reports have shown that quality standards are more difficult to maintain by low-volume providers. Some of the closed facilities reported that they were unable to afford the cost of upgrading their systems to meet the requirements as well as the accreditation fees and annual inspection fees.

Access to mammography services in Michigan, which enacted stringent standards five years before implementation of the MQSA, was not adversely affected by closing some of the facilities because there were enough resources to meet women's needs. At the same time, Michigan was outperforming most of the country in mammography usage and had one of the highest mammography screening compliance rates in the country. The National Cancer Institute reported that the technical quality of mammograms in Michigan improved, compared with other states.

Other studies are underway to examine the outcome effects of MQSA on breast cancer screening and should be available in 1997. In the meantime, all evidence points to positive benefits coming from the enactment of national quality standards for mammography.

Source: "Mammography Services: Initial Impact of New Federal Law Has Been Positive," U.S. General Accounting Office Report to Congressional Committees, October 1995; GAO/HEHS-96-17. (The committees were the Senate Committee on Labor and Human Resources, Nancy Kassebaum, Chairman, and the House Committee on Commerce, Thomas J. Billey, Jr., Chairman.)

New Technique May Reduce Lymph Node Removal

by Kendra McCarthy

Primary treatment for breast cancer usually includes surgical excision of the malignancy, either through mastectomy or lumpectomy. Lymph nodes are removed under the arm of the affected side and pathologically inspected to identify whether the disease has spread to local or distant places in the body. Usually, the absence or presence of malignant cells in the lymph nodes is used to determine whether additional treatment is indicated and how aggressive that treatment should be.

Many women who have undergone primary treatment for breast cancer will tell you that the morbidity related to the excision of lymph nodes was as debilitating and painful as their surgical mastectomy or lumpectomy. Loss of the lymph nodes can continue to cause difficulty throughout the life of the woman with breast cancer because of the increased vulnerability to infection and lymphedema.

Researcher Armando Giuliano, director of the Joyce Eisenberg Keefe Breast Center, reports in his article in the September, 1995, issue of the Annals of Surgery a new procedure which can help avoid lymph node excision by determining whether tumor cells have actually migrated to the lymph nodes. The procedure is called sentinel lymphadenectomy.

The procedure used for the sentinel lymphadenectomy includes injection of the primary tumor with a blue dye which, as the dye drains, stains lymph nodes. The first node to turn blue has been found to be the one most likely to contain cancer cells. This one, sentinel node is excised and inspected by the pathologist. If it contains cancer cells, all other lymph nodes are removed. If no tumor cells are found, no other lymph nodes are removed. The initial study found that use of the sentinel node dissection to be more effective as well as less debilitating.
The Virginia Breast Cancer Foundation's Annual Membership Meeting is scheduled for Saturday, June 1, 1996, from 10:00 am to 3:30 pm at the Virginia Museum of Fine Arts. The meeting will be held in the Orientation Theater and a luncheon will be served in the Member’s Dining Room.

We invite you to start the day by joining us at 9:15 am for a VBCF business meeting. Learn what VBCF has been up to during the past year—you'll be proud of what we have accomplished!

We are very pleased to have Janette Sherman, MD, as our keynote speaker. Dr. Sherman's keynote address will highlight information from a book she authored on the link between environmental chemicals and cancer, including breast cancer. During lunch VBCF President Margaret Borchard will provide an overview of VBCF activities and plans for the future as well as formally recognize VBCF "Volunteers of the Year."

Finally, afternoon sessions include a presentation on "Innovative Treatment Options: How to Access Clinical Trials" from 1:00 - 2:00 pm and a panel of professionals who will discuss "Helping Children Cope with Breast Cancer in the Family: Guidelines for Every Age" from 2:15 - 3:30 pm.

The VBCF Membership Meeting is a great way to educate yourself on breast cancer and the Virginia Breast Cancer Foundation, see old friends and make new acquaintances. Veteran VBCF volunteers will be available throughout the day to discuss how you can use your skills and abilities to help our organization in your community. Plan to attend—it will make you feel good!

The Virginia Museum of Fine Arts is at 2800 Grove Avenue, Richmond, VA 23221-2466, phone 804/357/0844.

The Museum is at the intersection of The Boulevard and Grove. From I-95, take Exit 76. Go south 1.5 miles on the Boulevard to the Museum (big brick building). Parking is in the rear.

The fee for the meeting is $30.00, which includes lunch.

Scholarships are available; please indicate on the form if you would like more information.

Seating is limited, so reserve your slot today!

Deadline for reservations is May 28. Fill out the form and return to VBCF, Membership Meeting, PO Box 17886, Richmond, VA 23226.

vbcf annual meeting registration

Name ____________________________________________

Address (include apt #: PO Box, etc) ____________________________

City __________________ State ______ Zip ______ Phone # ______

Do you have special dietary, physical or sensory needs? ________________________________

Do you require financial assistance? ________________________________

Ck# ______ Amount ______ $30.00 per person

Please return to membership meeting, vbcf, Box 17886, Richmond, VA 23226 by May 28.

Checks should be made payable to Virginia Breast Cancer Foundation.
**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
- ☐ Patron $100
- ☐ Supporter $25
- ☐ Friend $50
- ☐ Renewal
- ☐ Greater than $100
- ☐ Courtesy

☐ 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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**vbcb newsletter**

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 1-800-343-VBCF or write to:

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

virginia breast cancer foundation

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**calendar**

**April**

20  VBCF Board Meeting

**May**

5-6  NBCC 4th Annual Conf.
    Arlington, VA
    202/296/7477

9  Breast Cancer
    Advocacy Institute
    Univ/Richmond

18  VBCF Board Meeting

**June**

1  VBCF Membership
    Meeting
    10:00 a.m.
    VA Museum of Fine Arts
    Richmond (see pg 11)