8,000 Virginia Signatures Delivered to US Capitol

May 6 Rally Roaring Success

Virginia was well represented on the steps of the United States Capitol on May 6. Over 50 VBCF members, dressed in bright fuchsia T-shirts with the VBCF logo, joined hundreds of women from across the nation to deliver petitions to federal lawmakers demanding continued funding for a cure for breast cancer. VBCF collected nearly 9,000 signatures.

VBCF members from every area of Virginia met at the United Methodist building across from the Capitol at 8:30 am for a pre-rally briefing by National Breast Cancer Coalition President Fran Visco and VBCF’s Mary Jo Ellis Kahn. VBCF bus contingents from the Peninsula Chapter, Central Virginia, Waynesboro and Charlottesville were on the road before dawn.

At 9:15 am, hundreds of breast cancer advocates, many of whom had been in Washington to attend the NBCC annual conference, n to assemble at the Senate Swamp, a grassy, tree-lined area in front of the Capitol. NBCC staff members led the crowd in unified chants demanding funds for a cure for breast cancer.

A moving surprise for the VBCF contingent occurred when a large, blown-up photo of VBCF co-founder Sherry Kohlenberg, her son Sammy and husband Larry Goldman, arrived. The poster was from the NBCC photo essay The Face of Breast Cancer. Sherry is one of the four Virginia women depicted in the photo essay.

As the large crowd moved to the steps of the Capitol, the boxes of petitions became visible.

Men with hand trucks loaded the many boxes onto a nearby truck. ‘Campaign 2.6’ had reached its goal of 2.6 million signatures demanding money for breast cancer research and a voice in how it is spent.

From the steps of the Capitol, Fran Visco welcomed the crowd. Democratic Majority Leader Tom Daschle came out to speak and specifically said he will work for legislation to outlaw drive-through mastectomies. Fran noted that the Republican

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Moving Through Life—Many Journeys

by Patti Goodall

I have been pondering life's many journeys. Our lives are filled with many of them, some small and seemingly insignificant, like going to the store for groceries. Some are life-changing, like our journey with breast cancer; an individual's decision to move on; a national gathering to join with hundreds united in a single cause.

Moving on: Kendra McCarthy, past president, board member and founding member of VBCF tendered her resignation recently. Kendra was a driving force for many years in bringing VBCF from a small state organization to a nationally regarded model of grassroots advocacy. Our heartfelt thanks to her for her many years of dedicated service to VBCF and the fight against breast cancer.

Moving forward: This issue features the VBCF trip to Washington, DC, where we delivered the signatures of more than 8,000 Virginians to our senators and representatives asking for 2.6 billion dollars to be allocated to breast cancer research between now and the year 2000. On the VBCF bus from Richmond there were mothers, daughters, granddaughters and spouses who joined us on our journey. Truly, we are not fighting this disease alone!

Our efforts were rewarded: Senators Robb and Warner both signed on to support an increase in the amount of funding for the Department of Defense breast cancer research program. Please write to our senators thanking them for their support. We hope to have $175 million for this successful, innovative program. As we go to press, we hope that many of our Virginia representatives will have also signed on to the bill.

Moving ahead: We are pleased to announce that Dr. Susan Love will help us kick off Breast Cancer Awareness Month with a seminar and reception on October 7. The recipient of the Sherry H. Kohlenberg Healthcare Service Award will be announced that evening. This award honors individuals in the healthcare field who exhibit a deep and abiding commitment to the fight against breast cancer. Nomination forms may be obtained by calling the VBCF office.

Moving along: October 7 will also be the start of our Pink Ribbon Campaign. Volunteers across the state will prepare baskets of pink ribbons attached to VBCF cards for distribution in banks, hospitals, beauty salons, and similar locations during October. The campaign is the idea of Jessie Barrack of Peninsula Chapter, who distributed over 12,000 ribbons in the Peninsula area last October! Denise Allard has volunteered to lead the campaign this year in the Richmond area. This is a tremendous way to raise awareness about breast cancer and about VBCF. We provide funds for the ribbons, baskets, and cards. You use your creativity to do the rest. If you'd like to volunteer for a Pink Ribbon Campaign in your area, call us!

Moving together: If you are interested in becoming involved with VBCF, but aren't sure where you'd fit in, think about coming to a Board meeting. You will learn about VBCF activities and how you can use your time and talent in the fight against breast cancer.

Anne T. Wilson

This name will sound familiar to many readers but before continuing, please note the middle initial. The subject of this profile is not Virginia Breast Cancer Foundation Vice-President Ann H. Wilson; Anne T. Wilson is her sister-in-law.

Anne T. is one of the founding members of the Peninsula Chapter and has served as Public Education Coordinator since it was established in 1993. Anne has coordinated tabling events for an array of places, including shopping malls, schools, colleges, shipyards and county fairs—any opportunity to educate women about breast cancer and the work of VBCF. For her seemingly inexhaustible efforts in “getting the word out,” Anne was recognized as Chapter Volunteer of the Year at the 1996 VBCF Annual Membership Meeting.

Anne says that the thing that has impressed her the most during her four years with VBCF is how women want to find out as much as they can about breast cancer, whether they are immediately affected by it or not. “They want to know about it and be able to ask intelligent and educated questions,” says Anne. She intends to stay involved with her work for VBCF and continue to meet the public need for information about the epidemic of breast cancer. "It's so rewarding when you see how many people are really interested, when so many women and men stop by for information whenever we are out.”

The Virginia Breast Cancer Foundation has two openings on the board. We're also looking for district representatives in several areas of the state. If you are interested in serving on the board, please contact the VBCF office.

If you want to learn more about us, please feel free to join us at our next board meeting, August 2, in Richmond. We always welcome new ideas as well as representation from across the state.
Peninsula

The Peninsula Chapter held its fourth annual fashion show at the Omni Newport News on Saturday April 26. Following a week of chilly weather we were blessed with a beautiful day matched by the fabulous room at the Omni and the fashions presented by Paige Harrell of Nags Head, North Carolina. Thanks to everyone’s efforts to sell tickets, we had record sales this year with over 200 people attending this lively event. In addition to the models displaying the lovely clothes, there was a luncheon and a silent auction. Thanks to the talents of Paige Harrell as auctioneer, a basket of vacation package gift certificates raised close to $350 alone! Our thanks to Brenda Mason for her generous bidding.

Since over 150 individuals and businesses contributed in some way to the success of the show, we can’t thank each one individually. However, we’d like to acknowledge Jean Minor who chaired the event. In addition to her organizational contributions, Jean made a beautiful quilt which raised over $600 in raffle tickets. Peninsula Chapter members were pleased to present the results of all their hard work with a check for over $5,000 to the Virginia Breast Cancer Foundation. Plans are already afoot for next year’s show—look for information in the new year!

Northwest District—Waynesboro

Evelee Wheeler and the Bosom Buddies participated in the NBCC Rally Day on May 6. The Waynesboro group meets often for social gatherings, as well as breast cancer advocacy activities. If you live in the Staunton-Waynesboro area and would like to know more, contact Evelee at 540-248-0887.

Central Virginia District

Kendra McCarthy tendered her resignation from the Virginia Breast Cancer Foundation Board of Directors. Kendra was a founding member of VBCF and served as executive director and president in addition to being on the board. She played a pivotal role in the emergence of VBCF as a grassroots organization able to participate in the fight against breast cancer on a national level.

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 to submit a report, call Mary Huff at 804-973-0763. Let us hear from you!

Thanks to widespread participation in the Ukrop’s Golden Gift Certificate program, a total of $9,180.68 in receipts was collected in the Central Virginia District. The Virginia Breast Cancer Foundation received a check for $1,837.25 on April 7. VBCF Board member Wanda Bruce coordinated the fund-raising effort and thanks everyone who collected receipts. Special thanks go to Susan Bruce King, Gloria Barnes and Diana B. Knight. Diana, a breast cancer survivor and VBCF member, collected over $5,000 worth of Golden Gift certificates alone to help in the fight against breast cancer. And as always, thanks to Ukrop’s for their generosity in offering this fund raising event.

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 will be needed to set up a breast cancer awareness table at the events.

Contact Becky Morris 804-672-0661 or VBCF 804-285-1200. Call your local Jazzercise Instructor 1-800-FIT-IS IT and be sure they have committed to this event.
VBCF is soliciting nominations for the 1997 Sharon H. Kohlenberg Healthcare Service Award. VBCF gives the Kohlenberg Award each year in October (Breast Cancer Awareness Month) to a healthcare provider who shows a deep and abiding commitment to the fight against breast cancer. The award is named in honor of Sherry Kohlenberg, who was one of the original founding members and officers of the Virginia Breast Cancer Foundation. Sherry was a healthcare administrator before her death due to breast cancer in 1993. Nominations must be submitted by September 1, 1997. For more information about the nomination process, contact the VBCF office at 800-345-VBCF (8223).

The May 1997 issue of Redbook magazine has an article titled, “My Life or the Baby’s: What Happens When a Pregnant Woman Gets Cancer,” by Deborah Kent. It addresses one of life’s cruellest circumstances: six pregnant women diagnosed with cancer, including breast cancer. The author describes how each woman reached a decision about cancer treatment which could potentially save their lives, but harm their fetuses. A Virginia physician, Dr. Joann Bodurtha, associate professor in the department of human genetics at Virginia Commonwealth University and a VBCF member, is quoted in the article.

We are celebrating Richmond Jazzercise instructor and VBCF member Gloria Barnes’ 10th anniversary as a breast cancer survivor with the 4th Annual VBCF/Jazzercise ‘Dance for the Cause’ in October. Glo has organized this event in Richmond for the past three years and donated all of the proceeds to VBCF. It will be an exciting day with women from all over the state ‘working out’ together and working to support VBCF and breast cancer awareness. Contact Becky Morris 804-672-0061 or VBCF 804-285-1200. Call your local Jazzercise instructor (1-800-FIG-IT) and be sure they have committed to this event. Let’s Go for Glo and VBCF!

Virginia Senators John Warner and Charles Robb have signed the National Breast Cancer Coalition’s letter requesting continued funding, $175 million, for the Department of Defense peer-reviewed breast cancer research program.

The Journal of the National Cancer Institute has published conflicting studies concerning the length of time women should take tamoxifen as a treatment to prevent recurrence or metastasis of breast cancer. While the efficacy of the drug as a treatment has received general consensus, there remain strong differences of opinion on the length of such treatment. In November 1996, the Journal reported the results of two studies strongly suggesting that women with early breast cancer should continue therapy for five years; in December of 1996 the Journal reported that some women might benefit from up to ten years on the drug. One of the on-going concerns about long-term therapy with tamoxifen is its link to an increase in uterine cancer. The Washington Post, December 18, 1996.

VBCF is proud to present an evening with nationally acclaimed surgeon and breast cancer advocate Dr. Susan Love on Tuesday, October 7, 1997, at The Cornerstone in Richmond. Dr. Love, author of Dr. Susan Love’s Breast Book and Dr. Susan Love’s Hormone Book, will give a lecture beginning at 6:00 pm, followed by a reception. Admission is $30 for the seminar, followed by a book signing reception with hors d’oeuvres and cash bar. Discounted admission can be arranged for those with financial need by contacting the VBCF in advance at 800-345-VBCF (8223). Brochures will be mailed in early September, but seating is limited, so respond early!
Attend the Hearing

July 29 at 10 o'clock am
House Room D
General Assembly Building
9th & Broad Street
Richmond, Virginia

Studies have shown a beneficial effect for many women who have an altered body image following the loss of a breast to cancer. Reconstructive breast surgery is an option for those women. Many times when women plan reconstructive surgery, they are told symmetry of the breasts (both looking the same) can only be attained if surgery is performed on both breasts. Some insurance companies will not cover surgery on the affected breast; most will not cover surgery on the unaffected breast, classifying it as cosmetic surgery with no medical or psychological benefit.

Senate Bill 948 would mandate that insurance companies add coverage for reconstructive breast surgery performed as a result of a mastectomy to reestablish symmetry of the breasts. This bill was referred to the Legislature's Committee on Commerce and Labor during the 1997 General Assembly Session, where it was "left." In terms of the Legislature, this means that a bill dies or is tabled.

On July 29, 1997, the Special Advisory Commission on Mandated Health Insurance Benefits will meet to decide whether to recommend SB 948 to the 1998 General Assembly session. It is critical that we have a large physical presence in House Room D at the time of the hearing... standing room only would make a clear statement that this is necessary. We especially need women from Delegate Jean Cunningham's district—Richmond; Delegate George Heilig's district—Norfolk; Senator William Wampler's district—Western Virginia and Senator Steve Martin's district - Chesterfield.

Write A Letter to

Delegate George Heilig,
Chairman, Special Advisory Commission on Mandated Health Insurance Benefits
700 Newton Road
Norfolk, VA 23502

Whether you can attend or not, between now and July 29, please send a letter to the commission chairman, Delegate George Heilig, with a copy to VBCF, PO Box 17884, Richmond, VA 23226-7884. VBCF will send copies of your letter to Madeline Abbitt, Legislative Affairs Director of the Medical Society of Virginia, and to Isaac Worman, MD, Associate Professor of Plastic and Reconstructive Surgery, who are spearheading a campaign to have SB 948 passed.

Simply explain your story and why you feel this legislation is important. Explain the financial duress that some of you have been put under because of the lack of insurance coverage for surgery on the opposite breast, as well as the emotional duress of your mastectomy. Just tell it like it is. Even if you have not experienced this situation, send a letter stating why you think this legislation is needed.

The women of the Commonwealth of Virginia need this vital legislation passed.

We Need Your Help...
To Write Letters and Attend a Hearing
On Legislation Affecting Breast Cancer Survivors

Listed below are the members of the Special Advisory Commission on Mandated Health Insurance Benefits. If you live in their area, please consider sending a letter to them also.

Gubernatorial Appointees:
John T. Ashley
UVA Health Sciences Ctr.
PO. Box 236
Charlottesville, VA 22908

Johanna B. Chase
400 Wellington Dr.
Charlottesville, VA 22903

Myrna McLaughlin
Cross-Over Health Center
108 Cowardin Ave.
Richmond, VA 23224

Duval Dickinson
5420 Willis Way
Fredericksburg, VA 22407

Senate Appointees:
Senator Stephen H. Martin
PO. Box 36147
Richmond, VA 23235

House Appointees:
Delegate George Heilig, Jr.
700 Newton Road
Norfolk, VA 23502

Sitting on the Board:
Delegate Jean Cunningham
PO. Box 542
Richmond, VA 23204

Rowena J. Fullinwider
1300 Princess Anne Rd.
Norfolk, VA 23507

Matthew D. Jenkins
4110 Hanover Ave.
Richmond, VA 23221

Charles M. Hearn
721 Kemmore Ave.
Fredericksburg, VA 22401

Senator William C. Wampler, Jr.
473 Long Crescent Dr
Bristol, VA 24201

For more information, contact VBCF 804-285-1200.
Annual Meeting Highlights
Outstanding Volunteers of the Year Honored

The annual Membership Meeting of the Virginia Breast Cancer Foundation was held April 12 at the Virginia Museum of Fine Arts in Richmond. Approximately 55 people attended the meeting, many of them new members.

New Member Orientation
President Patti Goodall, Vice-President Ann Wilson, VBCF co-founder Mary Jo Ellis Kahn and Tidewater Representative Jennie Davies started the meeting with a new members' orientation session. Patti Goodall and Treasurer Nancy Golden then reviewed the VBCF 1996-97 annual report. Most notably, the Virginia Breast Cancer Foundation worked with the National Breast Cancer Coalition and other grassroots organizations to increase breast cancer research dollars to approximately $530 million for Fiscal Year 1997. This reflects a tremendous increase since 1991 when VBCF first organized and the federal budget for breast cancer research was $100 million.

Breast Cancer Reconstruction
Dr. David Teasley, director of the Williamsburg Plastic Surgery Center, spoke on breast cancer reconstruction and had many slides of his patients “before and after” reconstructive surgery. Of the women who elect to have reconstruction, 50% have the surgery immediately following mastectomy and 50% have delayed reconstruction. Dr. Teasley had two main points: 1) reconstructive surgery will never be able to exactly duplicate the breast that was lost, and 2) reconstructive surgery is not for every woman. He urges women who are contemplating surgery to “do it for themselves,” not for other people in their lives.

Legislative Issues
The next speakers were Mary Jo Kahn and Beverley Soble, vice president of regulatory affairs for the Virginia Health Care Association. Their topic, "Making Change Happen," highlighted how much can be accomplished when interested people organize to bring about change. They reviewed the process by which laws are passed in Virginia and tips for talking to legislators. Critical issues that will be addressed in the 1998 General Assembly include insurance coverage for reconstructive surgery and genetic discrimination. On the federal level, bills dealing with continuation of breast cancer research funding, FDA reform, genetic discrimination and quality of care for breast cancer patients will need scrutiny, input and support from breast cancer advocates. Mary Jo asked all VBCF members to consider volunteering their time in assisting with legislative issues. Contact the VBCF office if interested at 800-345-VBCF.

Outstanding Volunteers Named during Lunch
During the luncheon that was held in the museum member’s dining room, President Patti Goodall noted that the VBCF board of directors had been unable to choose one outstanding volunteer for the year. Despite the fact that its decision will “mess up” the plaque in the office naming the previous outstanding volunteers, the board had chosen five members to be recognized as outstanding volunteers for the year.

1997 VBCF Outstanding Volunteers
* Sharon Talarico
Sharon is a long time member of VBCF who has assisted in financial planning and has organized a fund raising golf tournament each year in Richmond to benefit VBCF. The 1997 Golf Tournament is scheduled for July 19.

* Laura Cooper
Laura is a new member who has spent many hours helping in the VBCF office and at various VBCF activities this year.

* Theresa Cernich
Theresa is another new member who volunteered this year in the VBCF office.
Dr. Louise Lubin steps from podium during the afternoon session.

Disruptions & Cancer

Louise Lubin, PhD, clinical psychologist and instructor of psychiatry at Eastern Virginia Medical School, resumed the meeting in the afternoon. Dr. Lubin has worked with women who have been diagnosed with breast cancer for over ten years. She discussed societal changes that have affected how women cope with breast cancer as well as individual coping mechanisms. She listed the five “D”s of disruption that accompany breast cancer: 1) distance—in relationships that can be initiated by either the woman or her significant others; 2) dependency—women are usually the caregivers and may have difficulty in switching roles, as may their significant others; 3) disability—breast cancer may interfere with the achievement of life goals, either temporarily or permanently; 4) disfigurement—surgery and chemotherapy alter body image both temporarily and permanently; and 5) death—the diagnosis of breast cancer presents a threat to long-term survival.

Dr. Lubin discussed the new field of psychoneuroimmunology, which is the study of the body’s response to emotions and stress. She wanted to emphasize that although women are encouraged to take an active role in their health and healing, recurrence should not imply guilt.

Another point she highlighted was the individual’s responsibility to clarify their needs to friends and family. One example she gave was the distance and isolation a person may feel when faced with unrelenting optimism; women need to voice their fears and state what they would find supportive. Her parting message was that disease can have meaning and purpose; one necessity of living with breast cancer is to live in the present and accept the uncertainty of the future.

New Antibody Research

The final speaker for the day was Dr. Lindsay Harris, assistant professor of medical oncology at Duke University. She discussed exciting research into the use of the humanized anti-HER-2/neu monoclonal antibody in fighting breast cancer.

Over expression of the HER-2/neu protein is seen in 20–30% of all breast cancer tumors and has been confirmed in 33 studies out of 40 to date to be associated with early recurrence and death. Currently, the HER-2/neu monoclonal antibody is being studied in small trials of women with metastatic breast cancer where it is combined with cisplatin and doxorubicin. There appears to be no overt toxicity to the drug. The antibody also seems to stimulate immune defenses as well as suppress mutant cell division. Although fever is a common side effect, patients so far have not experienced low white blood cell counts or renal dysfunction and the incidence of nausea and vomiting is low. More clinical trials are planned which will compare the effectiveness of the antibody with a chemotherapeutic drug against chemotherapy alone.

It was an informative and rewarding day. Thanks to the many VBCF volunteers who organized this successful event and congratulations to the outstanding volunteers of the year!
leadership had been invited to speak but declined.

Reassembling at the Senate Swamp, the throng was addressed by Congresswoman Louise Slaughter (D-NY), who promised her continued support for breast cancer issues and spoke about a bill she is sponsoring that deals with genetic discrimination. She spoke of the need for more research, especially for better detection than mammograms. "There are too many questions unanswered," she said. "It is a national disgrace that the incidence of breast cancer for our minority sisters is rising and we don't know why." Senator Pat Leahy, flanked by his constituents from Vermont, told the crowd he works every day to protect the Department of Defense breast cancer research program monties. He urged all breast cancer advocates to "...keep doing it. My colleagues were amazed by the number of phone calls they received from their constituents about the Department of Defense spending."

Four NBCC members read comments from the petitions. "There is no better use for my tax dollars than to save lives and do research." "We need to ask our legislative representatives, 'If your mother had breast cancer, wouldn't you want a cure?'" "There are no political parties in the issue of breast cancer. We need to take care of one another. The time is now." "I'm 63 years old, I have breast cancer, and I have a lot more living to do. I'm not giving up, so you can't either." "Matilda and Hanna no longer have their beautiful mother. Please help find a cure before they have to suffer a second time! Think of the children." "I lost a mother. I have two daughters. I need to live."

To close the rally, singer Kathleen Brown sang a song she wrote about her experience losing both her breasts to breast cancer this past year. Her song, *Flat in the Ring*, used the metaphor of running a race to describe her feelings about her battle.

Later in the afternoon, VBCF members met with Virginia legislators and their aides. The main topics of discussion were Department of Defense funding and genetic discrimination legislation.

"As a survivor there is nothing like meeting women from all across the United States who have breast cancer as a common bond, but on the other hand we must meet like this to carry this wicked torch to let our government know how important it is to help us by allocating the funds necessary for ongoing research. Our daughters' and granddaughters' lives depend on today's breast cancer survivors to keep this issue at hand in Congress. I personally wish every VBCF member, if they could, would attend next year's lobby day. They would come back changed forever.

-VBCF Vice-President Ann Wilson
Cigarette Smoking, Mutant Enzymes and Breast Cancer

by Phyllis Tyzenhouse

Cigarette smoke, direct and indirect, is known to be a risk factor for cancers of various organs and diseases of the cardiovascular and respiratory systems. The association between smoking and cancers of the lung, pharynx, larynx, esophagus, trachea, pancreas, stomach and bladder have been established for decades, but until recently epidemiologic studies have not shown a clear association between smoking and breast cancer. In fact, evidence was conflicting: several studies showed an increased risk while others showed decreased risk. This may seem puzzling until we consider work led by Christine B. Ambrosone of the National Center for Toxicological Research and her colleagues, as well as the viewpoint of epidemiologist Sir Richard Doll, discussed below. Jonathan E. Fielding observed in 1987 that women in this country already constitute a majority and their rapidly increasing smoking behavior has decreased the longevity advantage they used to have over men. It has increased women's risk for cardiovascular disease, lung cancer and other pulmonary diseases.

Differences in biochemical traits have been recognized for many years, but the mechanism was not understood until studies were done in 1952 on the kidney excretion products of tuberculosis patients who were given isoniazid. The chemical nature of the excretion products varied among patients and could not be explained until it was learned that the patients carried different versions of the enzyme "acetylator," or NAT2 (N-acetyltransferase 2). Acetylator enzymes can either counteract or activate substances, including aromatic amines in cigarette smoke and cooked meat. If the enzyme inactivates the amines no one is the wiser, but if the enzyme activates the substance to become a carcinogen, cancer may ensue. About half of white persons have defective acetylator enzymes called slow acetylators; the other half are fast or rapid acetylators. Depending on the type of acetylators carried by the individual, a substance may be either inactivated or altered to form a new substance. This occurs at different rates of speed in different people. NAT2 is a polymorphic ("many forms") gene. This means that there are at least two variants of the gene, similar to the polymorphic gene for eye color that can produce blue, brown or hazel eyes, depending on which type the individual carries.

Ambrosone and her colleagues hypothesized that slow NAT2 acetylators reduce capacity to detoxify carcinogenic aromatic amines in cigarette smoke, thus increasing susceptibility to breast cancer. Using a study population of 304 white women with incident primary breast cancer and 327 community controls who did not have breast cancer, researchers studied the women's DNA to identify their genotype of NAT2. They also collected data on age, menopausal status, reproductive history and history of cigarette smoking. In premenopausal women, there was no statistically significant association between NAT2 status and breast cancer risk. The situation was different for postmenopausal slow-acetylators and strong associations were found between smoking and breast cancer risk. Smoking for 20 years increased the risk, and risk was greater according to the number of cigarettes smoked per year (smoking

"there are no perfect [human] specimens. More and more genetic tests will become available and everyone will end up having a gene mutation predisposing to some disease," comments Francis Collins, director of the National Center for Genome Research at the National Institutes of Health.

intensity). Among postmenopausal rapid acetylators, risk was not increased by smoking when intensity and duration were considered and there was reduced risk of breast cancer for rapid acetylators who smoked more than 20 years. Therefore, cigarette smoking appears to be a risk factor for postmenopausal, but not premenopausal, women with the NAT2 slow acetylator genotype. Since this is the first study of this type, the authors recognize that further studies are needed to assure that their findings are correct.

What does all of this mean? Sir Richard Doll proposes that a strategy for cancer control could be developed by studying human enzyme polymorphisms to see how they interact with various substances to produce carcinogens. It has already been determined that amine compounds in cooked meat can be turned into carcinogens by acetylator enzymes, causing colon cancer. The enzyme has also been linked to increased risk of bladder cancer in dye workers. Doll believes that the discovery of the NAT1 and NAT2 genes may be a more important than finding the highly potent BRCA1, which accounts for only a small percentage of breast cancers, because the NAT genes increase the risk of more people to more external carcinogens, and therefore to cancers in various organs. The BRCA1 and 2 genes are but two of many genes that may be involved in the etiology of breast cancer.

It has been estimated that 30% of enzymes are polymorphic and about 7% of people have two forms of such enzymes, so the possibilities for "chemical individuality" are great. That means that different individuals, exposed to the same carcinogen, react differently: some may get cancer and others do not, based on the type of enzymes they produce. Comprehension of this process leads to an understanding of why not all people who are exposed to a certain carcinogen develop cancer. Francis Collins, director of the National Center for Genome Research at the National Institutes of Health, believes that all diseases have a genetic component. He comments that "there are no perfect [human] specimens. More and more genetic tests will become available and everyone will end up having a gene mutation predisposing to some disease."

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Breast Cancer Patients Want to Participate in Decisions

By Phyllis Tyzenhouse

Time was when surgical patients left decisions up to the doctor about what type of surgery was best. Now that patient-doctor communication has become less formal, patients feel free to speak up. They are better informed about their diseases than ever and less willing to let physicians make all the decisions. This is happening among women who have been diagnosed with breast cancer, now that television, books and other print media regularly feature information about treatment options. This, along with breast cancer support groups, consumer groups and videotapes, prepares them to decide on a course of action.

Degner et al. published a report of their survey of 1,012 Canadian women diagnosed with breast cancer to determine the extent of input the women wished to have in deciding what treatments they would receive. They found that 22% of the subjects wanted to select their own cancer treatment. Of the 1,012 study subjects, 44% wanted to select their treatments collaboratively with their physicians, while 34% wanted to delegate that responsibility entirely to their physicians. Although these figures reflect the women's preferences, only 42% believed that they had actually achieved their preferred role in treatment decision making; 14.9% felt that they had been pushed into assuming more decisional control than they wanted. On the other hand, only 21% of the women who wanted the most active role believed that they had achieved their goal. These women, or women like them, may be a source of activism. Women who desired a passive role in decision making were most apt to believe that they had achieved their preferred role—51%. Possibly some of the women felt that pressure to make decisions quickly led them to follow their physicians' recommendations. The closer to the time of diagnosis, the more likely the women were to have achieved their desired role.

A significant finding was that women's highest priorities for information following a diagnosis of breast cancer were not about treatment options, but about their chances of cure and the risk of their disease spreading. Treatment options were third among the topics of desired information, along with family risk. Possibly discussion of treatment choices should be framed within the likelihood of cure and spread of the disease. Of medium priority were the need to know about adverse treatment effects and the impact of the disease on their families and social activities. Younger women were concerned about the effect of surgery on sexuality. Predictably, the women's level of education influenced the amount of involvement they preferred in decision making; the more education, the greater the wish for involvement.

A cluster of articles related to various aspects of decision making among women who carry mutations in one or both of the BRCA1 and BRCA2 genes has appeared in both the Journal of the American Medical Association and the New England Journal of Medicine. The discovery of the link between mutated BRCA genes and both breast and ovarian cancer was one of the major scientific breakthroughs of 1994, and the rush began to discover other cancer-related genes. Now it is certain that additional genes are associated with cancer and research is trying to ferret them out. Once the BRCA genes were sequenced, it was possible to develop materials to test for carriers of the defective genes that would increase risk of breast or ovarian cancer. A woman who carries a germ-line mutation of BRCA1 faces about an 85% lifetime risk of breast cancer and a 60% risk of ovarian cancer. BRCA1 and BRCA2 are said to explain most cases of familial breast cancer. Among Ashkenazi Jewish women, about 87% of breast cancers and 64% of ovarian cancers can be attributed to the BRCA genes. Even among the general population of Jewish women, the figures are 50% and 16% respectively. So there is considerable risk of developing breast or ovarian cancer among this segment of the population with a strong familial history of breast cancer. The risk of BRCA mutations among the general population is not yet known. Kramer et al. conclude that carriers of BRCA2 mutations have a smaller increase in the risk of early-onset breast cancer than carriers of BRCA1.

The issues of screening for genetic mutations in the BRCA genes have been discussed in previous editions of this newsletter. When women have been found to have the mutations, suggested treatments are prophylactic mastectomy, oophorectomy or both, to reduce these risks. Since the procedures are drastic and irreversible, while the effects of the surgery on prevention of breast cancer and life expectancy are not known, the decision to undergo prophylactic surgery weighs heavily on the patient and her doctor. In order to provide guidance in deciding about prophylactic surgery, Schrag et al. constructed a hypothetical model based on data from the literature to calculate the efficacy of these procedures in 30 year old women, considering their various levels of risk.

The authors calculated that on average, 30 year old women who carry either BRCA1 or BRCA2 mutations gain a life expectancy of 2.9 to 5.3 years from having prophylactic mastectomy, and from 0.3 to 1.7 years from prophylactic oophorectomy, depending on their cumulative risk of cancer. If oophorectomy is delayed for 10 years to permit childbearing, there is little additional loss of life expectancy. As women age, the benefit from these procedures diminishes. The model suggests that prophylactic mastectomy provides more gains for young women with BRCA1 or BRCA2 than prophylactic oophorectomy. Healy considers
Double Reading of Mammograms May Not Improve Diagnostic Accuracy

Double-reading of the same screening mammogram by two radiologists has been proposed as a way to increase accuracy. Radiologists vary widely in the accuracy with which they read mammograms due to human variability. In some practices, it has been found that even when two experienced radiologists read the same mammograms, the rate of true-positive readings (meaning that the diagnosis of cancer is definitely proved to be cancer) has not increased. By pairing two radiologists, the gain in identifying true-positives could be expected to rise by 8% to 14%, but at the same time there would be a 4% to 10% increase in the false-positive rate—a diagnosis of cancer that is proved not to be cancer. Before pairing radiologists to double-read mammograms, comparing the diagnostic agreement of the two radiologists could be done to learn their rates of true and false positive readings.

Membership in the Virginia Breast Cancer Foundation

Annual Dues Information

- New
  - Basic $15
  - Family $20
  - Supporter $25
  - Courtesy (available if unable to pay membership fee)

- Renewal
  - Friend $50
  - Patron $100
  - Sponsor—Greater than $100

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

This gift is in memory of

Please fill out form and return with your check to VBCF.

Thank you for your support!

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

Volunteer

- Please contact me about becoming a VBCF volunteer.

Calendar

July

29 Mandated Health Insurance Benefits Commission Meeting
   House Room D of the General Assembly Building

August

2 VBCF board of directors meeting
   Virginia Museum of Fine Arts—Richmond

September

TBA VBCF board of directors meeting

1 Deadline for Fall Newsletter—Contact Mary Huff 1-804-973-0763

October

5 Dance for the Cure, Jewish Community Center—Richmond

7 Dr. Susan Love—Seminar, Reception and Book Signing
   The Cornerstone in Richmond—Call VBCF 1-800-345-8223

The newsletter is funded through a donation from the Board for Women's Health of Richmond, Virginia.

It's time we found a cure!