VBCF Board Member Honored at Gala

Bebon Parks Recognized for Advocacy

The Virginia Breast Cancer Foundation is proud to announce that board member Bebон Parks, Goodloe Parks was recognized at the National Breast Cancer Coalition Fund's Gala, held March 3, 1997, at New York's Pierre Hotel. The Gala is held annually to raise funds and to honor individuals who play pivotal roles in the fight against breast cancer on national and local levels.

"It was such quick trip, it almost doesn't seem real," said Bebon after her return to Richmond. "I got in on Monday morning, braved the awful weather, enjoyed the Gala and flew back to Richmond on the 6 AM flight so I could be at work Tuesday. I must say it was one of the most elegant affairs I've ever attended."

Three breast cancer advocates were recognized for their dedication and commitment to the fight for increased awareness of breast cancer in their communities and a cure. In addition to Bebон, Maria Emilia Rivera of New York City and Diane Chase of McLean, Virginia, were each presented with an engraved Tiffany trinket box by NBCC President Fran Visco. All three advocates are also breast cancer survivors.

United States Senators Edward M. Kennedy, D-Mass., and Olympia Snowe, R-Maine, were honored for their steadfast support of NBCC's mission and their leadership in the fight against breast cancer. On behalf of Revlon, Ronald O. Perelman accepted a special corporate leadership award for the corporation's commitment to NBCC since 1993. Revlon spokeswoman Claudia Schiffer was on hand to endorse the NBCC's 1997 petition campaign. Paula Zahn served as mistress of ceremonies.

"I was overwhelmed that VBCF thought enough of my activities to nominate me. That really was a reward in itself. But to be chosen as one of the three honoree's...well, it was just wonderful," said Bebон. Also representing VBCF at the Gala were board members Lyn Carroll and Mary Jo Kahn.

Another guest was talk show host Rosie O'Donnell. "I appreciated Rosie O'Donnell's demeanor," added Bebон. "The photographers wanted to get her alone, but she refused and would only allow them to take shots when she was with other breast cancer advocates. And although it was nice to meet to Claudia Schiffer, I much prefer to be photographed next to other short ladies closer to my age."

We understand! Please join us in congratulating Bebон on a well deserved honor.
My thoughts have been of volunteers recently. With the exception of our administrative director, we are an all volunteer organization. We simply could not function without our many enthusiastic, competent volunteers who are truly the lifeblood of VBCF.

On January 27, VBCF hosted its first formal reception to honor our volunteers at the Virginia Museum of Fine Arts. It was, by all accounts, a wonderful success. (Admittedly, our hidden-agenda is to keep our volunteers and to recruit even more!) In addition to recognizing all who have contributed their time and talents to VBCF, I was pleased to present Susan Allen with the first rendering of our very own VBCF pin in recognition of her efforts to raise awareness about breast cancer throughout the state of Virginia.

More proof that our volunteers are special: Beblon Parks, our newest member of the board of directors, was selected as one of three honorees to be recognized by the National Breast Cancer Coalition (NBCC). Beblon was formally recognized for her breast cancer advocacy activities at the NBCC Gala in New York City on March 3. We are very proud of Beblon’s accomplishments and NBCC’s recognition of her at the Gala.

VBCF volunteers were in malls and office buildings across the state during the months of February and March. We joined other states across the nation in a petition drive asking for an allocation of 2.6 billion dollars for breast cancer research between now and the year 2000. We cannot allow research efforts to slow down; we must keep the dollars flowing. Researchers are attracted to well-funded areas of research. The breast cancer gene was discovered quickly following an infusion of increased research dollars. Do your part to support breast cancer research! The cure that is found may be your own, or your mother’s, or your sister’s, or your daughter’s or your friend’s.

We need volunteers to staff petition tables or to collect signatures on their own. If you can help with the petition drive in any way, call the VBCF office. We can send you copies of the petition so that your friends, neighbors, and coworkers can sign. VBCF will be there when the petitions are delivered to the White House on May 6. Join us on our bus trip to Washington. Buses will be leaving Newport News/Williamsburg, Charlottesville, and Richmond. Call 1-800-345-VBCF for details. It’s a trip you—and Washington, D.C.—will never forget!

Now more than ever, we need your time, talents and the gift of your financial support. Membership renewals for 1997 were mailed in February. Thank you to those who renewed and who responded generously. If you haven’t sent in your renewal yet, please do so today. And consider volunteering a few hours a month for VBCF. We need your help and it’s a wonderful way to fight against breast cancer.

Katie Brynes became involved in VBCF because she lost her mother to breast cancer when Katie was twelve years old. “I consider myself a mental and emotional survivor of breast cancer,” says Katie. “I have memories of my mother, but I also have memories of the times she wasn’t there and when I felt her loss deeply.” The first of the latter memories occurred at her mother’s funeral, when she experienced her first menstrual cycle. “I remember looking at myself in the mirror in the bathroom of the funeral home and thinking, ‘Today you are a woman.’ My mother had prepared me beforehand, but she wasn’t there that day. There were other caring women in my life, but not my mom. I really hate this disease. I look forward to the day when other families won’t have to experience what we did.”

Katie was named one of the district volunteers of the year for 1996 for her community outreach activities in the cities of Virginia Beach, Norfolk, Chesapeake and Portsmouth. She participated in the Southside Chapter of the Tidewater District as the public education coordinator. She spent hours setting up tabling events and public education presentations. “Although I had experienced the emotional devastation of breast cancer, I didn’t realize how little I actually knew about the disease until I became active in VBCF. It was important to me to help other women learn as much as possible about breast cancer and self-exam. I’ve read stuff in the media lately about self exam not being effective, but I think its empowering. And since an overwhelming number of American women find their lumps themselves, I think it’s important to spread the word and make the information readily available,” says Katie. The Virginia Breast Cancer Foundation is proud to recognize Katie’s efforts in helping fulfill this important facet of our mission.
This chapter has, as usual, got off to a busy start. Two interesting programs have been presented to the group already, with more to follow. In January, Dr. David Teasley, a local plastic surgeon, gave us an informative and upbeat talk on the subject of breast reconstruction. For those interested in this subject, you will be pleased to know that Dr. Teasley has agreed to present this topic again to our entire membership at the General Membership Meeting in April. Frances Honich attended our February meeting with her daughter, Ellen. Frances is a breast cancer survivor who has written about her experiences in poetic form. Her daughter designed a T-shirt and tote bag which they sell to raise funds for Frances’ treatment; she has no insurance at present. If anyone is interested in Ellen’s work, please call Jennie Davies at 804-229-9812 who can put you in touch with her.

The big item on our agenda at present is our annual fundraiser—Fashion Show and Luncheon—to be held at the Omni, Newport News, on Saturday, April 26 at Noon. The event will include fashions by Paige Harrell of Nags Head, a fabulous silent auction and a drawing for a beautiful quilt made by one of our members. Tickets are available from Ann Wilson at 757-868-6969 and Jennie Davies at 757-229-9812. The cost is $20.00 for a great day out! Make it a party event by coming with your friends—we can reserve tables for groups of 10.

Northwest District Charlottesville

The Zeta Tau Alpha Chapter at the University of Virginia will hold its Third Annual Run for Life on April 12, 1997. The money raised will go to the Susan G. Komen Breast Cancer Foundation. For more information call Patty at 804-293-5599.

Northwest District Staunton

Everlee Wheeler, VBCF member and her Bosom Buddies collected over 600 signatures for the petition drive recently.

VBCF Board Retreat

The VBCF held an open board of directors retreat at the Roslyn Conference Center on February 15. We were pleased to welcome several visitors who came to learn more about VBCF. The retreat began with a presentation of the history of VBCF by Mary Jo Kahn, co-founder and past president. We marveled at how far we have come and how much VBCF has accomplished. Many thanks to Mary Jo for putting together a wonderful slide show and assembling a nostalgic display of archival materials from our early days! Our facilitator, Audrey Russo, guided us through a structured North Star process to clarify our long and short-term goals. In addition to a guide, the process involves a graphic recorder who designs a visual representation of our vision and dreams, as well as short, intermediate and long-term action steps to reach our goals. The document will be displayed on a wall in the VBCF office. We arrived at the end of the day exhausted, yet exhilarated by what we have accomplished and how much there is yet to do.

We reaffirmed our deep commitment to VBCF’s mission to eradicate breast cancer. Until there is prevention and a cure for breast cancer, until all women have access to quality screening, diagnosis and treatment, and until the next generation is free of this devastating disease—we must not falter in our mission to eradicate breast cancer!
Virginia Breast Cancer Foundation now has its very own pin with our logo. First Lady Susan Allen was presented with the first pin at The Pink Badge of Courage reception on January 27. Contributions of $5.00 for the pin would be greatly appreciated. The bus trip and rally in Washington, D.C. will be the perfect time to proudly wear the pin and demonstrate our unity. Call your local chapters, or our office at 1-800-345-VBCF or 804-285-1200 if you would like more information.

Federal officials have notified HMO’s that enroll Medicare and Medicaid patients that their patients are entitled to “advice and counsel from their physician on medically necessary treatment options that may be appropriate for their condition or disease.” There have been accusations that some HMO’s are either contractually blocking physicians from advising patients about expensive treatments or giving bonuses to doctors who do not recommend expensive treatments.

The Breast Cancer Fund is staging two-day bike rides on the weekend of June 14 and 15. Each ride will be approximately 100 miles long and the rider will be responsible to raise $1,500 in pledges. The East Coast Bike Against the Odds will go through upstate New York. Call 800-487-0492 for more information.

We would like to welcome all of our new members to VBCF and thank our renewing members. VBCF could not continue its mission to eradicate breast cancer and to advocate on behalf of all women and their families without your continued support. Remember that VBCF is a 501(c)3 non-profit organization. Consult your tax professional with questions in regard to tax-deductible dues and contributions. If you’re not a member, please join us. If you are a member, please send your 1997 dues now.

A new method to obtain core biopsies of suspicious breast tissue is mammotomy. Approved by the FDA in 1995, the Mammmotome probe is in use in 250 cancer centers nationwide. The advantage of the probe according to some radiologists is the fact it requires only one insertion. Most stereotactic core biopsies require multiple needle insertions.

Dr. Elizabeth Fries and Melissa Figueiredo, Department of Psychology, Virginia Commonwealth University, are studying women’s thoughts and feelings about breast cancer. If you have been diagnosed with breast cancer, are undergoing treatment and would be willing to answer a written questionnaire, contact Melissa Figueiredo at 804-828-5794.

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### Annual Membership Meeting – Agenda

**Location:** Virginia Museum of Fine Arts, Orientation Theatre, Boulevard and Grove, Richmond

- **Saturday, April 12, 1997 10:30 a.m. – 4:30 p.m.**

<table>
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<tr>
<th>Time</th>
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<tr>
<td>10:30-11:00</td>
<td>New Member Orientation</td>
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<tr>
<td>11:00-11:30</td>
<td>Business Meeting</td>
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| 11:30-1:30 | Program: Breast Reconstruction                                        
|            | David Teasley, MD, Williamsburg Plastic Surgery Center                |
| 1:30-2:30  | Program: Making Change Happen                                         
|            | Beverly Soble & Mary Jo Ellis Kahn                                    |
| 2:30-4:30  | Program: Volunteers of the Year Recognition Program                  |
|            | Program: Coping With Breast Cancer                                   
|            | Louise Lubin, PhD, Norfolk                                            |
|            | Program: HEB-2/ neu Antibody                                          
|            | Lindsay Harris, MD, Duke University’s Breast Oncology Program         |

**If you are a new member or would like to learn about VBCF, please join us for this special session.**

Join us to learn more about our plans.

Participants will have the opportunity to hear experts speak on topics related to breast cancer and advocacy. Please join us on April 12! Call 1-800-345-8223 or 804-285-1200 to register.
Legislative Alert


If you believe that medical decisions affecting women undergoing mastectomies and lumpectomies should be made by the woman and her doctor—and not by insurance companies—there is legislation pending before Congress that needs your support.

Please call your senators and representatives and ask them to support this legislation. Remember, when you call, leave your name and address; by doing so, your federal representatives will respond to your concerns.

When calling your representative, feel free to use this script:
Please support HR 135 by signing on as a cosponsor to the DeLauro-Dingell-Roukema Breast Cancer Patient Protection Act of 1997, which guarantees a minimum stay of 48 hours for a mastectomy and 24 hours for lymph node removal for the treatment of breast cancer.

Virginia Representatives who have not yet signed on to the bill:

Rep. Herbert Bateman
1st Congressional District
202-225-4261

Rep. Rick Boucher
9th Congressional District
202-225-3861

Rep. Bob Goodlatte
6th Congressional District
202-225-5431

Rep. Frank Wolf
10th Congressional District
202-225-5136

Representative Biley chairs the Commerce Committee. When you call him, tell him that you would like to see this bill on the calendar for committee action. (There has been no committee action on this bill so far.)

For Senators: Please support S 143 Breast Cancer Patient Protection Act of 1997 so that women and their doctors can decide how long a woman needs to be in the hospital following a mastectomy or a lumpectomy—not insurance companies!

Senators Robb and Warner have not yet signed on as co-sponsors of this bill.

Senator Charles Robb
202-224-4024

Senator John Warner
202-224-2023

Remember, your voice counts!

legislative news

Join our fight against breast cancer!

NBCC 5th Advocacy Training Conference

The 1997 Advocacy Training Conference will be held on Sunday and Monday, May 4 and 5, at the Omni Shoreham Hotel in Washington, DC. For more information on registration, call 202-296-7477.

NBCC Project LEAD

Project LEAD (Leadership, Education and Advocacy Development) is a science training course for breast cancer activists. There is no cost for the intensive four day science course. A Project LEAD course is scheduled for Washington, DC, on July 16-20, 1997. The application deadline is June 4. Call Margo Michaels at 202-973-0585 for applications.

Join the Rally to Fight for More Funding for Breast Cancer Research

Join the Virginia Breast Cancer Foundation on our bus trip to the Washington, D.C. rally with the National Breast Cancer Coalition and other grassroots organizations to support increased funding for breast cancer research!

VBCF has joined NBCC in collecting signatures from citizens calling on President Clinton and the U.S. Congress to recommit to the eradication of breast cancer by investing $2.6 billion in breast cancer research between now and the Year 2000. In addition, the petition stipulates that breast cancer activists are among those who decide how that money is spent. Women’s lives depend on this fight!

VBCF members are encouraged to travel together on May 6 from Richmond, Charlottesville and Newport News/Williamsburg to join the rally. Transportation will be provided. Contributions to cover the cost of the trip are greatly appreciated.

If you are interested in taking the bus from Williamsburg, please call Jennie Davies 757-229-9812. If you would like more information on taking the bus from Charlottesville and Richmond, please call Teresa Dayton at 1-800-345-VBCF or 804-285-1200.
VBCF Honors Its Volunteers at The Pink Badge of Courage: A Celebration of Volunteers


The Pink Badge of Courage: A Celebration of Volunteers was held at the Members Dining Room of the Virginia Museum of Fine Arts in Richmond. The reception honored VBCF volunteers as well as other volunteers in the community who assisted in VBCF activities.
Virginia’s First Lady Susan Allen was an honored guest at the Pink Badge Reception. “I am pleased to join the Virginia Breast Cancer Foundation in recognizing the contributions of volunteers throughout the Commonwealth,” said Mrs. Allen. “Thanks to their generosity and dedication, we are one step closer to winning the fight against breast cancer.”

To thank Mrs. Allen for her highly visible efforts to raise breast cancer awareness, the First Lady was given the first VBCF pin ever produced. On behalf of the future generations, Megan Strawderman, Michelle Kahn and Barbara Kahn presented her with a bouquet of pink roses.

VBCF also thanks B.A. Knott Prosthetics, Inc., Faceworks by Michelle’s, Hampton Machine Shop, Sweet Reflections, A Woman’s Healthcare Boutique and Jessica McClintock for contributing to the door prizes. VBCF is grateful to Rivah Florists for their beautiful flower arrangements!

Volunteers devoted countless hours helping VBCF with many education and outreach efforts and fundraising activities in 1996. President Patricia Goodall stated, “Volunteers are the lifeblood of our organization. We are pleased to be able to thank them for their tireless work helping the Virginia Breast Cancer Foundation in the fight against breast cancer.”
SENATE JOINT RESOLUTION NO. 363

Commending Mary Jo Ellis Kahn

Agreed to by the Senate, January 23, 1997
Agreed to by the House of Delegates, January 31, 1997

WHEREAS, through a new, unprecedented program begun in 1996 by Avon
Products, Inc., and Avon's Breast Cancer Awareness Crusade, a total of one
million dollars was granted to ten outstanding leaders in the breast
breast cancer community; and

WHEREAS, Mary Jo Ellis Kahn, co-founder and first president of the Virginia
Cancer Foundation, was one of the ten national leaders to receive an inaugu-
ar Avon Breast Cancer Leadership Award at a presentation in New York City,
in October 1996; and

WHEREAS, on October 2, 1996, the Virginia Breast Cancer Foundation
received the $100,000 Avon Breast Cancer Leadership Award bestowed upon
Mary Jo Ellis Kahn, and

WHEREAS, the Award will help the Virginia Breast Cancer Foundation to
fulfill its mission to make the epidemic of breast cancer a state and national
health care priority; and

WHEREAS, the Award recognizes the outstanding individual contributions
that Mary Jo Ellis Kahn has made toward educating Virginians about the pre-
vention, detection, causes, treatments, and cure of breast cancer; and

WHEREAS, the Award also recognizes Mary Jo Ellis Kahn's outstanding
individual contributions toward patient advocacy and encouraging women
with breast cancer to work for improved disease outcomes through high qual-
ty, accessible medical research, especially among underserved women; and

WHEREAS, Mary Jo Ellis Kahn was one of a small group of women who
founded the Virginia Breast Cancer Foundation in 1991 and envisioned it as a
grassroots, nonprofit organization dedicated to promoting research into the
prevention, detection, causes, treatments, and cure of breast cancer; to
improving access to screening, diagnosis, and treatment of breast cancer, and
to educating the public and policymakers about breast cancer; and

WHEREAS, in the five years since its founding, the Virginia Breast Cancer
Foundation has grown to over 800 members, which includes women with
breast cancer, family members, friends, health care professionals, and other in-
terested people; and

WHEREAS, in addition to her advocacy and recruiting work on behalf of the
Virginia Breast Cancer Foundation, Mary Jo Ellis Kahn co-chairs the Hered-
itary Susceptibility Working Group of the National Action Plan on Breast
Cancer, whose mission is to advance research in cancer genetics without
putting women at risk for genetic discrimination or issues of this powerful,
personal information; and

WHEREAS, as a breast cancer survivor herself, Mary Jo Ellis Kahn stands as
an inspiration to all Virginians to dedicate themselves in service for the bet-
terment of our communities, our state, our country, and our world, now, there-
fore, be it

RESOLVED by the Senate, the House of Delegates concurring, That the
General Assembly commends Mary Jo Ellis Kahn on her most well-deserved
1996 Avon Breast Cancer Leadership Award; and be it

RESOLVED FURTHER, That the Clerk of the Senate prepare a copy of this
resolution for presentation to Mary Jo Ellis Kahn, as an expression of the Gen-
eral Assembly's admiration for her outstanding individual contributions toward
educating Virginians about the prevention, detection, causes, treatments, and
cure of breast cancer and for her national leadership on the issue of genetic
testing for hereditary susceptibility to breast cancer.

Report on the 1997 Legislative Session

by Jean Hashall

Senate and House Pass Resolutions Honoring VBCF Members

Two of our VBCF members were honored in resolutions during the
1997 General Assembly session. Mary Jo Ellis Kahn received her honor in Senate Joint Resolution
363, for the Avon Breast Cancer Leadership Award, her work as a
cofounder of the VBCF Foundation and her membership on the

In House Joint Resolution 511, Bert Aaron, a member of
VBCF and chairman of the 1995 Primary Care Perspectives Confer-
ence sponsored by the VBCF, was honored on his 75th birthday,
for his long-term commitment to his community, to his professional career and to his
commitment to the cause of breast cancer.

Congratulations to both of our "Members of Resolve."

Genetic Information Subcommittee Retains Authorization

During the 1997 legislative ses-
sion, the Virginia Senate re-
newed the Joint Subcommittee studying the legal and policy
ramifications of genetic re-
search. In 1995, the Senate es-
tablished this Joint Subcommit-
tee and, in 1996, the General
Assembly passed important leg-
islation providing limited pri-
vacy protection which prohib-
ited health insurers' use of ge-
netic information in determin-
ing health insurance coverage,
as well as the unauthorized re-
lease of such information to
third parties. However, the 1996 legislation contained a two-year sunset
clause, premised on expected na-
tional standards and or laws.
Since genetic privacy issues and other issues regarding genetic information are still in limbo,
Virginia's Senate resolved to con-
tinue the Joint Subcommittee's
monitor developments at the fed-
eral level and in other states. It is
constituted to make specific rec-
ommendations to the General
Assembly and to propose legisla-
tion, if needed.

Genetic information and its potential impact on every indi-
vidual continues to be a major fo-
cus issue of the VBCF. Mary Jo
Ellis Kahn, cofounder, past presi-
dent and board member of the
VBCF, cochaired the Hereditary Susceptibility Working Group of
the National Action Plan on
Breast Cancer of the National Insti-
tutes of Health and has been
instrumental in developing edu-
cational language to address the
labyrinth of issues arising out of
science's increasing ability to ge-
netically code individuals and their lifetime disease risks. The
VBCF will continue to monitor the work of this subcom-
mittee and will report on legislative de-
velopments as they occur.
Reconstructive Rights Die in Committee

Another legislative issue before the 1997 General Assembly session was Senate Bill 948, patroned by W. Roscoe Reynolds, which would have guaranteed coverage by health insurers, health maintenance organization and corporations for reconstructive breast surgery performed as a result of a mastectomy.

The Bill was referred to the Committee on Commerce and Labor, where "it was left." In the terms of the Legislature, this is basically a way to allow a Bill to die or be tabled. The VBCF was asked to comment on the proposed legislation.

The VBCF’s commitment to women's health issues means that we will work diligently with legislators to educate them on the importance of such protection.

Medical

Psychosocial Effects of Breast Cancer

By Phyllis Tyzenhouse

Most of the literature on the outcomes of breast cancer treatment addresses the physical effects of surgery, chemotherapy and radiation on individuals. While this is important information, helpful to the patient and family in anticipating and dealing with the aftermath of the treatment, there is very little information and guidance on the psychosocial effects of surviving breast cancer. Now there is an article, written by oncology nurses, that identifies some of survivors' experiences.

The list follows:

1. Fear of breast cancer recurrence (local, regional or distant), exhibited by expressions of denial of these fears, avoidance of physicians, exaggerated general health worries or hypochondriasis.
2. Conversational isolation when family members block discussion of the patient's fears of breast cancer recurrence, because of their own anxiety and fear.
3. Avoidance by others because of identification with the patient's plight.
4. Concerns that disclosure of the breast cancer might affect dating, intimacy and rejection.
5. Concern over a possible relationship between the patient's breast cancer and development of breast cancer in the patient's daughters.
6. Distress caused by hovering behavior by loved ones.
7. Work and/or insurance discrimination.
8. Need for clarification about the individual nature of the patient's cancer compared with friends' cases and information about breast cancer seen in visual and print media.
9. Grief over changes in important relationships that appear to be permanently altered as a result of the cancer diagnosis.
10. Dysfunction within the marital or sexual relationship, particularly if issues related to the breast cancer were unresolved and troubling during the early phases of diagnosis.
11. Emotional concealment to minimize psychosocial trauma.
12. Uncertainty about the likelihood of dying sooner than expected.
13. Grief over the inability to pursue pregnancy if that option is in question.
14. Anger over chronic or acute physical problems related to the therapy.
15. Resurfacing of emotions at anniversary dates and special occasions associated with the breast cancer.
17. Reassessment of values resulting in increased zest for, and appreciation of life.

This article was published in a journal for nurses to enable them to recognize breast cancer patients' needs for assistance in resolving non-medical outcomes of breast cancer treatment. Major points are summarized here to inform patients of common post-treatment experiences of other breast cancer patients, so that they may seek guidance from health providers to help ease their way back into healthy, active, productive lives.

Medical Short Takes

by Phyllis Tyzenhouse

Ethnic Groups Other Than Ashkenazim Are Found to Have Gene Mutations

In 1995, an important announcement was made that Ashkenazi Jews carried BRCA1 and BRCA2 genes in higher frequencies than other population groups, and carried a higher risk of breast and ovarian cancer. That finding held true as late as October, 1996. Then in January, 1997, an announcement was made that scientists had found two distinct BRCA1 mutations in Norway and BRCA2 in Iceland. The Japanese have their own common BRCA1 mutation, along with the Swedes, Italians in Tuscany and a group of African-Americans in south Florida. The discovery of common mutations among other ethnic groups opens the door to genetic testing of expanding population groups.

Sometimes the mutation can be traced back to a common ancestor who carried the gene, and then the descendants can be tested for the gene. Unfortunately, tracing the first ancestor to have the mutation (the "founder") may be impossible and families of other than Ashkenazi derivation do not know they carry it. Since early ancestors migrated into other parts of the world, the mutations may be widely dispersed. For example, Iceland was settled by people from Norway and Ireland, so testing of populations rather than specific ethnic groups is a consideration, but the high cost of testing makes this unfeasible, especially since the percentage of women with BRCA1 or BRCA2 is far lower in these groups than in Icelanders and Ashkenazi Jews. Genetics and genetic epidemiology are emerging as exciting, growing disciplines that can unlock the mysteries of genetic mutation-linked diseases.

Brad Keoun, "Ashkenazim Not Alone; Other Ethnic Groups Have Breast Cancer Gene Mutations, Too," JNCI, 89(1), January 1, 1997, pp 8-9;

Alcohol Triples Effect of Estrogen

Drinking alcohol can substantially increase blood levels of estrogen in postmenopausal women who take oral estrogen, but it does not change the level of naturally produced estrogen. Researchers at Brigham Women's Hospital in Boston studied 24 postmenopausal women who were on estrogen replacement therapy (ERT). After ingesting alcohol, levels of estradiol, the most important of the estrogen hormones, was measured and found to have increased by 327%. There was no increase in estradiol in women who did not use estrogen replacement therapy.

There are estimates that about 25% of postmenopausal women use some sort of estrogen replacement therapy and are protected to a large extent against osteoporosis and heart disease. However, the benefits of ERT have risks and adverse effects that include breast cancer, uterine cancer and gallstones. The higher the level of circulating estradiol, the greater the risk of harmful effects. If alcohol alters the expected biological effects of ERT, the risk-benefit ratio could shift in an undesirable direction. Evidence shows that regular alcohol consumption has a cumulative effect on estradiol in postmenopausal women, which adds to their risk of breast cancer. Even though moderate alcohol consumption appears to decrease the incidence of coronary artery disease, it may increase the incidence of breast cancer by raising blood estradiol levels. Dr. Elizabeth S. Ginsburg, who led the Boston study, recommended that women who drink more than occasionally should use a lower dose of estrogen. No study has yet looked at the effect of alcohol on estrogen when taken in the form of Premarin (Wyeth-Ayerst), a tablet containing estrogen, used by about 80% of women who are on ERT.


Diet and Estrogen

According to the October 2, 1996 Journal of the National Cancer Institute, estrogen levels can be reduced by dietary modification. For the study, 21 premenopausal African-American women were placed on a high-fat, low-fiber diet, consisting of 40% of calories from fat and 12 grams of fiber per day. Then they were changed to a low-fat, high-fiber diet with 20% of calories from fat and 40 grams of fiber per day, for 7 to 10 weeks. The change resulted in a 9% decrease in estradiol, 16% drop in estrone, and an increase in androstenedione levels. Androstenedione is converted to estrone, high levels of which are associated with upper body fat.

Previously, the same diet was given to 68 premenopausal Caucasian women resulting in a decrease in all three hormone levels. The researchers found that the African-American women had higher hormone levels to begin with than the Caucasian women; they speculated that this finding may explain the lower survival rates among black women who have breast cancer.

From Women's Health Advocate Newsletter, 3(9), Nov. 1996, p.2.
Hormone replacement therapy (HRT) for postmenopausal women helps to prevent osteoporosis and cardiovascular disease, but it also has a downside: increased risk of breast cancer and endometrial cancer. Now a new class of drugs may become available to replace HRT and tamoxifen (Nolvadex), which are less likely to increase risk for estrogen-related diseases. Suzanne Oparil, MD, announced the new drugs at an American Heart Association meeting in July, 1996. She calls the drugs SERMs, standing for selective estrogen receptor modulators and announced that SERMs mimic estrogen, protecting women against osteoporosis and cardiovascular disease. But SERMs act as estrogen antagonists in some tissues and are less likely to be associated with estrogen-induced cancers.

Two of the SERMs now in clinical trials are Raloxifene and Drotifox. Raloxifene was compared with Premarin (conjugated equine estrogens) since both decrease bone turnover and reduce lipid levels. Women who took Raloxifene along with a progestin did not show endometrial changes, but those who took Raloxifene alone showed significant changes. Some women reported having hot flashes while taking Raloxifene. The drug is being tested in women with metastatic breast cancer and a study is being considered to test its use in cardiovascular disease.

The second drug, Drotifox, is being studied to compare it with tamoxifen in 1400 women. Early results suggest that the drug does not contribute to uterine, and possibly, liver cancer. Trials are underway to test its use in preventing osteoporosis and lowering LDL cholesterol. So far, findings indicate that Drotifox's effect on reducing LDL and preventing bone loss will be similar to that of Premarin.

From Women's Health Advocate Newsletter, 3(8), Oct. 1996

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"I am a ten-year survivor of breast cancer."

Stereotactic Biopsy...A for Aching or A for Awful

...Mary Munton

Last year I underwent a stereotactic biopsy for a questionable mammogram unresolved by sonogram. My oncologist felt follow-up would be a good course to follow and agreed with the suggested stereotactic biopsy. I was totally unprepared for what turned out to be a two and half hour ordeal with my breast in compression for over two hours. The location and extraction were very painful as was the joint pain from being in the same position for such a long period of time. I have discussed my experience with the radiologist and my oncologist, but the most receptive medical professionals were the members of the National Mammmography Quality Assurance Committee to whom I spoke during an open three day meeting in October (see VBCF newsletter Oct/Nov/Dec. 1996, Some Thoughts about Stereotactic Needle Biopsy, page 10).

I have talked with friends and family and other women who have had difficult biopsies, but I began to wonder if we were a minority. The members of the National Mammography Quality Assurance Committee were astounded when a woman from California and I recounted the terrible experiences we had. They need to hear from you, the women who are undergoing this procedure. The National Committee members felt that 20 to 30 minutes was the normal amount of time and that pain relieving measures were administered.

If you have had a stereotactic biopsy, help all of us by taking the time to answer these questions. You may send your correspondence to Dr. Finder or to me (addresses below). Your answers will go to the committee.

Please include your name, location, month and year the stereotactic exam was done.

- Did you find the lump yourself or was it detected by a clinical examination or mammogram?
- Was the stereotactic procedure performed by a surgeon or radiologist? (no names, please)
- Did you know the qualifications of the person who performed the biopsy?
- How long did the procedure take?
- What discomfort or pain, if any, was associated with the procedure?
- Was anything done to decrease pain or discomfort?

Briefly describe your experience during the procedure.

- What were the results of your biopsy?
- Did you have to have a repeat test done?

The National Committee is in the process of establishing standards and needs the input of women who have undergone the procedure. Send your comments to either or both:

Dr. Charles A. Finder
Division of Mammography Quality and Radiation Programs
HFZ-240
Office of Health and Industry Programs
Food and Drug Administration
Rockville, Maryland 20857

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7915 Provincetown Drive
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April

12 VBCF Membership Meeting
Richmond

24 Peninsula Chapter Fashion Show
Newport News

May

4-5 5th Annual Advocacy Conference
Washington, DC

6 Bus Trip to White House & Congress
Washington, DC

17 VBCF Board Meeting
Richmond