Save the Date for Dr. Susan Love!

VBCF is proud to partner with Bon Secours Women to bring Dr. Susan Love back to Richmond to talk to the breast cancer community on Tuesday, October 18th.

Dr. Love is the author of Dr. Susan Love's Breast Book and Dr. Susan Love's Menopause and Hormone Book. A Clinical Professor of Surgery, she was one of the "founding mothers" of the breast cancer advocacy movement. Dr. Love is also the President and Medical Director of the Dr. Susan Love Research Foundation, a nonprofit dedicated to the prevention of breast cancer.

Visit www.vbcf.org or call VBCF at 800-345-8223 for ticket details and mark your calendar now for this exciting event!

*Sponsorship is available for individuals who must travel over 100 miles to attend. VBCF will reimburse 2/3 the cost of hotel and travel. Contact Elisa Romans at 800-345-8223 or Elisa@vbcf.org for a sponsorship application.

When: Tuesday, October 18, 7 p.m.
Where: Sheraton West Hotel, 8624 West Broad St., Richmond

Era of Hope Meeting for the Department of Defense (DOD) Breast Cancer Research Program (BCRP)

by VBCF Board Member & Blue Ridge Chapter Member Rita Handley

This conference inspired hope for a disease that is often so full of despair. The Era of Hope meeting gave me the opportunity to reconnect with several people I met last summer as a research proposal reviewer on the DOD Peer Review Panel. I am so honored, privileged and humbled to have been invited and able to attend. The following excerpt is from an "Era of Hope Preliminary Report" written by Sharon Ford Watkins of the National Breast Cancer Coalition (NBCC). Individuals can also check the DOD BCRP website for more information at http://cdmrp.army.mil/bcrp/era.

The BCRP began as a result of NBCC's 1992 campaign to dramatically increase federal funding specifically targeted to breast cancer research. This program created an unprecedented partnership that unites the military, scientific, medical and breast cancer survivor and advocacy communities to develop and carry out research to end breast cancer. It is the federal government’s only breast cancer research program that involves consumer advocates at both the scientific peer review and the programmatic review stages and at all levels of a scientific meeting.

The scientific peer review panels that evaluate each proposal for merit and the programmatic review panel have benefited from the voices (and votes) of 399 consumers, individuals that come from 255 separate organizations, providing an incredible reach into the world of breast cancer nationwide.

An important part of the DOD program is the Era of Hope meeting (Continued on page 9)
This spring and summer have turned out to be very busy and exciting for VBCF and often challenging for me. I am happy to report that things are on track, and I am looking forward to a productive fall.

In February, our Executive Director, Chris Clarke, tendered her resignation. We had to establish a search committee and advertise the position only 2 months after my term as President began. We were fortunate enough to receive over 40 applications and interviewed almost a dozen excellent candidates. I am pleased to announce that we hired Shirley Storms, who started July 18.

I also need to say a huge “thank you” to Chris Clarke. She has done a tremendous amount in the past 4 years to move VBCF forward and make us the great organization we are today. I am personally very thankful Chris committed to stay until we found the right Executive Director. That took a lot of pressure off the search committee and is just one example of how dedicated Chris has been to this organization.

In late May, VBCF members attended the National Breast Cancer Coalition (NBCC) Annual Advocacy Conference and Lobby Day in Washington, D.C. In my opinion, this was the best annual conference yet. We celebrated the 10th anniversary of Project LEAD with several great scientific workshops culminating in a dinner presentation by National Cancer Institute Director, Andrew Von Eschenbach. The conference presented over 600 advocates with timely plenary sessions and workshops. In addition to the topics covered by articles in this issue, plenary sessions included “Breast Cancer Research: Your Tax Dollars – Who Benefits?” “New Trends in Breast Cancer Research,” “The Environment and Breast Cancer,” “Breast Cancer Care – Who Decides and How Safe are We?” and “Politics and Health Care Access.” Lobby Day was also a great success, and we were able to present Senator Allen and Representative Wolf with awards for their 100 percent voting records on NBCC legislative priorities.

Following closely on the heels of the NBCC conference came the Department of Defense (DoD) Era of Hope Conference in Philadelphia, PA. The DoD Breast Cancer Research Program invited all consumer advocates who had served on scientific peer review and integration panels to attend—and several of us VBCF consumers did. The purpose of the Era of Hope Conference is for researchers who were funded by the DoD program in the past 2 or 3 years to report to the public on their results of their research. The unique aspect of the DoD program is that consumer advocates are involved at all levels of the program. I was honored to be asked to make a presentation on “Emerging Opportunities in Preventing Metastasis” for one of the plenary sessions. My presentation occurred only 2 days after my first chemotherapy treatment for metastatic disease, and I was lucky my hair did not start falling out until after the second treatment.

I think all of us from VBCF at the conference were excited about what we heard in terms of prevention, diagnosis, and treatment. However, a big challenge for all of us who are impatient for new and better ways to deal with breast cancer is to realize that much of what we heard is not yet ready for the clinic. While we are impatient, we want to be sure our medical decisions in the clinic are based upon the best possible evidence.

Finally, VBCF continues to work to educate Virginians about breast cancer and has conducted some outstanding local programs. Please make your calendars for October 18, when Dr. Susan Love will be coming to Richmond. I look forward to seeing you all there!

Karin Deker Moss

The Virginia Breast Cancer Foundation is a grassroots organization committed to the eradication of breast cancer through education and advocacy.

Educate. Advocate. Eradicate.
The Central Virginia Chapter elected new officers who are as follows (from left to right): Barbara Geisler, Corresponding Secretary; Carol Snyder, Recording Secretary; Maureen Cassidy, President; and Minnie Harris, Vice-President.

This past winter, the Central VA Chapter held Breast Cancer Talks, a free educational program featuring three separate talks related to breast cancer. The program focused on donating blood and the importance of blood products, the NIH Sisters Study and the connection between ovarian and breast cancer.

Hampton Roads Chapter

New officers for the Hampton Roads Chapter are as follows: Eunice McMillan, President; Jewelle Harmon, Vice-President; Lynn Briley, Secretary; Ruth Shumate, Corresponding Secretary; Paulette Turner, Treasurer; and Shirley George, Public Relations.

Health Care Technology HOSA (Health Occupations Students of America) students at the Chesapeake Center for Science and Technology (CSST) presented the Hampton Roads Chapter with an anatomical breast model to assist the chapter in educational outreach. Pictured above are the students with Chapter Members Pearl Harmon and Ruth Shumate, along with Chapter Advisor D. Bailey and Principal William Joe.

Peninsula Chapter

The Peninsula Chapter held another successful fashion show in March! The show had the theme “Out of the Box - Fashions and Flowers,” featured fashions by Dillard’s and raised over $16,000 for VBCF! Thank you to the chapter members for their hard work and dedication to this memorable event.

Models show off the latest styles at the Peninsula Chapter Annual Fashion Show.

VBCF trains 16 new Speakers Bureau Presenters

On June 7, VBCF trained 16 breast cancer advocates and VBCF volunteers to be presenters in our Stay Abreast Speakers Bureau Program. Armed with this important educational presentation, these trainees are now prepared to help educate Virginians on breast health, statistics and VBCF’s efforts to eradicate this disease.

The Speakers Bureau program is a statewide initiative and VBCF seeks to train volunteers in different areas of Virginia. If you are interested in VBCF holding a training session in your area (or if you know of a speaking opportunity in your area), please contact Elisa Romans at (804) 285-1200 or (800) 345-8223 or Elisa@vbcf.org today. Help us continue this important community outreach!
Focus on Quality: A Report on Project LEAD: Quality Care
by Program Committee & Central VA Chapter Member Julie Shelton

I recently attended Quality Care Project LEAD and the National Breast Cancer Coalition's (NBCC) Annual Advocacy Conference. As outlined in the last issue of One Voice, one of NBCC's goals is to increase access to and improve the quality of breast cancer care. As noted in its position statement on this issue, "NBCC believes that quality breast cancer care is a patient-centered, evidence-based system of care that fulfills the following overlapping core values: Access, Information, Choice, Respect, Accountability, and Improvement."

NBCC focuses on three strategies to achieve this goal: 1) Educate breast cancer patients, advocates, and the public about what quality care is, how to get it and how to be an advocate for it; 2) Influence health care providers to implement NBCC's vision of quality care; and 3) Influence policymakers to create a national health care system that reflects this vision.

One component of the educational effort is Quality Care Project LEAD. This is a training course that educates advocates on quality care and how to advocate for systems-wide improvement in quality of care. The substance of the course is a combination of science, policy and advocacy. Topics covered include the following: how the health care system is structured and financed; how to critically evaluate health care information, clinical standards of care and practice guidelines; and evidence-based health care and creating quality measures. The course is a combination of lectures and small group sessions taught by a well-qualified and enthusiastic faculty.

Several entities are now involved in quality measurement efforts, including the Centers for Medicare and Medicaid Services (CMS), the Agency for Healthcare Research and Quality (AHRQ), the Institute of Medicine (IOM), and the National Quality Forum (NQF). NQF is a private, non-profit voluntary consensus standards setting organization, whose goal is to develop and implement a national strategy for healthcare quality measurement and reporting. The National Cancer Institute (NCI), the American Society of Clinical Oncologists (ASCO) and the National Comprehensive Cancer Network (NCCN) have information about treatment guidelines on their web sites.

Breast cancer advocates should be involved in breast cancer decision-making because we bring an important perspective to the table. To be effective, advocates need to be knowledgeable. One of our faculty at Project LEAD noted that sometimes we don't know what we need to know unless we ask the right questions. I hope that I ask the right questions and will be an effective advocate in the breast cancer community. I encourage other VBCF members to consider attending a Project LEAD course, NBCC's Annual Advocacy Conference or participate in VBCF's State or National Lobby Day. We are fortunate to have an established and well-respected organization in Virginia that advocates for the needs of individuals affected by breast cancer. Of course, I'm referring to the VBCF!

VBCF welcomes new Executive Director

After an extensive search, VBCF is proud to welcome Shirley Showers Belkowitz as our new Executive Director. Shirley brings over 10 years of leadership experience in nonprofit and association management. She received her Bachelor's degree from Virginia Commonwealth University, has completed some coursework in VCU's Nonprofit Management Program and has training in mediation. Shirley will be our third Executive Director. We are confident she will help us continue to grow as an organization and achieve our goal - the eradication of breast cancer.

From left to right: Connie Deagle of Rappahannock General Hospital; Monica Morris, MD, of VCU's Massey Cancer Center; and VBCF Vice-President Gay Rudis.

Rappahannock Educational Program a Success!

VBCF was proud to partner for the first time with Rappahannock General Hospital on June 16 to present The Emotions of Breast Cancer, which featured Monica Morris, MD, of VCU Health System's Massey Cancer Center. Dr. Morris discussed the emotional journey that an individual faces after a breast cancer diagnosis, as well as the difficulties encountered and how others can best be supportive. This rural outreach drew a crowd of 50 community members and received positive feedback from participants. VBCF thanks Pfizer for its support of this program and looks forward to future programs in other rural areas as we continue our work to educate Virginians on the truth about breast cancer.
Volunteer Spotlight on Blue Ridge Chapter
President Myrtle Kite

This issue's Volunteer Spotlight features Myrtle Kite, VBCF Member and President of the Blue Ridge Chapter. Myrtle found a lump in her breast and had it removed in November of 1994. A few days later her doctor called with the news that the biopsy showed cancer. Myrtle had a mastectomy in December of 1994 and took tamoxifen for 8 years. She and her doctor discussed her options, and since the cancer had not spread to her lymph nodes, she decided to forgo radiation.

Myrtle joined a breast cancer support group and became good friends with other women with breast cancer. Talking helped her deal with her experience, and she began to learn as much as she could about the disease. Myrtle became acquainted with VBCF by attending lobby day and other programs, and with the help of her friends, she co-founded the VBCF Blue Ridge Chapter on January 11, 2004. As President of the Chapter, her personal goals are to lead the chapter to the best of her ability in its mission to bring awareness about breast cancer to the Valley and to give back to the community.

Myrtle has been married for over forty years to James and has a daughter, Lisa, a son, DeWayne, and two granddaughters. In addition to VBCF, Myrtle has been very active with ARC (Association for Retarded Citizens) of Augusta, serving as President, and helped build a home for the mentally retarded in her community. Myrtle retired in 1993 after working for Hollister, Inc, and now focuses on her passion for buying and selling antiques. Myrtle enjoys sharing her message to others in the Blue Ridge area that, for her, breast cancer was not the end but the beginning.

All Chapters Meeting

Members from all four VBCF Chapters – Blue Ridge, Central VA, Hampton Roads and Peninsula – met at VBCF's 3rd Annual All Chapters Meeting to exchange stories, give updates and participate in a media training. Sherri McKinney with the Farm Bureau and Message Media, who has a background as a reporter, anchor, and producer, used her experience and sense of humor to train chapter members on how to effectively build relationships with the media. (Sherri also produced VBCF's first video PSA this year – VBCF thanks Sherri for her support.)

Thank You! VBCF thanks WTVR Channel 6 for their support, which allowed VBCF to create copies of our video PSA to send to stations throughout Virginia.

VBCF is ON-THE-GO!

The following is a sample of where VBCF advocates have journeyed to work toward our mission to educate, advocate and eradicate:

January 4: VBCF Member spoke to support group in D.C.
January 25: Hampton Roads Chapter spoke to support group in Portsmouth.
February 7: Central VA Chapter spoke to nursing students in Richmond.
March 3: Central VA Chapter educational table in Richmond.
March 10: Blue Ridge Chapter spoke to high school students in Staunton.
March 19: Peninsula Chapter Fashion Show in Newport News.
March 24: Blue Ridge Chapter spoke to Vocational students in Fishersville.
April 2: Blue Ridge Chapter spoke at church in Columbia.
April 2: VBCF and Sisters Network educational table in Richmond.
April 7-10: National Breast Cancer Coalition's (NBCC) Project LEAD: Quality Care Course in D.C.
April 14: VBCF member spoke to women’s club in Midlothian.
April 15-20: American Association for Cancer Research (AACR) Conference in Anaheim, CA.
April 18: Blue Ridge Chapter spoke to support group in Woodstock.
April 21: Central VA Chapter educational table in Richmond.
April 25: Central VA Chapter Member spoke to support group in Petersburg.
April 28: VBCF Member spoke to professional association in Richmond.
April 30: VBCF Member participated in panel on women’s health in Richmond.
May 4: VBCF Member spoke at organizational meeting in Richmond.
May 7: Central VA Chapter educational table in Richmond.
May 12: Blue Ridge Chapter spoke to professional association in Staunton.
May 13: Peninsula Chapter educational table in Newport News.
May 14: VBCF Member spoke at church in Richmond.
May 21: Central VA Chapter educational table in Chesterfield.
May 21-24: NBCC Annual Advocacy Conference in D.C.
May 24: National Lobby Day in D.C.
June 3: Blue Ridge Chapter educational table in Staunton.
June 8-11: DOD Era of Hope Meeting in Philadelphia.
June 10: Central VA Chapter educational table in Glen Allen.
June 11: Educational table at health fair in Richmond.
June 11-15: American Association of Cancer Research (AACR) Scientist-Survivor Program Workshop in Bethesda, MD.
June 21: VBCF Member spoke at organizational meeting in Richmond.
And VBCF is still on-the-go...
Review of NBCC Conference Workshop Working and Changing the System by VBCF Board Member Frank Poynter

Many of us are aware that the health care system in this country is reaching a boiling point. If we don't solve the problem soon this country is in for a crisis that we may not recover from in the foreseeable future. NBCCF and VBCF's number one legislative priority is Access to Quality Health Care for All. This is a basic human right, which the NBCC Annual Advocacy Conference addressed in a workshop.

Joanne Howes, an experienced political advisor to NBCC, conducted the workshop and gave an overview of US healthcare as it is now, citing the following problems:

- Lack of universality
- Complexity—especially in the public system
- Lack of consistency in scope of coverage within sectors and across sectors
- Cost
- Dependency on link to employment
- No national consensus on how to fix it

Ms. Howes then provided more data on how the U.S. population is covered or not covered by health insurance. Her report showed that only 17% of uninsured individuals are not working, and 2/3 of the uninsured are workers whose employers do not offer insurance. The question is, do we want a social contract or socialism? Joanne reviewed the barriers to health care by insurance status, showing that many are not receiving adequate health care (underinsured) or too much health care (over insured), which may include unnecessary procedures.

The workshop reviewed the various models that are in place around the world today and their pros and cons. She discussed the new approaches to reform from both political parties and the philosophical divide that exists. Ms. Howes also covered the issues surrounding and challenges to achieving quality health care. She identified the various players that now exist, and how they work together or (don't).

Ms. Howes also addressed legislative efforts. She advised that a number of legislative initiatives were introduced in the 108th Congress with no action and that we should expect significant action in the 109th Congress. All of this will affect health care consumers and we are all health care consumers. For a complete transcript or to order an audio CD of this workshop, visit www.stopbreastcancer.org.

In conclusion, after talking to legislators, healthcare providers, and fellow advocates, I have come to believe that a whole new paradigm is required to institute the needed radical overhaul of our healthcare system. The impetus for this change must come from advocates like us as a grassroots movement. Together we can affect the necessary change. This overhaul must happen for the welfare of our children and grandchildren!
Nominations for the 2004 Nancy Dopp Volunteer of the Year

The Nancy Dopp Volunteer of the Year recognizes a volunteer whose contributions of time, energy or talents have had a significant impact for VBCF in 2004. (Please note that an individual who served on the VBCF Board of Directors in 2004 cannot be selected as Volunteer of the Year.) The recipient will be awarded on Tuesday, October 18, 2005 at the program, An Evening with Dr. Susan Love, in Richmond. Please take the time to nominate someone who you think deserves this award today!

Name of the VBCF Member(s) completing this form: 

__________________________________________________________

__________________________________________________________

Telephone: ( )________________________ e-mail: ____________________________

Should you choose to nominate more than one individual, please copy this form and submit per nomination.

Please provide the following information about the individual nominated:

Name: ________________________________

Address: __________________________________________

__________________________________________________________

Telephone: ( )________________________ e-mail: ____________________________

This individual should be recognized as The Nancy Dopp Volunteer of the Year because:

Please submit form to VBCF statewide office at 5001 W. Broad Street, Suite 201, Richmond, VA 23230 or by fax at (804) 285-7735 by Monday, September 26, 2005. If you have questions please call (800) 345-8223 or (804) 285-1200.
Review of NBCC Conference Workshop Strategies of Effective Lobbying by Central VA Chapter President Maureen Cassidy

At the National Breast Cancer Coalition's (NBCC) Annual Advocacy Conference, I had the opportunity to attend the Strategies of Effective Lobbying Workshop. Panel Members included Jean Doyle of Representative Lowey's Office, Stephanie Foster of Georgetown Strategies, Sarah Hale, Jason Money of Senator George Allen's Office, and Christine Norton of the MN Breast Cancer Coalition.

The Panel shared tips on how to get our foot in the door. We were told that we were already experienced lobbyists: We have negotiated with our partner (I'll make the coffee if you make the bed), the boss (I worked hard on this project; I deserve a raise), and our children (you must clean your room before you go to the pool). Realizing I was an "experienced lobbyist" boosted my confidence; it wouldn't be too hard to ask the representatives to support the fight against breast cancer. Listed below are some of the tips we heard:

**BE PREPARED:**
1. Know your facts: How much money is needed and how will the money be used? What agencies will direct the spending?
2. Be comfortable.
3. Determine if there are people in your group with a connection to the representative. Who in the group is a voter in their district?
4. Check the representative's past voting record.
5. Don't forget that staffers are important and build relationships with them. Give pink and white M&Ms; they do take "bribes."
6. Stay focused. Remember the goal is eradicating breast cancer - not about any one individual.

**THE ACTUAL MEETING:**
1. Be on time. Remember that time is valuable to the representatives and their staff.
2. Keep the message short and concise. If pertinent to the goal of the visit, briefly relate your story; do not underestimate the potential effect of your personal experience.
3. Be direct. Use good manners yet keep the focus on the message.
4. Be direct, organized; state the problem and what would happen if the problem is not addressed; state the solution; acknowledge the other side of the argument, and ALWAYS ASK for their support.
5. If the representative has not been supportive on this issue in the past, find out what information you can provide to help them make a better decision in the future.
6. If asked a question you can't answer, do not guess or give misinformation. Tell the person that you will research the subject and get back to them - be sure to follow up!
7. Find out the best (or preferred) method of communication - get a business card.
8. Thank the representatives for their time and support.

**AFTER THE MEETING:**
1. Evaluate how the meeting went and what was accomplished.
2. Determine the next step and how to work for the cause "from a distance."
3. Send a note thanking them for their time.

Seeing the Team Leaders in action on Lobby Day, I realized that they were using these effective lobbying strategies.
Health Disparities and www.clinicaltrials.gov
by Becky Morris, VBCF Advocacy Chair

What is your internet search engine if you are looking for a clinical trial possibility? Do you know where to start? Is the information from a reliable source? If you live in southwest Virginia, where access to basic health care is over the mountain and far away, can you be assured of access to new treatment options? While attending the recent National Breast Cancer Coalition (NBCC) Conference, the DOD Era of Hope Meeting and the American Association for Cancer Research (AACR) Scientist-Survivor Workshop, various perspectives were presented on the issue of full disclosure of new discoveries and its impact on widening the health disparities gap.

VBCF has always supported evidence-based treatment which depends on sound research evidence. To maintain this position, promote access to quality care for all, the goal of preventing, treating and curing breast cancer depends on the ability to test and safely bring to market new drugs and treatments. These discoveries must be available to everyone, regardless of race/ethnicity, urban vs. rural residence, gender, age, or socio-economic status. Through diversity enrollment in clinical trials, we can look at these differences, but we test on the average population, which is often a flawed design. The Human Genome Project results showed that the variation within a population is more distinct than between all human populations. Unless we address these disparities, the gap between the haves and the have-nots will increase as new discoveries are made.

One of our primary responsibilities is to ensure that everyone has access to health care, cancer care, participation in clinical trials and the results of clinical trials. As the development of more targeted drugs for breast cancer treatment occurs, increased disparities among the less fortunate will increase and equate to lower access to health care and research. The challenge is to divert the savings we will realize from the over treatment of some patients to cover the uninsured and diverse populations.

Albert Einstein once said, "The search for truth is more precious than its possession." We must have a formal, complete, reliable summary of all research. Currently, the results of only half of all clinical trials are published. When investigators are asked why they did not publish their results, some respond that they just didn't write it up! No enforcement regulation requires publication, and reporting becomes selective. Publication bias is often associated with the study sponsor and the pharmaceutical industry is not required to publish. Failure to publish also becomes an ethical issue when participants in the trial are not always informed of the results. Negative results are not published, reviews are not accessible, and over-reporting on some trials exists, so patient participation decreases. Only 4% of adults enroll in trials, while 70% of children enroll. The war on cancer is a costly battle and we may well be paying for duplication of effort. A 'black hole' of medical research exists, where information is unavailable to the public and the scientific community. The New York Times reported on Dec. 12, 2004 that the best idea of 2004 was a complete drug registry.

What do we have? Many independent registers, three unique IL systems, and no standardization or centralization. The site www.trialscentral.org alone has 10,000 trials/drugs listed. We need a virtual, global unified register of trials with unique trial ID's, standardization across registers, minimum information about trial protocol, results disclosure and centralized processing and dissemination of the study.

National legislation enacted in 1997 by Congress required the DoH's Office of Health and Human Services (DHHS) Secretary to establish a publicly accessible data bank of information about clinical trials for serious and life-threatening diseases and conditions. This law was enacted eight years ago but the database is still not comprehensive. As of Sept. 2004, the FDA's Office of Special Health Issues presented a report on industry compliance, showing that only 48% of industry's trials were in the NIH www.clinicaltrials.gov database. On Feb. 2, 2005, PhRMA (Pharmaceutical Research and Manufacturers of America) issued a press release stating that beginning July 1, 2005, PhRMA member companies will post, on a voluntary basis, information about all new hypothesis-testing clinical trials. All ongoing hypothesis-testing trials are to be posted by Sept. 13, 2005.

If we want to increase patient accrual to clinical trials and win the war on breast cancer, we must demand enforcement of the law (FACT Act §470). Recent legislative efforts in Virginia to require complete clinical trial registration compliance to the NIH website met defeat in our General Assembly. Under pressure from Pharmaceutical companies, the original language (to enroll in www.clinicaltrials.gov) was changed to "The Secretary of Health and Human Resources (of Va.) shall make available on the appropriate state health-related websites information directing citizens of the Commonwealth to publicly available information on clinical drug trials" etc. The explanation given for this change was that requiring registration at www.clinicaltrials.gov would (1) place a burden on the person conducting the trial; (2) create an issue with the registration of multi-state trials; (3) use language not understood by the public; and (4) cause loss of funding concerns by public institutions and private industry.

If we are to move new therapies into clinical practice more quickly, increase enrollment in clinical trials and efficiently translate the results to the bedside of all cancer patients, we must remove the mystery about trial participation and positive or negative results from the equation. Access to quality health care and universal access to oncologists is our goal. Our emphasis should not only be on what we know about the disease of breast cancer, but what we don't know. "Today's self-educated patient becomes tomorrow's advocate and patient navigator. We must be able to evaluate and have access to all emerging literature. Open access feeds innovation, the times may change, but the goals remain the same,' as breast cancer advocate Musa Mayer stated. Have we perhaps thrown away the key to a cure by denying open access to the collective results of all clinical trials by scientists, patient advocates and patients?"
Era of Hope - Con't from Cover that occurs every two or three years. The purpose of this meeting is to have all research funded by the program in certain years presented to the public, through platform presentations and poster sessions.

Advocates Involvement in Era of Hope
The 276 consumers from 95 organizations registered for the meeting represented 1 in 6 conference attendees, unprecedented for scientific meetings where consumers are usually a rarity.

Other Unique Features of Era of Hope

- The conference had 8 plenary sessions, 2 innovator sessions, 38 symposia that featured 226 research projects and more than 1000 poster presentations. Acceptance of DOD BRCP funding requires reporting of all findings, whether they are positive, negative, or inconclusive.

- This meeting maintained a strong focus on the broad vision of preventing and curing breast cancer.

- The conference structure fostered an atmosphere and provided stimulation for collaborative thinking by offering educational sessions that well-established experts in diverse fields presented.

Scientific Themes

Breast cancer as a heterogeneous disease: Gene expression profiling technologies have allowed researchers to identify several breast cancer "types" that include those dubbed Luminal A and Luminal B (tumors that are positive for hormone receptors and arise from luminal cells); HER2 (tumors that test positive for HER2 and negative for hormone receptors); BRCA (tumors that arise from mutations of the BRCA1 or BRCA2 genes); and Basal (tumors that are negative for estrogen and progesterone receptors and for HER2/neu). Recognition of the heterogeneous character of breast cancer will allow for better selection of patient subgroups for clinical trials testing targeted therapies. Without taking this into account, we dilute risk among our test populations, and we obscure recognition of real risk factors and effective treatments.

Tumor progenitor cells: Several researchers presented on their investigations of the role of tumor progenitor or breast cancer stem cells. This line of investigation hypothesizes that a tumor is an abnormal organ growing within the breast from abnormal progenitor cells. The implications of this research are that the cancer cannot be finally arrested unless and until the stem cells underlying it are killed. Choosing stem-cell specific targets for future treatments may therefore prove far more effective in stopping cancer from progressing. This type of hypothesis could explain:

- Why tumor regression does not correlate with survival if chemotherapy is killing differentiated cells but sparing cancer stem cells;
- Why the real disease is carcinogenesis, not cancer;

- Why some micro-metastatic cells never develop into metastasis and others - the ones that are stem cells - do;

- How negative environmental exposures during late puberty (such as atomic bomb fallout after World War II) can lead to breast cancer 20, 30, or 40 years later; and

- Why a small percentage of ER positive tumors - those that arise from ER negative stem cells - remain resistant to tamoxifen treatment, while others - those that arise from ER positive stem cells are completely arrested.

- In addition, this model could explain why even early diagnosis is, in fact, late diagnosis. It opens the door for more biologic, rather than chemotoxic treatments - leading to fewer side effects for women with breast cancer.

Individual Presentations

A few of the projects presented at the meeting are summarized below:

- Without treatment, about 50% of DCIS will progress to invasive breast cancer. This means that 50% of the women treated with radiotherapy for breast cancer do not benefit from the treatment. This presenter proposes that we start tailoring treatments based on ER and HER2 status.

- Levels of two estrogen metabolites (4-hydroxyestradiol and estrogen-3,4-quinone conjugates) were found to be nearly four times higher in women with breast cancer than in women who did not have the disease, suggesting that problems in estrogen metabolism that may lie at the root of breast cancer.
The Virginia Breast Cancer Foundation gratefully acknowledges the individuals, companies, and organizations, whose generosity during the calendar year 2004 made it possible for us to continue our work in the fight against breast cancer.

Donations

In honor of

In honor of Jeanne Akers
Rita Hull

In honor of Evelyn Biles
Wendy Sprout

In honor of Mary Jane Bohlen’s 60th Birthday
Frances Boczko
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In honor of Mrs. Angelika Bolt
Edythe Lichtenstein

In honor of Gloria Braverman
Lois E. Brooker

In honor of all breast cancer victims
Debra Costello

In honor of the 50th Anniversary of Frank & Marlene Carver
The Legum Bangel Foundation, Inc.

In honor of Maureen Cassidy
Patricia & James Perkins

In honor of her mother, Anna C. Clay
Anne C. Almond

In honor of her daughter, daughter-in-law, & granddaughter
Joan Cousins

In honor of Barb Dittmeier
Karen A. Raschke

In honor of the fight against breast cancer
Dillon Technologies, LLC

In honor of Edith Frischknecht
Arlene Opgenorth

In honor of Barbara Fuhrmann
Wendy Sprout

In honor of Libby Gatewood
Anne M. Ray

In honor of Patti Goodall
Margaret W. Hubbard

In honor of the guests at the wedding of Julie Jarvis & John Graves
Kathryn Jarvis

In honor of the Hampton Roads Chapter
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In honor of herself
Captain Doris R. Vall, USN

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In memory of Margaret Wakefield
Rita L. Harding

The 19th Annual Women's Memorial Golf Tournament broke yet another record, raising $28,677 to help us continue our work on behalf of Virginians affected by breast cancer. The tournament was held on July 30th at The Crossings Golf Resort.

Thank you to Sharon Talarico, Tournament Director and all of her dedicated volunteers for their countless hours of hard work devoted to making this tournament a success. VBCC would also like to thank all of the tournament sponsors and donors for their generosity.
In memory of Jamie Wells
Anne Shannon-Butcher

In memory of Arthur Zeigler
Joyce Zeigler

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Free Brochures & Health Resource Guides Available

VBCF’s Lesbian Outreach Project has free brochures and Health Resource Guides available! The guides include a list of lesbian-friendly healthcare providers in Central VA. Please contact Elisa Romans at (800) 345-8223 or Elisa@vbcf.org for copies. VBCF thanks the Susan G. Komen Foundation Richmond Affiliate and Diversity Thrift for their support in making this project possible.

Interested in Volunteering?

If you would like to volunteer at the VBCF State Office in Richmond or for one of VBCF’s Chapters contact Elisa Romans, Program Coordinator, at 800-345-8223 or by email at Elisa@vbcf.org.

Sherry H. Kohlenberg Healthcare Service Award

The Virginia Breast Cancer Foundation (VBCF) is pleased to announce that we are now accepting nominations for the Sherry H. Kohlenberg Healthcare Service Award. VBCF annually presents this award to individuals working in a breast cancer-related healthcare field who go above and beyond the call of duty in caring for those affected by breast cancer. Given in the past to a wide range of healthcare providers—from surgeons to nurses to social workers—the Kohlenberg Award enables you to recognize someone who made a difference in your life.

The nomination form is available on our website, www.vbcf.org. Feel free to make copies and share it with others. The deadline for nominations is September 23rd and the award will be presented on October 18th at An Evening with Dr. Susan Love.
MEMBERSHIP
Please fill out form(s) and return with your check to VBCF.

☐ Please contact me about becoming a VBCF Volunteer.

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This newsletter, published by the Virginia Breast Cancer Foundation, focuses on breast cancer issues and the activities of VBCF members. If you wish to join VBCF, or have any editorial comments, please call 1-800-345-VBCF or write to: Virginia Breast Cancer Foundation, 5001 W. Broad Street, Suite 201, Richmond, VA 23230

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