25 Years of Work

2016 marks VBCF’s 25th year of service to Virginians. We are commemorating this milestone in several ways.

VA General Assembly Commending Resolution: During State Advocacy Day this February, VBCF advocates were recognized from the House and Senate floors with Joint Resolution No. 201 commending VBCF for its 25th Anniversary. Special thanks to Delegate Jennifer Boysko (D-86), Delegate Daun Hester (D-89), Delegate Chris Peace (R-97), Delegate Sam Rasoul (D-11) and Senator Siobhan Dunnavant (R-12) for sponsoring this resolution.

More than a Pink Ribbon Virtual Quilt: With your help, we are creating a virtual quilt—a unique piece of art that highlights the names and faces in the fight against breast cancer. Housed on-line, the quilt titled, “More than a Pink Ribbon” will serve as a symbol of our strength and honor our roots, while being appropriate for the 21st century. Our goal is to collect 6,100 squares—the number of Virginians expected to be diagnosed with breast cancer this year. For a small donation you can help us commemorate 25 years and submit your square at www.morethanapink-ribbon.org. Continued on page 6.

Check out our 2015 annual report at vbcfannualreport.org!
What an exciting time to be President of the Board of Directors for VBCF! This year, we celebrate our 25th anniversary. Our organization has grown and changed a lot during this time, but what has not changed is the passion and dedication of the women and men who are a part of this great organization.

My awareness of breast cancer began in the 1970s. During the course of a year, both my mother and her sister were diagnosed with breast cancer. They were both among the lucky ones, neither of them saw a recurrence. But the 1980s changed my world forever. It began with the loss of my cousin Cathie, at age 31, and five years later, my sister Sherril died at age 39. My awareness changed to fear.

In 2007, I was diagnosed with breast cancer. Although it was caught early, I learned that I had the BRCA1 mutation and knew I had to take action. I learned all that I could about my breast cancer and BRCA and learned to become my own advocate. And during that journey, I found VBCF and learned to be an advocate for all women and men who face breast cancer.

I write this having just returned from serving as a consumer reviewer for the US Department of Defense’s Breast Cancer Research Program. I sat at the table with scientists, clinicians, and other consumer reviewers and helped decide the future of breast cancer research. What a privilege it was to be a voice for those who have been, and those who will be, affected by breast cancer. I was able to do this because of VBCF. VBCF not only helped me to develop my advocacy skills, but also has advocated to continue funding this innovative research program. Research funded by this program has brought about the use of Herceptin with HER2-positive breast cancer, sentinel lymph node biopsy, and the discovery of one of the BRCA2 mutations.

As we begin this year, I look forward to working with our new board members: Salud Astruc, Gabriele Conn, Heather Hodges, and Stacy Price. I will continue to work on being proactive and implementing our strategic goals, which include updating our educational materials and getting our new full-time Education Manager, Erin Steigleder, out in the community.

To commemorate our 25th anniversary, please join me in submitting a square on our virtual quilt. This “More than a Pink Ribbon” quilt will be a unique piece of art that highlights the names and faces in the fight against breast cancer. It will serve as a symbol of our strength and show that there is more to breast cancer than the omnipresent pink ribbon. Visit www.moretthanapinkribbon.org to check out our virtual quilt and submit your square today.
Visit us online at www.vbcf.org.

Board of Directors

Congratulations to our new 2016 Board of Director’s Officers - President Susan Siegel and Vice President Clifford Deal III, MD, FACS! Ms. Siegel is a breast cancer survivor, involved with FORCE: Facing Our Risk of Cancer Empowered, and is a Senior Claims Technical Specialist with Genworth Financial. Dr. Deal is a Breast and General Surgeon with HCA Richmond Surgical and recently spent time in Afghanistan as a Lieutenant Colonel in the US Army Reserve with the 946th Forward Surgical Team. A huge thanks to each for their service and leadership!

Welcome to our new 2016-18 Board members - Salud Astruc, a breast cancer survivor and Program Manager with Dominion Transmission, Inc; Gabriele Conn, Practice Administrator with Peninsula Physical Therapy and Associates; Heather Hodges, RN, CNRN, CCRC, a breast cancer survivor and Clinical Coordinator for the Department of Neurology at Hunter Holmes McGuire Veterans Medical Center; and Stacy Price, a breast cancer survivor and Operations Manager at the University of Richmond School of Law Library. We are excited to have their new perspective, engagement, and energy!

Thank you to departing Board Members - Tuwanna Okafor; Meg Shrader, RN, BSN, CBCN; and Lisa Branner Stickley - we know they will continue to make great VBCF Ambassadors in their local communities and beyond!

2016-18 Strategic Goals

VBCF undertook strategic planning in 2015 and over the next three years will work to:

- Provide factual, unbiased, up-to-date breast cancer information
- Proactively provide educational outreach opportunities for Virginians in need
- Connect Virginians with local, state, and national breast cancer resources
- Make breast cancer a state priority for policy and research efforts
- Share the latest breast cancer policy information and encourage action
- Be the go to organization for Virginia researchers needing educated consumer reviewers
- Recruit and engage volunteers to become breast health peer educators and advocates in their local communities
- Increase awareness of VBCF’s program and resource offerings in Virginia
- Strengthen existing donor relations and diversify revenue streams

If you are interested in helping VBCF accomplish these goals, visit www.vbcf.org/volunteer to learn more.

Follow us on Facebook: facebook.com/virginiabreastcancerfoundation
VBCF recently hosted "Advocating for Your Breast Health" at Bon Secours Mary Immaculate Hospital in Newport News on February 27. This event featured local medical professionals speaking on breast screening and density, genetic testing, the latest research trends, and local resources available. We hope to replicate this event in different areas across the state, so stay tuned for information on an event near you.

In the Shenandoah Valley area, we will be hosting a Becky’s Place educational station at the upcoming Remote Area Medical (RAM) clinic in Buena Vista, Virginia on March 5-6. Volunteers will be educating people attending the clinic on breast health and the importance of early detection. RAM clinics take place in medically underserved areas across the United States, often providing the only dental and medical care that clinic attendees receive all year. There are multiple RAM clinics in Virginia each year, and in 2016 VBCF plans to be at all of them. To learn more about RAM, visit their website, ramusa.org.

VBCF continues to revise and revamp the educational information we make available. The Newly Diagnosed packets recently went through an update and we now have a caregiver support packet available. This packet includes information on how to keep track of doctor’s appointments and medication, support groups for caregivers, and how caregivers can care for themselves as well.

We have also updated our Stay Abreast breast health education presentation. If you know of a group in your community that would be interested in learning more about breast health and breast cancer, please contact Erin Steigleder at (804) 285-1200 ext. 202 to set one up. These presentations are offered at no cost.

New VBCF Staff Member

Erin Steigleder, MSW joined VBCF as our full-time Education Manager in mid-November, managing our educational programming and maintaining breast health resources across the Commonwealth. Her key projects include educating local communities, raising awareness about VBCF’s services with health care providers and potential community partners, and maintaining accurate and relevant educational materials and resources. Erin has a Bachelor’s in Psychology and Studio Art from the University of Mary Washington and a Master of Social Work from Virginia Commonwealth University. Prior to coming to VBCF, Erin worked for the Virginia Interfaith Center for Public Policy in their health program, Virginia Consumer Voices for Healthcare. Welcome Erin!

VBCF is Awarding $5,000 to a Deserving Breast Cancer Advocate!

Are you passionate about ending breast cancer? Do you have a desire to learn about the science of breast cancer?

The Karin Decker Noss Scholarship was created to honor the memory of Karin Decker Noss, a dedicated board member and past president of VBCF. The scholarship funds training in medical research and legislative advocacy to carry on the work that Karin began.

A $5,000 reimbursable award will be available to the recipient for two calendar years after the award is made. The funds may be used for expenses, such as travel, lodging, meals, and registration fees for approved conferences and educational courses.

Visit www.vbcf.org/karin-decker-noss-scholarship to learn more and to apply. The deadline to apply is April 4, 2016.
Advocacy Action

State Breast Cancer Advocacy Day

VBCF hosted the 2016 State Breast Cancer Advocacy Day on February 4. The day followed a new format with attendees encouraged to make appointments to meet with their representatives. VBCF also invited all legislators to a morning reception in the General Assembly building. As a result, more than 30 breast cancer advocates were able to meet with over 40 senators, delegates, and aides. Advocates especially enjoyed hearing the personal remarks shared by the legislators who spoke during the reception. It was a great day, and VBCF thanks all the advocates who made their voices heard!

State legislative VBCF priorities for Advocacy Day:

Closing the coverage gap — VBCF supports Medicaid expansion to ensure that all Virginians would have access to breast cancer screening and treatment. While Governor McAuliffe has included federal funding to close the coverage gap in his budget, the House and Senate budget bills do not include these federal dollars. The HAV (Healthcare for All Virginians) Coalition, of which VBCF is a member, continues to advocate for closing the coverage gap. VBCF supports Medicaid expansion to ensure that all Virginians would have access to breast cancer screening and treatment. While Governor McAuliffe has included federal funding to close the coverage gap in his budget, the House and Senate budget bills do not. This failure of Virginia’s legislators to accept federal funding to close the coverage gap for the third year in a row hurts Virginians’ health and Virginia’s economy. The HAV (Healthcare for All Virginians) Coalition, of which VBCF is a member, continues to advocate for closing the coverage gap.

Prescription Drug Tiering – SB 442 (Dance) and HB 702 (McClellan) would have prevented insurers on the insurance exchange from placing all medications in the same class of drugs on a high specialty drug tier, thus requiring patients to pay high costs for their medications, even generics. These bills failed to move forward this year but the Bureau of Insurance has been directed to investigate whether it has the authority to examine and cease any adverse tiering practices. Through VBCF’s work with the Fair CoPay VA coalition (www.faircopayva.org), we will continue to advocate against adverse tiering.

Parity of Coverage for Oral Chemotherapy Medications – SB 383 (Vogel) was introduced to strengthen and expand the current 2012 provisions to require that oral chemotherapy be provided to users at a cost no greater than other forms such as intravenous chemotherapy be treated equally by insurers. Unfortunately, the bill was carried over until 2017 in the Senate Commerce and Labor Committee. VBCF looks forward to supporting strengthened parity efforts in 2017.

VBCF also followed other state legislation during the General Assembly session including:

SB 701 permitting the production and use of cannabis oil for medical purposes. Studies indicate cannabidiol helps to reduce nausea and vomiting and can improve food intake, preventing weight loss, side effects linked to chemotherapy. WVTF ran a story on a breast cancer patient and her use of cannabis oil - http://wvtf.org/post/state-lawmakers-debate-medical-marijuana

Two bills related to the possible impact of environmental factors on breast cancer. SB 537 would require the closure of coal ash ponds but was defeated in committee, and SB 706 which allows oil and gas well operators not to disclose the chemicals they continued on page 6.
Advocacy Action - Continued

inject into wells to boost production. This bill was pulled by its patron and will not move forward in this session.

National Legislation

VBCF continues to support the National Breast Cancer Coalition’s efforts to introduce The Accelerating the End of Breast Cancer Act (S 746/HR 1197) focused on creating an innovative commission to identify strategies for breast cancer prevention and understanding and preventing metastasis (the spread of cancer) which is responsible for 90% of breast cancer deaths. VBCF thanks the following Virginia legislators supporting this bill:

U.S. Senators Tim Kaine and Mark Warner; Representatives Robert Wittman (R-1), Scott Rigell (R-2), Randy Forbes (R-4), Donald S. Beyer, Jr. (R-8), Morgan Griffith (R-9), Barbara Comstock (R-10), and Gerald Connolly (D-11).

Read more about this bill at www.govtrack.us/congress/bills/114/hr1197/summary.

In addition, continued funding for the US Department of Defense Breast Cancer Research Program is currently being considered through the congressional budget appropriations process, and VBCF continues to support its progress.

2015 Kohlenberg Award

Congratulations to Meg Helsley, MSN, RN, AOCNS, recipient of the 2015 Sherry H. Kohlenberg Healthcare Service Award! Ms. Helsley is an Oncology Clinical Nurse Specialist at The Cancer Center of Henrico Doctors’ Hospital (HDH). She is well-known for going above and beyond the expected duties of her position. She is the organizer and a founding member of HDH’s weekly multi-disciplinary breast cancer conference, serves as a genetics nurse educator, and provides consultation to HDH’s Every Woman’s Life program to identify resources appropriate for patients in financial need.

Ms. Helsley also developed an advanced stage breast cancer support group, recognizing that patients with late-stage disease needed a group dedicated to their needs and concerns. Additionally, she co-created the Hallway of Hope at HDH with a former breast cancer patient who wanted to liv en up the drab walkway between the parking lot and radiation therapy office. Together, they received approval to display rotating student artwork from Henrico County.

In addition to her many contributions to HDH, Ms. Helsley is the president of the Richmond Area Oncology Nursing Society, mother of three children, and long-term survivor of a childhood cancer. She has served on the advisory board for Camp Kesem University of Richmond since its start in 2008. Camp Kesem supports the often-overlooked population of children affected by a parent’s cancer through a national network of summer camps run by passionate college student leaders. Since 1995, VBCF has presented the Kohlenberg Award annually to recognize individuals employed in the healthcare field who exhibit a deep and abiding commitment to the fight against breast cancer. The award also honors the memory of Sherry Kohlenberg, a healthcare administrator and co-founder of VBCF, who died from breast cancer in 1993. We know that Meg will keep up her great work!

25 Years of Work - Continued

Turning the Virginia Governor’s Mansion Pink! Stay tuned for more information about an exciting October 2016 event to light the Governor’s Mansion pink in honor of VBCF’s work to support Virginians with breast cancer.
San Antonio Breast Cancer Symposium by Yvonne Eisenberg, RN, CNOR, CRNFA

San Antonio Breast Cancer Symposium (SABCS) 2015 in one word - Wow! I feel fortunate to have had the opportunity to attend this event. There was so much interesting information presented over the course of the symposium. It was difficult to select which topics to cover in this article.

Experts covered everything from targeted therapy; critical decision making in radiation therapy; Anastrazole versus Tamoxifen in ductal carcinoma in situ; endocrine therapy; lumpectomy vs. mastectomy; metastatic breast cancer; and much more.

One session focused on breast cancer management in low and middle income countries. Mammography remains the gold standard for breast cancer screening in the developed world. We learned that it may not be an option for low and middle income countries due to high cost. Another challenge is the lack of breast cancer awareness which leads to poor compliance to screening.

Indraneel Mittra of Tata Memorial Centre in Mumbai, India, told us about a randomized trial that is underway in Mumbai to study the effectiveness of clinical breast exam (CBE) and breast self exam (BSE) without screening mammography.

The Mumbai study recorded 70% compliance, but it came at a high manpower cost. Personnel made repeated door-to-door visits to persuade women to follow through with breast screening. Results of the study will be available later this year.

At present, there is little evidence to recommend clinical breast exam as a screening tool in these countries. The incidence of breast cancer, although rising, remains lower in low-income countries than in developed countries. Thus further raising questions about the cost effectiveness of screening. Is funding better spent strengthening breast cancer treatment facilities or trying to fix the many deficiencies in the health care delivery system?

This particular session left me with a lot to think about in regards to the health care available to people with limited resources that live in low income countries.

Another interesting study covered the effects of hair loss (alopecia) due to chemotherapy among women with breast cancer. This temporary hair loss is among the most distressing and traumatic side effects of breast cancer treatment reported by patients. Women who experience hair loss due to chemotherapy report lower self esteem, poorer body image, and lower quality of life, and in some cases, switch therapy as a result.

A self-contained scalp cooling system with circulating coolant has proven to be safe and effective for preventing chemotherapy-induced alopecia in most women with early stage breast cancer.

The research presented at SABCS offers much hope to those living with breast cancer.

Yvonne attended the San Antonio Breast Cancer Symposium as a recipient of the Karin Decker Noss Scholarship. To learn more about the scholarship, see page 4.
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