Board of Directors

**Officers**
Kevin O’Connor, President
Open, President Elect
Kathy Mortimer, Secretary
Al Valentino, Treasurer

**General Board Members**
Nicholas Cady
Eric George
Stephanie Grass
Jeff Krecek
Murai Johnson
Terry Lamb
Stacey Noble
Dorothy O’Connor

**Staff**
Kelly Waters, Executive Director
Dee Schullery, Bookkeeper
Heather Conner, Administrative Assistant

Our Mission
Dedicated to serving and supporting the needs of those impacted by a bleeding disorder through education, advocacy, and community.

Our Vision
Become the recognized voice and go-to resource for those impacted by a bleeding disorder.
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President’s Message

As I review and think about the past year for the Virginia Hemophilia Foundation, there are so many positive factors to mention. We have maintained outstanding financial stability and strength that is so important to our continued fulfillment of the mission of serving and supporting the needs of the genetic bleeding disorder community through education, advocacy, and community.

We have a schedule of programs literally every month throughout the year including educational, social, disease awareness and fund raising.

Our success is a result of the combination of an expanded and revitalized board and especially our two staff members who are fully committed and recognized as one of the best managing teams of any organization in the Hemophilia Community. They have worked with and maximized industry support which continues to be essential for our success.

Finally, it is all about the members of our bleeding disorder community who participate in and volunteer at our many programs and support the VHF and each other.

Kevin O’Connor
Board President
Executive Director’s Report

It is hard to believe another year has passed and that I have been with the Virginia Hemophilia Foundation (VHF) for 6 years. I feel so honored and blessed to work with all of you to foster community, support, education, and advocate for the things that are important to you. This year has been one filled with accomplishments including participating in the first Amazing Raise online fundraising event, increasing our participation at programs, continuing to support families and individuals with our Lyman Fisher Scholarship program and Patient Assistance Program, as well as continuing our wonderful partnerships with our industry friends, HTC’s, PSI, and Camp Holiday Trails. This year has also been filled with sadness as we said good-bye to our good friend, bo ard member, and patient advocate Terry Lamb. I can still feel/see his energy, smiling face, can-do attitude, and hear that cowboy accent. To carry on his memory VHF created the Terry Lamb Memorial Fund. I hope you will learn more about it and consider making a contribution in Terry Lamb’s name.

As we move into a new year continue to expect quality programming with opportunities for growth, education, and networking. I hope you will also consider making a gift to VHF and support all that VHF has done for you over the years.

Sincerely,

Kelly Waters, LCSW
Executive Director
## Financial Statement

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<td><strong>44,071.44</strong></td>
<td><strong>10.5</strong></td>
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*Please note that we have changed our method of accounting in 2011-2012 to the modified cash basis of accounting.*
Fundraisers

Golf Tournament
We hosted our 7th Annual Golf Tournament at Birkdale Golf Club in Chesterfield, VA on October 24, 2011. Beautiful weather, 12 foursomes, a profit of over $12,000, sponsorships by terrific companies, and wonderful volunteers all contributed to another successful fundraiser. We particularly want to thank our Title sponsor – CSL Behring! We appreciate your ongoing support year-after-year. We also couldn’t have done it without the financial support of our $2,500 sponsors – Novo Nordisk, Baxter, and Pfizer, $1,500 sponsor – Bayer, our $350-500 sponsors - AHF, Octapharma, Coram and $150 sponsors - Accredo’s HHS, B2L Consulting, LeClair-Ryan, MedPro Rx, PSI, and In Memory of Charles Valentino (by Al and Marijane Valentino). A special thank you goes to our tireless golf volunteers; Donna Bordone, Paul Brayshaw, Stephanie Grass, Tanya Keller, Terry Lamb, Shirley Moorehead, Dorothy and Kevin O’Connor, April Owens, Linda Pollhammer, Gina Raymond-Duncan, Elizabeth Tawil, Al and Marijane Valentino, and Woody and Lisa Womack.

Youngblood 5K
The 8th Annual Youngblood 5K was great fun as the community came together to run and help send kids to camp. Everyone got a bag of goodies donated from various companies and random door prizes were also given out throughout the morning. Favorite prizes include Kevin O’Connor’s original wood art. A special thank you goes out to our major sponsors – CSL Behring, Baxter, NovoNordisk, and Coram. Thanks to our generous sponsors and participants; we had a net income of over $11,000. Our volunteers include Sabrina Adams, Kevin and Dorothy O’Connor, Gina Raymond-Duncan, Terry Lamb, and Jack Shoff.
Wine Tasting & Raffle Event
The 8th Annual Wine Tasting and Raffle was held on April 22nd at Art Works in Richmond, VA. Our wine tasting committee (Dorothy O’Connor, Marijane Valentino and Stephanie Grass) outdid themselves this year as we took a trip to “Las Vegas” with special entertainment by Elvis Presley (aka Richard Parker). We dined on delicious Vegas inspired appetizers, ate homemade desserts from Marijane Valentino and Krecek Kakes, sampled wine, and a few lucky winners won Raffle Baskets and Silent Auction items. A special Thank You to our Major Sponsors – Cabernet ($3,000) – Bayer, Novo Nordisk, Pinot Noir ($2,500) – Baxter, Shiraz ($2,000) – Biogen Idec Hemophilia, CSL Behring, Merlot ($1,000) – Pfizer, and Chardonnay ($500) - Accredo’s Hemophilia Health Services, as well as to our many raffle item/silent auction donors. Our volunteers that day were incredible. Thank you to Dorothy and Kevin O’Connor, Marijane and Al Valentino, Stephanie Grass, Becky Bowers-Lanier, Sue Cowell, and Nicole Valentino. We had a net income of over $15,000. Thank you for your generosity and having fun with us!

Amazing Raise
Everyone’s a Winner! On October 5-6 VHF was excited to be one of the many nonprofits in Central Virginia to participate in the first ever Amazing Raise. The Amazing Raise 2011 was an online donation based event that provided an opportunity for people to come together and raise as much money as possible for local nonprofits in a 36 hour time period. We were fortunate enough to raise $890.62 during that time period and we were awarded two double your dollars prizes which amounted to $50! Thank you to everyone who participated.
Bakers Crust
Thanks to VHF member Zack Bordone whose idea it was to set up a fundraising night at the Baker’s Crust in Chesapeake, VA. Attendance for the VHF fundraising night was great and we received 15% of sales on the night of November 16, 2011 totaling $317.03! Thanks to all the friends and families who came out in support of VHF. If you ever have a fundraising idea that you would like to share we would love to hear about it!

Miller & Rhodes Charity Christmas Tree Event
Was held on December 6, 2011. This was a wonderful opportunity to highlight our organization, educate the community about bleeding disorders, raise money, and have fun. Thank you to CSL Behring for sponsoring our tree and the Board of Director’s dinner to celebrate our accomplishments, as well as Frame Nation, our entry fee sponsor. We particularly want to acknowledge Marijane Valentino, our Christmas tree designer and volunteers Al Valentino, Dorothy and Kevin O’Connor. Their time and effort paid off and the beautifully decorated tree earned a prime spot in the front window of the Richmond Hilton Garden Inn Downtown. The tree received many compliments throughout the unveiling ceremony, and to many in attendance it was the prettiest tree out of the 40+ trees that were on display.
Other
VHF also received donations and support from Community Health Charities (almost $900) and United Way (almost $1400). Individual donors included: Sabrina Adams, Julie Baker, David Beck, Jr., Tina Brown, Nick Cady, Regina Ann Cottman, Douglas Coventry, Eric George, Lisa Harrison, Angela Hawkins, Christine Heaton, Diana Still Holsinger, Theresa Ihrig, Christine and Jeff Krecek, Tina Lamell-Kay, Terry Lamb, Anita Mayo, Sharon Moore, Kim Moyers, Tim and Mary Randall, Aleah Ricks, Todd Ruppenthal, Donald and Beth Smith, David Rexal Stone, Al and Marijane Valentino, Susan Vignone, Amy and Eric Walker, Kelly Waters, Jerry West, Davida Wickline, Larry and Debi Williford, Jennifer White

VHF also received several donations in Honor of very special individuals these include:
Honor of the Marriage of Ryan Rottenberry & Jarrod Seeley by Ruth Jones
Honor of Donald Regan by Valerie M. Jansen
Honor of Toby and Patty Kerns’ 50th Wedding Anniversary by Wayne Grindle
Honor of the Valentino Family by David Valentino
Honor of Christine Krecek’s Birthday by Barbara Higgins

Donations in Memory of Terry Lamb and the Terry Lamb Memorial Fund:
Nicholas Cady, Eric George, Murai Johnson, Rebecca Bowers-Lanier, Randy and Kathy Mortimer, Stacey Noble, Kevin and Dorothy O’Connor, Jack Shoff, Steve Schofield, Elizabeth Tawil, Marijane and Al Valentino, Kelly Waters, and Jennifer White

Additional support came from PSI for our patient assistance program ($3,000), PACT Foundation Grant ($19,000) for our advocacy efforts in partnership with the Hemophilia Association of the Capital Area, and the Hemophilia Alliance for board development ($5,000).
Programs

Adult Retreat
On September 24 and 25, 2011, 29 adults participated in our highly successful Adult Retreat in Richmond, VA at the Hotel Sierra. Saturday night was filled with fun and included Steve Kohrherr’s “Team Building Through Theater” and dinner and a show at the Funny Bone Comedy Club. On Saturday the Inalex workshop focused on “Goal Setting for Life” by Joshua Potter-Eforn, LCSW. Thanks to Baxter for sponsoring this great event.

Advocacy
Speaking out on hemophilia and other bleeding disorders is our shared responsibility, and this year was especially important. Thanks to continued PACT funding, Becky Bowers-Lanier helped to guide our advocacy efforts, and Sabrina Adams continues to chair our Advocacy Committee. In addition to our highly successful Richmond day in January 2012, we worked to amend proposed legislation that would have eliminated the Hemophilia Advisory Board for the Virginia Bleeding Disorders Program. While the Board was eliminated in the Code of Virginia, our community will maintain a presence as being part of the Genetics Advisory Committee of the Virginia Department of Health. We believe that the new advisory process will guarantee our voice to the VDH for our community. In addition, VHF is a charter member of a new coalition opposing specialty-tier drug pricing, which is an emerging concern for individuals with rare and chronic conditions like hemophilia. Our coalition, the Virginia Alliance on Medication Access and Affordability, joins us with advocates for multiple sclerosis, cancer, arthritis, HIV, and other stakeholders to speak out against insurance practices that raise the co-pay and co-insurance costs for some high-priced drugs. We look forward to introducing a bill in the 2013 General Assembly that will mitigate the cost burden to our community. Finally, VHF has maintained a presence at all meetings of the Virginia Health Reform Initiative, and we presented public comments on the essential health benefits and health insurance exchange, which are components of the federal health reform law.
Programs

Annual Meeting & 35th Anniversary
On June 16, 2012, 142 VHF members and exhibitors joined us in Williamsburg, VA for our Annual Education Meeting. Folks participated in one of three break-out sessions (Advocacy Update by Becky Bowers-Lanier, HFA’s Dads in Action by Doug Hartsough, and Transitioning by Lauren Dunn, MSW, Megan Midura, MSW, and Megan Shiflett, MAT), followed by a progressive exhibit visit. Dr. Christopher Walsh presented Life Stages during lunch and Henry Mead’s MBA, MPA talk on New Horizons in Hemophilia Treatment was in the afternoon. Kids had a great time with CSL Behring’s Gettin’ in the Game with Peter Dyson, the Ted E. Bear Hospital with Judy and Matt Igelman (sponsored by MedPro Rx), and/or “Just for You” teen programming with VHF and HTC staff.


The day culminated with our 35th Anniversary celebration where we wore our 35th Anniversary T-shirts in style. The event included the presentation of our $2,000 Lyman Fisher Scholarship winners, the NHF Annual Meeting drawing, VHF Favorite Memories read by Murai Johnson, a special tribute to our beloved friend Terry Lamb by Ed Wilson, speaker Art DeMario, and the children’s program presentations by Judy Igelman and Peter Dyson. During dinner we enjoyed listening to the music of Mary Smith and Gregg Kimball and watching a VHF slide presentation. Special highlights included our JNC winners – Lovie Lamell and David Hull. And the prize swap – Marijane Valentino (original winner of the NHF Annual Meeting trip) with Tina Lamell-Kay (original winner of the Father’s Day Toolkit). Tina Lamell-Kay is now off to the NHF Annual Meeting in Orlando, FL with her 2 children. This is what community and support is all about! Thanks to our generous sponsors and individual donations we raised almost $4,000.
Programs

Camp Youngblood - Summer
Camp was held July 22-27 with a record breaking – 47 campers! This was the 6th year we partnered with Camp Holiday Trails, an American Camp Association Accredited Camp, and the Hemophilia Treatment Centers (HTC) to provide an incredible week of fun, fostering self-esteem, instilling independence, and improving one’s understanding of how best to manage their disease. Camp is offered at no charge to the families. We couldn’t offer this wonderful experience without your generous donations and the support of our sponsors: Accredo’s HHS, AHF, Baxter, Bayer, Coram, CSL Behring, CVS Caremark/CarePlus, Factor Support Network, MedPro Rx, Novo Nordisk, and Pfizer.

Camp Youngblood - Family
The 6th Annual Family Camp was held with roaring success. We were completely filled with 14 families. The Memorial Day weekend (May 25-27) tradition is filled with fun; which included Dads in Action presentation by Marc Gilgannon, PT and Scholarship 101 by Sue Cowell. Families also got the opportunity to participate in challenge courses, riding horses, going for a canoe ride, and networking and supporting each other. One attendee stated, “Memories were made that will last a lifetime and many planned to meet again next year for another great year of Family Camp. It does not matter who you are, where you are from or if you are new, you will always be welcomed into the group with open arms!” Thanks to Baxter, Novo Nordisk, Pfizer, Biogen Idec, and Drug Co Pharmacy for their generous donations to support our families.
Programs

Family Overnight
We continued the tradition of our Family Overnight. This year 111 participants returned to the Virginia Aquarium and Marine Science Center in Virginia Beach, VA and had fun sleeping with the fish. The event included an educational program for parents, special programming just for the kids, dinner, snack, and tickets to the museum for the next day. We appreciate MedPro Rx for helping to sponsor this popular event.

First Step
VHF continues to participate in the NHF First Step program, which is for parents and families of children newly diagnosed with bleeding disorders. VHF has trained mentor families, continues to provide “Welcome Bags”, and held its annual picnic at Lewis Ginter Botanical Garden in Richmond, VA. We had 28 people participate and had special guest speakers, Lauren Dunn, MSW and Jan Kuhn, RN, MPH from the VCU HTC. Thanks to Baxter and Novo Nordisk for their support of our new parents programming.

Holiday Parties
In partnership with our three local HTC’s, Saturday, December 10, 2011 was a busy day as we celebrated the holidays. Santa Claus made an early trip to see our families, where there was between 35-50 people per party in Charlottesville, Norfolk, and Richmond. This continues to be one of the most highly anticipated events. Many of you donated toys to help Santa this year. Your ongoing support is much appreciated! Accredo’s HHS has been a consistent sponsor of this event - Thank you!
Programs

Family Fall Event
Our now annual Fall Event was held on Sunday, October 30, 2011 at Oak Ridge Estate in Arrington, VA. We had 58 VHF members join us for an afternoon of fun and education; which included a trip to the pumpkin patch, face painting, mansion tours, freshly picked apples, and hot apple cider all supported by AHF. Pfizer sponsored the dinner and wonderful educational portion presented by Dr. Christopher Walsh of Mount Sinai Medical Center.

Back to School Picnic and Baseball Event
We are continuing the tradition of a back to school event and annual Baseball Game with the Flying Squirrels. Thanks to CSL Behring for their ongoing support of this great event. This year we had 106 VHF members join us on Saturday, August 20 for an evening of food, fun, and knowledge building. Thanks to Peter Dyson for sharing his experience and love of athletics.
Special Events

Throughout the year we have been fortunate to have some special programs and events.

1. We co-hosted the Batter-up Event in Norfolk, VA in partnership with CHKD for the first time this year. 70 people joined us on June 2, 2012 for a Norfolk Tides double header game that was generously sponsored by MedPro Rx. Prior to the game there was an educational dinner program sponsored by Bayer that focused on healthy nutrition presented by Kristen Jaworski, RN from the Pittsburgh HTC. In previous years the event was planned by our own Terry Lamb and the CHKD social worker. In memory of our good friend, the event will be named after him as the Terry Lamb Batter-Up Event.

2. On March 24, 2012 VHF headed to Washington, DC. The afternoon started with an educational event sponsored by Baxter at District of Pi, which was followed by a Wizards NBA game at the Verizon Center that was sponsored by MedPro Rx. VHF had the privilege of going down on the court to “high-five” the Atlanta Hawks as they entered the court. The players sure are tall! The game was a true nail-biter. The Washington Wizards were ahead almost the entire game, but a last minute 3-pointer made the Atlanta Hawks the winner at 95-92.

3. On July 9, 2011 we had our Celebration of Summer event at Ocean Breeze Waterpark. 78 individuals joined us for lunch, an afternoon of fun, and special guest speaker, Megan Midura, MSW from CHKD. Novo Nordisk was the generous sponsor of this event.

4. We sent Chris George’s Family to the NHF Annual Meeting in Chicago, IL – our lucky winner from VHF’s Annual Meeting. Chris stated, “I love seeing our Hemophilia and blood disorder community coming together, sharing stories, and discovering new ways to overcome challenges.”

5. We exhibited at three school nursing outreach initiatives where we had the opportunity to talk with hundreds of school nurses about bleeding disorders and shared with them available resources to support their important work. CSL Behring generously supported our efforts.
   a. The Summer Institute for School Nursing at Longwood University, July 11, 2011 Farmville, VA
   b. Virginia Association of School Nurses, Fall Conference, November 4-5, 2011 – Williamsburg, VA
   c. 8th Annual School Nurse Retreat, March 21, 2012 – Charlottesville, VA

6. VHF hosted two educational dinners.
   b. Overcoming Challenges by Pfizer in Charlottesville, VA on June 5, 2012. With 17 attendees and Nick Cady as VHF’s representative/volunteer.
HTC Support

VHF works hard to support our local HTC’s (UVA, VCU, and CHKD). Some of what we provided included clinic lunches, gas cards, educational brochures, Medic Alert bracelets, NHF Annual Meeting registration for HTC staff, and World Federation of Hemophilia International Congress registration fees for HTC staff.

Affiliation / Memberships

VHF is affiliated with the National Hemophilia Foundation and a member of the Hemophilia Federation of America, Medication Alliance Coalition, the Virginia Quality Healthcare Network, Virginia Association of Fundraising Executives, and Virginia Consumer Voices for Healthcare, and Healthcare for All Virginians.

Resources

Family Assistance Program
VHF provides financial support, based on availability of funding, to help pay for expenses incurred in the care, treatment, or prevention of a bleeding disorder, as well as other basic living expenses and MedicAlert bracelets on a case by case basis. This year VHF has helped over 43 families/individuals. Thank you to Novo Nordisk and PSI.

Lyman Fisher Scholarship Fund
Shannon Phelps and John Taylor Newman were the deserving members of the bleeding disorder community who received a $2000 scholarship for their higher education endeavors. The awards were presented at our 35th Anniversary Celebration in Williamsburg, VA.

Terry Lamb Memorial Fund
VHF created this fund in memory of our good friend Terry Lamb. The fund will be used to keep alive the memory of Terry Lamb and what he stood for by promoting and financing:

• Individual/family assistance to attend national meetings
• The Terry Lamb Volunteer of the Year Award
• Financial assistance for programs and/or classes that focus on leadership, volunteerism and/or health promotion.
Resources

Facts N’ Factors Newsletter
VHF publishes this important communication tool on a quarterly basis. You can receive a copy via email or postal mail. Issues include information on upcoming events, legislative issues, and other topics of interest. The Newsletter is also available on the website.

www.vahemophilia.org
Be sure to check out our website. Here you will learn more about all the resources, fundraisers, and program/events that VHF offers.

Facebook and Twitter
Become VHF’s fan on facebook and be sure to follow us on Twitter. We are looking forward to getting your thoughts/tweets on these exciting social media tools.

Goodbye Friend
Terry Lamb, VHF Board Member, friend, advocate and all around amazing man passed away on May 29, 2012, of a cerebral hemorrhage at the age of 61. Terry was born and raised in Lynchburg, VA. He was diagnosed as a young child with severe hemophilia but as anyone who ever met him can tell you he never let his diagnosis get in his way. He was a role model and advocate for active involvement in community programming, regular exercise, healthy diet and good treatment for those living with a bleeding disorder. He lived each moment to the fullest with a huge smile on his face and we are so blessed to have had him in our lives.
How You Can Help

We have the expertise and experience to provide the needed programs and services, but we are continually in need of financial support to make this happen. Without that support, individuals with bleeding disorders may not get the treatment and support they need which can lead to greater risk of complications and permanent, debilitating injury. Please join us in helping make a difference in their lives so that they can lead a long, productive, and healthy life.

☐ YES, I can help children and families living with bleeding disorders

☐ $2,000 pays for a Lyman Fisher college scholarship for an individual affected with a bleeding disorder

☐ $1,000 supports the Terry Lamb Memorial Fund and will send an individual to an NHF/HFA Annual Meeting

☐ $500 sends a kid to a week of camp at Camp Youngblood

☐ $250 provides one family emergency assistance

☐ $100 supports a family’s attendance to our annual state education meeting

☐ $50 pays for a family of five to attend one of our Holiday Parties

☐ $25 helps pay for a lifesaving Medic Alert Tag

DONATE NOW! It’s as EASY as 1, 2, 3!

1. Send a check to: VHF, P.O. Box 188, Midlothian, VA 23113
2. Visit www.vahemophilia.org to make a donation online
3. Call 800-266-8438 to make a credit card donation