



Virginia Hemophilia Foundation

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## *2010-2011 Annual Report Virginia Hemophilia Foundation*

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### *Virginia Hemophilia Foundation 2010-2011 Board of Directors*

#### *Officers*

Jeff Krecek, President  
Open, President Elect  
Dorothy O'Connor, Secretary  
Al Valentino, Treasurer

#### *General Board Members*

Murai Johnson  
Terry Lamb  
Kathy Mortimer  
Kevin O'Connor

#### *Staff*

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



Financial Statement:

Current Assets		June 30, 2011	June 30, 2010	\$ Change	% Difference
	Checking and Saving	417,388.58	310,042.16	107,346.42	34.6
	Total Receivables	14,679.00	51,900.00	-37,221.00	-71.7
	Total Fixed Assets	2,571.40	1,833.45	737.95	40.2
	<b>Total Assets:</b>	<b>434,638.98</b>	<b>363,775.61</b>	<b>70,863.37</b>	<b>19.5</b>
Current Liabilities					
	Accounts Payable	2,941.54	2,050.00	891.54	43.5
	Other Liabilities	19,320.69	5,415.55	13,905.14	256.8
	<b>Total Liabilities</b>	<b>22,262.23</b>	<b>7,465.55</b>	<b>14,796.68</b>	<b>198.2</b>
Total Equity					
	Equity	412,376.75	356,310.06	56,066.69	15.7
	<b>Total Liabilities &amp; Equity</b>	<b>434,638.98</b>	<b>363,775.61</b>	<b>70,863.37</b>	<b>19.5</b>



## Executive Director's Report

This past fiscal year, 2010-2011, has been another great year. We have welcomed a new part-time Administrative Assistant and have continued to see an increase in programming and participation. Members are giving back financially more than ever before, HTC's are strong partners, industry support has continued despite changing regulations, and the program evaluations have been outstanding.

The Virginia Hemophilia Foundation continues to serve you! Emergency Financial Assistance and Medic Alert bracelets have helped 35 families, two \$2,000 scholarships were awarded to deserving members, as well as ongoing targeted programming for new parents, teens, families, and women. Educational programs covered the spectrum from fitness, advocacy, returning to school, and overcoming challenges.

In order to become even more successful – we need you! Please consider contributing your time, money, or special talents.

Sincerely,

A handwritten signature in blue ink that reads "Kelly Waters".

Kelly Waters, LCSW  
Executive Director

## **Fundraisers**

***Golf Tournament*** – We hosted our 6<sup>th</sup> Annual Golf Tournament at Birkdale Golf Club in Chesterfield, VA. It was a great event. We had 18 foursomes and had a net income of over \$12,000. Thank you to our title sponsor – CSL Behring and to our many volunteers. We also couldn't have done it without the financial support of AHF, Axiom, B2L Consulting, Baxter, Bayer, BioRx, Coram, Grifols, LeClaireRyan, MedProRx, Novo Nordisk, Octapharma, Pfizer, PSI, Talecris and In Memory of Charles Valentino (by Al and Marijane Valentino) and In Honor of Angel Roque (by Janet and Art Roque). We hope to see you this year on October 24, 2011 at Birkdale Golf Course.

***Wine Tasting and Raffle Event*** – The 7th Annual Wine Tasting and Raffle was held on April 17th at Art Works in Richmond, VA with Special Entertainment by The Hye Keys (an Armenian Band) and Mary Smith (a singer of traditional songs and ballads). We dined on delicious appetizers and desserts and sampled new wines. It was a fun event and if you missed it, you should plan on coming next year. Dorothy O'Connor (committee chair) and committee members Marijane Valentino, Kendall Dean, Stephanie Grass, and Susan Shomaker did a wonderful job organizing the event. A special thanks to our Major Sponsors – Bayer, Baxter, NovoNordisk, Pfizer, Accredo's Hemophilia Health Services, and Coram. Thanks also to all of the generous donors who helped to make this event possible. We had a net income of almost \$14,000. Thank you for your generosity and having fun with us!

***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 almost \$10,000.

***Other*** – VHF also received donations and support from Community Health Charities (almost \$1,700) and United Way (almost \$1,200). Individual donors included: Laura Aylmer, Stephanie Higgins Bingler, Karen Dyson, Judith Harrold, John Jakubec, Karen Jones, Jeff Krecek, Jan and Dana Kuhn, Rosalie Niedermayer, Wanda Preddy, Paul Regal, Dorothy Schladitz, Susan Vignone, Ann and Bruce Beck, Aaron Bunn, William Bunn, Amy Chesky, Bob Gilliam, Murai Johnson, David Valentino, Woody Womack, Todd Ruppenthal, Jerry West, Brandon Price, Edward Southeran, David Killmeyer, John Parron Jr., Debi and Larry Williford, Brendell Osuchukwu, Dwight and Kathleen George, Sabrina Tucker, Chris George, Jerry West, Danielle Compton, Eric Walker, Linda Price, Gita Massey, David Rexal Stone, Marijane and Al Valentino, Dorothy and Kevin O'Connor, and Jennifer and Gene White.

**VHF also received several donations in Memory of very special individuals these include:**

*Donations in Memory of Beryl DeMario:*

Cynthia Corbin,  
Lola Ernest,  
Richard Forr,  
John Mills

*Donations in Memory of Karen Gutermuth:*

Betsy Badgett,  
William Gutermuth,  
Brandon Price

*Donations in Memory of Sue Collins:*

Linda Woolman, Helen Minton, Dr. Vickie Vaughan, Sharon Jones, Langley Federal Credit Union

## **Programs**

**Adult Retreat** – On September 25 and 26<sup>th</sup> we held a very successful Adult Retreat in Williamsburg, VA. The weekend focused on health and wellness. Highlights included tickets to Colonial Williamsburg, a presentation on healthy living through the lifespan, time for networking and support, dinner at a Historic Tavern, and an Inalex workshop on Managing Your Stress: Happy Times Ahead presented by Ken Glickman. Close to 30 attendees participated in this highly rated event. Thanks to Baxter for sponsoring this great event.

**Advocacy** – This year we continued our collaboration with HACA on the PACT grant. Our advocacy activities included:

- Another successful Richmond Days on January 16 and 17. Over 75 individuals attended and we made over 40 visits to different Virginia legislators. Through this annual activity, we are cementing relationships with our legislators who are increasingly aware of our policy concerns.
- Attended NHF's annual Washington Days (over 15 representatives from VHF and HACA) and met with 9 Senators/Congressmen's offices.
- Used VoterVoice, sent out 10 calls-to-action for state and federal issues.
- Submitted written comments twice and verbal comments once to the Virginia Health Reform Initiative on the subject of essential health benefits.
- Were successful in obtaining full funding for the FY 11-12 budget year for the Bleeding Disorders Program, which had been faced with a threatened 48% budget cut.
- Worked with three VHF members to serve as advocacy coaches.
- Monitored the actions of the Joint Commission on Health Care as it reviewed health care

- delivery options for uninsured individuals with chronic life-threatening conditions.
- Heard from Delegate Rosalyn Dance (63<sup>rd</sup> House District) at the VHF/HACA joint annual meeting, who encouraged members to become grass roots activists.

**Annual Meeting** – On June 18, 2011 over 100 folks joined us at the Second Baptist Church in Richmond, VA for the 1<sup>st</sup> VHF – HACA State Educational Meeting. The event started off on Friday night with the Diggity Dudes band. We have quite some dancers amongst us. On Saturday participants learned about Genotyping, Joint Health, and Advocacy. The kids had a great time with Gettin’ in the Game, Steve Kohrherr’s Drama Workshop, and Mad Science demonstration. Thanks to our Platinum Sponsor – CSL Behring, Gold Sponsor – Pfizer, Silver Sponsor – NovoNordisk. And thanks also goes to our Corporate Sponsors Accredo’s Hemophilia Health Services, AHF, Axiom Healthcare Pharmacy, Inc., Bayer, Baxter, BioRx, Coram, CVS Caremark/Caremark Rx, Factor Support Network, Grifols, MedProRx, Octapharma, and Walgreen’s Infusion Center. We also appreciate our Friends – PSI and Camp Holiday Trails.

**Blood Buddies Fitness Promotion Program** – This year we gave over \$650 in fitness promotion activities, including golf lessons, a golf summer program, and lifeguard camp. If this is of interest be sure to apply for the grant to help you increase your fitness and activity level.

**Camp Youngblood - Summer** - This was the 5<sup>th</sup> year we partnered with Camp Holiday Trails, an American Camp Association Accredited Camp. The Hemophilia Treatment Center (HTC) staff was amazing; not only did they encourage kids to attend, but they ensured we had HTC nursing support throughout the week. In July 37 kids attended camp at no cost to them. The feedback from Camp Holiday Trails was “GREAT session. Really – OUTSTANDING!” Will you be joining us in July 2012? Thanks to Accredo’s HHS, AHF, Baxter, Bayer, Coram, CSL Behring, CVS Caremark/CarePlus, Factor Support Network, Grifols, MedPro Rx, Novo Nordisk, Octapharma, Pfizer, and TACO for their generous donations to help send our kids to camp.

**Camp Youngblood – Family** – We are also continuing with our successful camp program with our 5<sup>th</sup> Annual Family Camp in partnership with Camp Holiday Trails. Over Memorial Day weekend 9 families got together to ride horses, canoe, participate in challenge courses, and network and support each other. This continues to be one of our most popular events. Thanks to Baxter, NovoNordisk, and Pfizer for their generous donations to support our families.

**Family Overnight** – We continued the tradition of our Family Overnight. This year we visited the Virginia Living Museum. Here we had an educational program for parents, and special programming just for the kids. We had close to 70 adults and children join us for a night of fun. Thank you to MedProRx for their ongoing sponsorship of 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 the Ocean Breeze Water Park in Virginia Beach, VA. Over 80 individuals joined us for networking and support. Thanks to Baxter and NovoNordisk, in their support of our new parents programming.

***Holiday Parties*** – In partnership with our three local HTC’s, December 11 and 12, 2010, were busy days as we celebrated the holidays. Santa Claus made an early trip to see our families in Charlottesville, Norfolk, and Richmond for breakfast or cookies. This continues to be one of the most highly anticipated events of the year. If you are interested in helping Santa with toys this year and/or making financial contribution please let us know. Your ongoing support is much appreciated!

***Special Events*** – Throughout the year we have been fortunate to have some special programs and events.

1. Won NHF’s Award of Distinction for Health Education with our “X-Factor” play.
2. “The X-Factor” traveled to New Orleans and performed to the NHF Annual Meeting with rave reviews.
3. Thanks to a CSL Behring grant 25 folks joined us for our “Just for You” teen program and went tubing down the James River.
4. We have also partnered with Factor Support Network to focus on health and fitness. Over 30 individuals joined us for a ropes course adventure (Charlottesville, VA) and day of bowling (Charlottesville, VA and Norfolk, VA).
5. Bayer sponsored a “Living Fit” program in Richmond, VA that included our own Marc Gilgannon, PT, sharing some important information. The program ended with some bowling fun.
6. CSL Behring and AHF sponsored our Fall Event at the Shenandoah Caverns in Quiksbury, VA. The day included over 100 participants who listened to an educational presentation titled “Promoting Healthy Lifestyles,” went on a guided cavern tour, entered/watched a costume contest, enjoyed face painting and balloon animals.
7. CSL Behring sponsored our 1<sup>st</sup> Back to School Picnic at Crump Park. Approximately 50 folks enjoyed a delicious picnic dinner, networked, and played on the playground.
8. We sent the George Family to the NHF Annual Meeting in New Orleans – our lucky winner from VHF’s Annual Meeting.

### ***HTC Support***

VHF works hard to support our local HTC’s (University of Virginia, VCU, and CHKD). Some of what we provided this year included clinic lunches, gas cards, flash drives, educational brochures, Medic Alert bracelets, NHF Annual Meeting registration for HTC staff, etc.

### ***Affiliation/Memberships***

VHF is affiliated with the National Hemophilia Foundation and a member of the Hemophilia Federation of America, and the Virginia Quality Healthcare Network.

### ***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 35 families/individuals. Thank you to NovoNordisk and PSI.

This year we also assisted select children with tutoring assistance. NovoNordisk allowed us to offer this unique tutoring opportunity. Thank you!

***Lyman Fisher Scholarship Fund*** – Daniel Schofield and Pat DeRatto were the deserving members of the bleeding disorder community who received a \$2000 scholarship for their higher education endeavors. This year we were particularly fortunate to have Dr. Gwen Fisher present these awards at our annual state education meeting in June.

***Facts N' Factors Newsletter*** – VHF publishes this important communication tool on a quarterly basis. 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 @VAHemophilia. We are looking forward to getting your thoughts/tweets on these exciting social media tools.

## ***Ways to Get Involved***

VHF is in an exciting time of growth and you can be part of it. Best of all, it is easy to get involved by making a tax-deductible contribution, signing up for a committee, volunteering at an upcoming event or fundraiser, telling your friends and family about VHF, and writing or meeting with your state senator and delegate to tell them about you and your connection with bleeding disorders.