



Virginia Hemophilia Foundation

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## *2008-2009 Annual Report Virginia Hemophilia Foundation*

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### *Virginia Hemophilia Foundation 2008-2009 Board of Directors*

#### *Officers*

Jeff Krecek, President  
Terry Lamb, Vice President  
Jennifer White, Secretary  
Dorothy O'Connor, Treasurer

#### *General Board Members*

Kevin O'Connor  
Janice Cole  
Al Valentino  
Steve Schofield

#### *Staff*

Kelly Waters, Executive Director  
Dee Schullery, Bookkeeper

## President's Report

The one thing often lost in a non-profit corporation is that it is a corporation. The Board of Directors is required to ensure that the corporation meets legal requirements as a business entity and works for the long term sustainability of the Virginia Hemophilia Foundation (VHF) until a cure is found and the mission is completed.

A few years ago, the financial position of the VHF was bleak and the future was in question. The Board approached long term sustainability in three ways: strategy, people, and technology.

Last year the Board created a Strategic Plan for the VHF. Strategic Plans strike fear and/or loathing in most. The Strategic Plan is nothing more than an outline for work that will be accomplished. This past year, as examples, we created a welcome packet for newly diagnosed individuals, updated the bylaws, and implemented a direct giving campaign. Next year we plan to create a fundraising plan, increase our outreach, and standardize and increase our communication to the community. With the Strategic Plan the Board has the foundation to ask, "Should we do this?", rather than "What are we doing now?"

Secondly, the Board is a small group of volunteers and can only do a finite amount of tasks. In order for the VHF to be successful, we needed to look at volunteers and paid staff. At the top, the Executive Director is critical to the communication and connectivity of the VHF to the HTC's, the community, our partners, and industry. The Board took large steps to adjust the Executive Director's compensation package to adequately reflect the requirements of this professional position. Next, persons from outside the community with particular skill sets or non-profit experience have been asked to join the Board to increase diversity. Changes to the bylaws have ensured succession and rotation on the executive committee. Lastly, we continue to have a bookkeeper on staff and look for the next need in staff. In the coming years, the Board hopes to increase the volunteer base and empower the community to direct the various operations of the VHF.

Lastly, increase the use of technology when appropriate. Technology, in particular software and hardware, is often used as the panacea for organizational difficulties or short-comings. Technology is a tool and not a solution. Technology will be applied when the organization is ready for the use of a better tool. This past year, the website was upgraded for look, content and ease of usability. A new mail service was used to provide a better form of communication. The VHF is now on Facebook and tentatively entering the world of social networking. Next on the list, the current community database will be upgraded and consolidated with the various lists that exist.

These are troubling times, but the steps necessary for long term sustainability and increased emphasis on the mission have been taken and planned.

A handwritten signature in black ink, appearing to read "Jeff Krecek".

Jeff Krecek  
Board President



## Treasurer's Report

## Financial Statement:

Over the past year, the Virginia Hemophilia Foundation implemented the largest budget in the recent history and was still able to increase the reserves by \$50,000. This includes a decrease in direct support from industry and the first annual direct mailing.

Current assets		15-May-09	15-May-08	\$ change	% difference
	Checking and Savings	219,048.44	170,796.82	48,251.62	28.30%
	Assets	2,903.78	444.03	2,459.75	554.00%
	Total Assets	221,952.22	171,240.85	50,711.37	29.61%
Current Liabilities					
	Accounts Payable	2,864.61	4,332.77	-1,468.16	-33.90%
	Other Liabilities	-16,227.88	-16,542.29	314.41	1.90%
	Total Liabilities	-13,363.27	-12,209.52	-1,153.75	-9.50%
Total Equity					
	Equity	235,315.49	183,450.37	51,865.12	28.30%
Total Liabilities and Equity		221,952.22	171,240.85	50,711.37	29.61%



## Executive Director's Report

The Virginia Hemophilia Foundation (VHF) continued to be busy serving the needs of the bleeding disorder community through education, advocacy, and support. Thank you to the Board of Directors and the many volunteers who actively help the chapter move forward strengthening its programs and services.

### Top Ten Ways We Are Making A Difference:

1. Distributed over 400 copies of our popular quarterly Facts & Factors Newsletter with information on research, resources, and programs.
2. Created a newly redesigned and more functional website for members and the public to get the latest bleeding disorder and chapter news.
3. Ensured we had an advocacy presence by meeting with our legislators, learning all we can about advocacy efforts through in-person trainings and webinars, and creating an advocacy work group to make sure our efforts continue.
4. Helped several families in financial crisis with medical bills, rent, utilities, etc.
5. Provided two college scholarships worth two thousand dollars each.
6. Continued our outreach to school nurses and the general community through conference presentations, health fairs, and distribution of flyers to select Red Cross donor sites.
7. Offered several quality educational programs, including one on health insurance.
8. Hosted an annual meeting with record-breaking attendance covering topics on nutrition, future treatments, and plasma product development.
9. Held two camps in partnership with Camp Holiday Trails – Summer and Family.
10. Reached out to adults with bleeding disorders via Adult Only Retreats.

To continue with our outstanding programs and services we need you. Please think about donating your financial and personal (time, skill, etc.) resources to YOUR Chapter. We need your support as we continue to grow. I look forward to working with you to make VHF a model chapter. Please contact me about making a financial donation or joining one of our committees.

Sincerely,

Kelly Waters, LCSW  
Executive Director

## **Fundraisers**

**Direct Mail** – This was a new initiative for VHF, which will now be an annual program (if not more frequently). So, be sure to check your mailboxes and return your donation! We were thrilled to have raised \$1200! Have you asked your friends and family about supporting a cause that is important to you?

**Festevents** – This is the third year we were chosen as a Norfolk Festevents Service Club. Jennifer White and Tracy Cleghorn from the Tidewater Area successfully coordinated our participation last year. Thanks to our wonderful volunteers, we raised \$1445. We are currently looking for individuals who live in the Tidewater Area and are interested in spearheading this project in the future. Please contact us if this is something you could do to give back.

**Golf Tournament** – We hosted our 4<sup>th</sup> Annual Golf Tournament at Birkdale Golf Club in Chesterfield, VA - It was a great event. We had 19 foursomes and made almost \$18,000. Thank you to our title sponsor – CSL Behring. We also couldn't have done it without the financial support of AHF, Baxter, BioRx, CVS Caremark, Factor Health Management, Factor Support Network, Accredo Hemophilia Health Services, Novo Nordisk, and Wyeth. We look forward to seeing you on October 5, 2009 for our 5<sup>th</sup> Annual Golf Tournament.

**Night Under the Stars** – For the third year in a row, VHF participated in this local fundraiser at Short Pump Town Center in Glen Allen, VA. The event was a special evening of private shopping where the \$5 ticket cost went directly to VHF for our programs and services. We raised \$710. Thank you to all that sold tickets.

**Wine Tasting and Raffle Event** – If you missed our 5<sup>th</sup> Annual Wine Tasting and Raffle Event this year, you will want to make sure you join us next year. Some of the highlights included: delicious food, Total Wine & More sponsorship, the beautiful Agecroft Hall and Gardens for the location, almost 100 attendees, over 50 individuals/companies donating to the raffle baskets and silent auction items and generous sponsors (including Baxter as the premier sponsor, followed by Bayer, Wyeth, NovoNordisk, Accredo Hemophilia Health Services, and CSL Behring). We raised just under \$12,000. Thank you for your generosity and having fun with us!

**Youngblood 5K** – The 6<sup>th</sup> 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. Runner Bill's gift certificates continue to be popular prizes. A special Thank you goes to our premier sponsor – CSL Behring. Baxter and NovoNordisk were also generous sponsors and helped us raise almost \$4,000.

**Other** – VHF also received donations and grants from companies (such as Townebank and L.E. Ballance Electrical Service, Inc.), individuals, the National Hemophilia Foundation, CSL Behring Foundation, PACT Foundation, Community Health Charities, and the United Way. These donations totaled more than \$55,000.

## **Programs**

**Adult Retreats** – This year we partnered with the Hemophilia Association of the Capital Area (HACA) in order to increase the programming available to adults in Virginia. This past November we held a very successful retreat in partnership with Baxter and Inalex in Natural Bridge, VA. Over 30 attendees participated in this highly rated event. In April, HACA organized an adult retreat in Annapolis, MD. This was also well attended. Look forward to seeing you this fall for our 3<sup>rd</sup> annual retreat.

**Advocacy** – In 2008-2009 we worked closely with Becky Bowers-Lanier, our advocacy consultant. Sixty of us convened during Richmond Capital Hill Day to advocate for maintaining funding for the Virginia Bleeding Disorders Program (VBDP), maintaining individual and small group insurance policies that require coverage for hemophilia and congenital bleeding disorders, and access to the full range of products and services needed by people with bleeding disorders. Although we did not get everything we requested, we did accomplish many things – a presence in the General Assembly, increased knowledge of bleeding disorders by our legislators, and a strengthening grassroots effort so we can become even more effective as we move forward. In February, eleven of us walked the halls in Washington DC to advocate on overall health reform, increasing lifetime caps, and educating about the importance of the Hemophilia Treatment Center. We have also held three Advocacy Webinars and created an advocacy work group. Thank you to Sabrina Adams and Sabrina Tucker who will be co-chairing this group. Thank you to our sponsors and partners: Access, Baxter BioScience, Bayer, CSL Behring, Hemophilia Federation of America (HFA), PACT Foundation, Patient Services Incorporated, and National Hemophilia Foundation (NHF).

**Annual Meeting** – In June 2009 over 100 folks joined us at the YMCA in Richmond, VA to learn about the Factor 8 Updates, Advocacy, and Exercise and Fitness. The kids had a great time with field day activities and fun educational programs. The event will end with a dinner cruise around the James River. Thanks to our premier sponsors - Baxter, Bayer, BioRx, and MedPro Rx. And thanks also go to Accredo's Hemophilia Health Services, AHF, Coram, CSL Behring, CVS Caremark/Caremark Rx, Factor Health Management, FactorSource America, Factor Support Network, Grifols, HomeCare for the Cure, NovoNordisk, and Wyeth for exhibiting at our special event.

**Camp Youngblood - Summer** - This was the second 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. This year 39 kids attended camp at no cost to them. Will you be joining us in July 2009? Thanks to AHF, Baxter, Bayer, Critical Care Systems, CSL Behring, Factor Health Management, Factor Support Network, Grifols, HHS/Medco, MedPro Rx, Novo Nordisk, and Wyeth 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 3rd Annual Family Camp in partnership with Camp Holiday Trails. Over Memorial Day weekend 11 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, TowneBank, Bayer, NovoNordisk, and Wyeth for their generous donations to support our families.

***Dads in Action*** – Dads enjoyed a great night of dinner and baseball in July 2008 as they watched the Norfolk Tides take on the Pawtucket Red Tides. Lance Cleghorn is the VHF representative for this great program. He is busy planning other programs to help fathers build strong bonds with all of their children by giving dads support, a sense of belonging and keys to strengthening family ties. Thanks to Critical Care Systems, NovoNordisk, and Wyeth for their support of our “dads”.

***First Step*** – VHF continues to participate in the NHF First Step program, which is for new parents and families of children newly diagnosed with bleeding disorders. The VHF program has a three prong approach. First, in November we held our second mentor training with the Children’s Hospital of the King’s Daughters (CHKD) and the Virginia Commonwealth University (VCU) HTC. Three Moms were successfully trained to provide support to those “new” families. Second, Welcome Bags were created that provided education, resources, and helpful items to those newly diagnosed families. Our three HTC’s were each give five bags to share with new families. Third, in August we held a First Step picnic in conjunction with CHKD. Over 50 individuals joined us at Maymont in Richmond for networking and support. The picnic, hayride, tips for back to school, and feeding the animals were all hits for the day. Thanks to NHF, Factor Health Management, NovoNordisk and Wyeth in their support of our new parents programming.

***Fit for All*** - VHF is one of six sites in the country chosen to participate in an exciting new fitness initiative. The chapter is partnering with the Central VA Center for Coagulation Disorders, the NHF, and the YMCA to enable patients and their families with bleeding disorders to join the YMCA. Participants will receive reduced rate membership and participate in fitness, wellness, aquatics and sporting programs with your family in a safe and comfortable environment. Currently we have 24 individuals who have signed up for the program.

***Holiday Parties*** – In partnership with our three local HTC’s, December 13, 2008, was a busy day 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. Thanks to Critical Care Systems and Factor Health Management for their support to bring the holidays to our community.

***Special Events*** – Throughout the year we have been fortunate to have some special programs including a ***hiking and fishing event*** at Mint Springs, VA - We had over 100 attendees (our best participation ever!). Thanks to CSL Behring and AHF for their support. We also held a ***cooking class and educational program*** for women with bleeding disorders. We had 18 people participate with rave reviews. CSL Behring was the generous sponsor. In addition, VCU’s Lauren Dunn present on ***health insurance issues***. We had 20 attendees learn about the hottest issues related to health insurance while enjoying a delicious seafood dinner. Thanks to AHF!

### ***HTC Support***



VHF works hard to support our local HTC's (University of Virginia, VCU, and CHKD). Some of what we provided included clinic lunches, gas cards, flash drives, educational brochures, Medic Alert bracelets, etc.

### **Affiliation/Memberships**

VHF is affiliated with the National Hemophilia Foundation and a member of the Hemophilia Federation of America, the Virginia Network of Nonprofit Organizations, the Center for Nonprofit Advancement, 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 on a case by case basis. This year VHF has helped close to 20 families/individuals, as well as provided over 10 medic alert bracelets. Thank you PSI, Bayer, CSL Behring, HHS/Medco, NovoNordisk, and Wyeth.

***Lyman Fisher Scholarship Fund*** – Harvey Gates, Jr., and John McNeil were the deserving members of the bleeding disorder community who received a \$2000 scholarship for their higher education endeavors.

***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.

***[www.vahemophilia.org](http://www.vahemophilia.org)*** – Be sure to check out our newly redesigned website. Here you will learn more about all the resources, fundraisers, and program/events that VHF offers.

***Facebook*** – VHF has entered the technological era. Check out the Virginia Hemophilia Foundation Group page and become a “friend”.

### **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.