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The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the bleeding disorders community.

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## EXECUTIVE'S REPORT

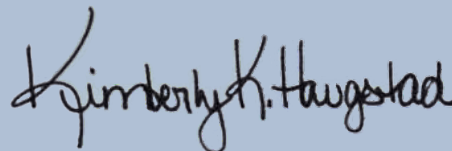
*By Kimberly Haugstad and Chad Stevens*

It is with great pleasure that Chad and I write this introduction. We soon approach the one year mark to our return to Washington D.C. and look back to a year of change and action at HFA and in the community. The momentum is growing so stay tuned and get involved. From our programs to policy outreach, we've got a lot happening!

Despite the often polarizing politics, we are able to come together and agree as a community on our key non-negotiable: safety, affordability and accessibility of care and products we require. This is the cornerstone platform HFA was created for and continues to support.

Individuals like Nathan and Sonji Wilkes inspire us as champions and self advocates. Our individual views may differ on what system, plan or legislation would work best, but we all can applaud our peers for taking the risk and using their energy to reach out and ask for positive change.

We're very proud of the efforts of individuals who have reached out and told their stories in this community. We hope that each of you had a wonderful summer; and if you haven't yet, make sure your own Voice is heard either through our campaign or in some other way! You count too. 💧



## SAVE THE DATE

### 2010 Educational Symposium

April 23-24

The Westin Crown Center  
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## BARRY HAARDE ENCOURAGES OTHERS TO STAY ACTIVE!



Barry Haarde, a 43-year-old man with hemophilia, HIV, and hepatitis C from Woodlands, Texas hopes to inspire others in the hemophilia community to stay active. After a childhood of being told he could not participate in most sports because of fear of internal bleeding, Haarde took up biking with the motivation of improving the health and strength of his body.

Haarde began biking in the late 1990s with hopes of strengthening his leg before his knee replacement surgery. Biking has become a lifestyle for Haarde, who has biked more than 50,000 miles. This last April, Haarde participated in the BP MS 150 for his seventh time. The BP MS 150 is a 150-mile bike ride benefiting multiple sclerosis, starting at Tully's Stadium in Houston, Texas. Haarde hopes by telling his story it will encourage others in the community to be active!

To read more about Barry Haarde's story, visit our website and search the Voices Campaign. ♦

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## 2009 HFA SCHOLARSHIP AND GRANT WINNERS!

**Dale Michael Brisson** Artistic Encouragement Grant

Dale Michael Brisson is the third of five boys, the only one with hemophilia, but this didn't stop him from leading an interesting life. Dale has worked as a live show announcer, radio personality, night club emcee, air show narrator, voiceover artist, television talk show host and published writer. His award-winning short stories, articles and poems have been published worldwide. But, ask Dale what his greatest accomplishment is? "That's easy," he beams. "My children, Michael, Spencer and Michelle."

**Ellen Klein** Educational Scholarship

Throughout her life, Ellen has followed Ghandi's maxim to "be the change you wish to see in the world." To better fulfill this mission, Ellen co-founded, and is now president of, the non-profit organization, the Semi-Professional Scientists. The Semi-Professional Scientists is a group of kids exciting and informing kids about science through science demonstrations, hands-on science experiences, and science columns in the newspaper the *Snowmass Sun*.

Even as Ellen excited and informed others about science, she continued her own education. In high school, she took advanced chemistry, biology, and physics courses. In 2008, Ellen graduated from the University of Minnesota Talented Youth Mathematics Program, completing Honors College Level Calculus III before she graduated from high school.

**Eric Shepard** Educational Scholarship

I am a twenty-year-old junior at Wright State University in Dayton, Ohio. I am in the process of receiving a degree in Biology while meeting the Pre-Med requirements and pursuing medical school. I love to travel and have done service work in Russia, Ghana, and Burkina Faso. Currently I am preparing for a trip to the Amazon Rainforest to study plants and animals that will take place over my winter break. In my free time I enjoy playing playing golf, spending time with my friends and family, and helping out with my local hemophilia chapter, the Southwest Ohio Hemophilia Foundation.

**Shawna Garrett** Artistic Encouragement Grant

Shawna Garrett is the winner of the Artistic Encouragement Grant. She is a young woman with Von Willebrands disease. She intends to use the grant to assist her in her research regarding chronic pelvic pain conditions and overlapping bleeding disorders. Her ultimate goal is to write a book. She hopes to empower women with this information so that they can be active in their own healthcare and obtain accurate diagnoses as early as possible in their lives.

**Juanita Fish** Parent Continuing Education

I am thirty-three years old. I have a nine-year-old son who has moderate Hemophilia A named Johnathan. I hope to become a registered nurse very soon. I love reading, writing, and singing.



## **Nathan Strauss** Educational Scholarship

I'm 21 years old, and about to start my senior year at Harvard, where I will graduate with a Bachelor's degree in Applied Mathematics and a minor in Statistics. I was diagnosed with severe Hemophilia A immediately after birth, and I've learned to treat my condition as an opportunity to become more self-sufficient as opposed to letting it hinder me. When I'm not in class or working on problem sets, I'm most often at The Harvard Crimson, the college's daily student paper, where I serve as a News Executive. I also run the semester-long program to train new writers who want to join the news staff. I interned this summer with the Federal Housing Finance Agency in Washington, DC, and am currently planning to go on to law school.



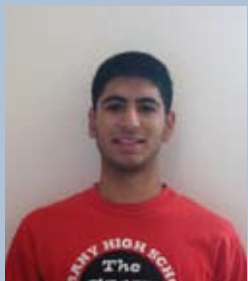
## **Nicolas Hilgeman** Educational Scholarship

Nicholas Hilgeman is currently a senior at Case Western Reserve University in Cleveland, Ohio, where he is majoring in political science and international studies. He is especially interested in Middle Eastern politics and history and has studied abroad in Morocco. After graduation, he plans to pursue further training in the Arabic language and to obtain a graduate degree in Middle East studies. When not in school, Nicholas enjoys watching movies and playing drums for a local band. He lives in Whitehouse, Ohio.



## **Nicolas Popp** Educational Scholarship

Nicholas Popp graduated from Freeburg Community High School, in Freeburg, Illinois, as the class Valedictorian. While in high school, he participated in a number of extracurricular activities including Literary Club and Science Club. He also competed in academic tournaments for the Math Team, Worldwide Youth in Science and Engineering (WYSE), and the Scholar Bowl team, where he was the Varsity Captain. This fall, he will be attending the University of Chicago with a proposed major of Biochemistry, hoping to focus his work on the study and future treatment of genetic disorders. In addition to his many school activities, Nicholas has been a volunteer at Camp Barnabas, in Missouri, during the summer, and has aided the St. Louis hemophilia community with its outreach into public schools. He also works part-time at a local pizzeria, and while not working or studying, he enjoys spending his free time with friends and family or browsing the local music and bookstores for up-and-coming authors and musicians.



## **Perseus Patel** Educational Scholarship

I am currently an 18-year-old student with severe Hemophilia A attending the University of California-Los Angeles (UCLA). I have recently completed my first year of college and look forward to the second year of my pre-medical studies. My passion for helping others, as well as my drive to pursue a career in medicine, was cultivated not only by Camp Hemotion (the Northern California camp for children with bleeding disorders) but also by my doctors and nurses. It is my dream to alter a child's life and perspective the way my doctors have changed mine.



**PERSPECTIVE OF A  
BLOOD BROTHER**

*By Dan Bond, Texas*

This weekend at the South Texas Bleeding Disorder Conference, I had a small revelation. I was sitting in a

session for adult men listening to the speaker talk about how enriched his life has been because of his hemophilia. I suppose my response would have been different had I not postponed treating a knee bleed so that I could attend the session. While his life has no doubt been enhanced because of his condition, mine has been pretty great in spite of it. I've been to dinner with the Thunderbirds, lunch with Al Unser, Jr.'s crew chief, and flown upside down over a 1000' high mountain ridge. I've been to the grand opening of the National Air & Space Museum and seen my work on permanent display there.

While I'll be the first to admit that hemophilia helped shape who I am today, none of these things happened because of it. Hemophilia shapes our lives, but it should not dominate them. I hope you get as much joy as I do from realizing that there may be limits to what we can do, but not to what we can accomplish. 💧

**DID YOU KNOW...**

- The Blood Brotherhood Chat site draws participants from over 20 different states? Nearly 200 registered members are chatting on more than 300 topics. Is there someone "chatting" from your state? Visit <http://hemophiliafed.net/hfabbb/> to register.
- The BBs now have 8 local sites, with the newest site in the Southern Tier of New York (BDAST)? The co-coordinators of this group are Chad Blair, Homer Everson, and Bob Graham. Welcome

BDAST!! To find out more about BDAST or other local BB sites, visit <http://hemophiliafed.org/programs-and-services/blood-brotherhood/> or email [programs@hemophiliafed.org](mailto:programs@hemophiliafed.org).

- The Blood Brotherhood Webinars are drawing rave reviews?

"I THOROUGHLY ENJOYED the presentation!!! Terrific job! Professional, and yet it seemed to be personal as well."

*"Living in the Age of CJD/vCJD," June 17, 2009*

"Another very informative webinar. Please convey my thanks to Dr. Colvin. He does a great job."

*"Sex, Kids and HIV Today," July 29, 2009*

Did you miss a webinar? Want to know when the next BB webinar is scheduled?

Visit <http://hemophiliafed.org/> to learn more! 💧

**ANNOUNCING THE FORMATION  
OF A HEMOPHILIA HIV/AIDS  
NATIONAL MEMORIAL**

RELEASE DATE: IMMEDIATE

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A national memorial fund has been established to honor those who have lost their lives to Hepatitis C and HIV/AIDS as a result of tainted blood products in the 1980's. The memorial's mission is to create a public statement showing the enormity of this medical tragedy, in order to preserve history, to effect change, and protect the future of the blood supply. Visit HFA website at [www.hemophiliafed.org](http://www.hemophiliafed.org) - community news for full copy of press release.

## “BACK TO SCHOOL” IS NOT JUST FOR KIDS

by Mark J. Borowski, M.S.

The fall season always renews my thirst for learning, probably because it signals a time of change...the crisp coolness of the air, the vibrant colors of the leaves, and the new school schedules for my kids. It compels me to think that I should be learning something new too, just as they are. Well, one of the things I have learned in the past couple years is how much of an impact dads have on their kids' school success.

According to studies by the U.S. Department of Education (DOE) in 1998 and 2001, children whose fathers were highly involved in their schools were more likely to do well academically, to participate in extracurricular activities, and to enjoy school, and were less likely to have ever repeated a grade or been expelled compared to children whose fathers were less involved in their schools.

What's even more interesting, perhaps, is that this effect held for both two-parent and single-parent households, and was distinct and independent from the effect of mother involvement. This is no knock on mothers. Trust me, as a part-time at-home dad, I know that parenting is definitely a two-parent job (with occasional help from grandparents too). My point is that dads need to realize the significant, and often unique, impact we have on our children. School success is just one area dads have a unique, positive impact on their kids.

The DOE study in 2001 also found that father involvement in schools is associated with the higher likelihood of a student getting mostly A's. Again, what is interesting is that this was true for fathers in biological parent families, for stepfathers, and for fathers heading single-parent families. With a larger number of today's families reflecting those various situations, it's compelling that the dad's role is key to school success and here are five ways to be more involved in your children's school:

1) Help with Homework – there are plenty of opportunities since kids have homework almost every day and on weekends. If you're intimidated by certain subjects that were never your favorites, help out with the subjects where you feel more comfortable.



*Dads in Action member Matthew Compton & son*

2) Volunteer for a Field Trip or School Activity – Field trips are a fun and casual way to get involved and school activities often offer the opportunity to use skills you possess and enjoy using.

3) Ask Questions Throughout the Week – I often ask my kids for their “high” and “low” of the day – the best and worst part – which provides a quick pulse of their day.

4) Implement a Watch D.O.G.S. Program – The National Center for Fathering (NCF) offers a Watch D.O.G.S. (Dads of Great Students) program which helps create a safe and secure learning environment in our nation's schools. It's easy, find out more at [www.fathers.com](http://www.fathers.com).

5) Attend Sporting and School Events – this should go without saying but kids really enjoy seeing their parents in the stands or audience. And go ahead and “embarrass” them by yelling and cheering, they really don't mind. It's better than embarrassing them by not showing up.

Our kids are ultimately responsible for their school success but parents are also responsible, particularly in the elementary school years when good habits are formed. And while both parents are important, it's motivating to know that it is the dad's involvement that can be key to school success. Let's start looking at homework and school activities not as a burden, but as opportunities to ensure our kids' success in school and in life. And at the same time, we'll be supporting our wives by allowing them more time for their career and own interests.

Mark Borowski, speaker and author of “Big Slick Daddy: Poker Strategies for Parenting Success” works with HFA's Dads in Action, facilitating their monthly webinars. To find out more about Mark, go to <http://bigslickdaddy.com/> or email at [mark@bigslickdaddy.com](mailto:mark@bigslickdaddy.com). ♦



## HELPING HANDS

HFA is grateful for all memberships (fees dedicated to the Helping Hands program) and for the anonymous donor who has kept the Helping Hands fund afloat for the last couple of months. We know these are tough economic times for most of our community and we appreciate those of you who have helped others.

Recently a family with a new baby benefitted from this generosity and was able to keep their home because of your donations. In July, the father required emergency gall bladder surgery, which led to further health complications and an unpaid medical leave from work. His wife also took unpaid leave to care for their child and visit her husband in the hospital, which in turn left them without an income for one month. Thus, they were unable to pay their mortgage, and the threat of losing their home became a stressor that no family with a new baby wants to face.


Fortunately, the Helping Hands program, along with the local hemophilia chapter, was able to provide financial assistance to the family to help with their mortgage payment. The financial assistance provided the family with a roof over head and peace of mind. Once again, this story highlights the mission of HFA's Helping Hands program – to help individuals and families in need so that they can ultimately help themselves.

Please keep those memberships and donations coming. Along with your support, HFA can continue helping individuals and families in need. 💧

## THE WASHINGTON D.C. ADVOCACY INTENSIVES

The Advocacy Intensives Program is designed to be delivered in an intensive, 3-5 days of experiential learning. The program encourages and provides tools necessary for the bleeding disorders community to stretch their personal potential and champion their own needs through self-advocacy at both state and federal levels. Participants will arrive in Washington, D.C. and engage in a variety of hands-on activities including team building and communication exercises, special projects and legislative topics training. Participants will spend time authoring and practicing their own "Personal Story" and then meet their legislators to deliver it. Additional activities will include preparing a media plan to be implemented at the local level, as well as development of an action plan in partnership with the Executive of the participant's chapter, to identify next steps for keeping their VOICE heard!

Eight participants have been selected to join in the HFA's first Advocacy Intensives Program, scheduled for October 2-6. Visit <http://hemophiliafed.org/programs-and-services/intensives/> or email [programs@hemophilia.org](mailto:programs@hemophilia.org) for additional information on HFA's Intensives Program. 💧



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## MASS IN ACTION:

*Placing the Massachusetts Model and Healthcare Debate in a National Context*  
by Steve May, Public Policy Director, State Affairs

A universal health access plan was passed in 2006

in the state of Massachusetts. That means every Massachusetts resident has access to a health insurance policy. Bay Staters go to an online insurance marketplace where they compare privately run plans and select one as their insurance carrier. These private insurance policies are subsidized in part by the Commonwealth of Massachusetts. Failure to enroll in a plan results in a substantial income tax penalty. Mass Health, the State of Massachusetts' managed Medicaid plan was opened to low income beneficiaries, but is managed by HMO's and insurers.

This is not a single payer system like social security or Medicaid that administers government healthcare benefits for the people of the state. Massachusetts is still a guaranteed issue state. That means every resident is entitled to an insurance plan. It does not however, guarantee a particularly good one. Income is a consideration in issuing policies but policies for the vast majority of residents are quite expensive. From a public policy standpoint there is the question of duality between actual positive health outcomes and the responsibility of a corporation to make a profit for its shareholders.

Speaking as a resident of Massachusetts, it seems that Mass Health has done a remarkable job of providing care to folks who had no options for healthcare. If you were uninsured before the law took effect, government has effectively incentivized through a series of carrots and sticks near universal compliance. Chronic illness has been addressed less well. Particular of note are the continued caps on health insurance policies.

Progress does not come cheaply. Creating the health infrastructure that serves this small, resource intense community is sizable. The clotting factor patient use to help stop bleeds, ancillaries associated with treatment

like, gauze needles, alcohol wipes can cost an average patient upwards of \$250,000 per year. Enormous resources are expended to bring factor meds to market that people with hemophilia rely on.

The course of necessary treatment for a patient with von Willebrand's Disease is materially different from that for traditional Hemophilia. Massachusetts has taken the first step toward limiting the range of access to product in recent years by imposing a preferred drug list. There are no generic versions of factor available to community members in the United States at this time. Hemophilia however should be thought of as not one disease, but a series of inter-related bleeding disorders requiring multiple products. The infrastructure described above makes it possible for community members to live routine lives; work, raise families and pay taxes. If this system is compromised, our neighbors will go from paying taxes to drawing social security and Medicaid benefits.

Healthcare reform promises to challenge this community and our larger country in ways inconceivable to us, even five years ago. It will redefine how we access care, what care looks like, our relationship with medical providers, and our relationship with government. I have learned there is no perfect system. But it appears, based on the Massachusetts experience, that people with chronic illness generally were an afterthought. For that reason alone our country must consider a wider range of solutions to secure healthcare for all of us.

### *About the author:*

Steve May is the Hemophilia Federation of America's Public Policy Director, State Affairs. Steve is based near Boston, MA and works remotely in statehouses around the country. Since joining HFA, Steve has been focused on serving HFA member organizations, and addressing developing political problems at the local and state level. Steve leads HFA's efforts in developing and maintaining relationships with the State Legislators and officials at

*Continued on Page 11*

## HFA NATIONAL NOTES


by Kisa Carter, HFA Public Policy Director, Federal Affairs



### PLASMA USERS COALITION (PUC) DEVELOPS HEALTH CARE REFORM PRINCIPLES

HFA has joined forces with several national patient organizations to form the Plasma Users Coalition.

The group was created to address the unique needs of users of “plasma protein therapies” (plasma-derived and recombinant therapies). To highlight the uniqueness of PUC’s membership, the group developed health care reform general principles for rare diseases. HFA is a member of the PUC and fully supports the elements outlined in Principles for Health Care Reform and the Rare Disease Community. To read the principles, please visit:

<http://hemophiliafed.org/2009/08/06/plasma-users-coalition-puc-develops-health-care-reform-principles/> 

### CONSUMERS IN ACTION: AMY’S TOWN HALL MEETING EXPERIENCE


by Amy Madera

The tumultuous town-hall meetings depicted by the media did not keep an Iowan mom from attending two meetings held by Senator Chuck Grassley, Ranking Member of the Senate Finance Committee. After driving over 130 miles to attend two meetings, one in Afton, IA and the other in Panora, IA, Amy Maeder, a mom with two severe Factor IX deficient boys, described the meetings



as civil and well organized and felt the prominent Senator allowed everyone to share their concerns and ask questions. Disruptions were limited at both meetings, with one person being escorted from the meeting in Afton.

Amy arrived at both meetings well prepared to address the concerns of the hemophilia and rare disease communities. Feeling supercharged and excited, Amy had the opportunity to ask three questions, two of which resulted in brief, but detailed answers. She was elated to find out the Senator expressed concern for capping out-of-pocket cost; however, his response, a 13 percent cap left her with a bittersweet feeling of whether the proposed cap is appropriate for high cost, rare chronic disorders. She was equally disappointed to discover that the Senator could not pinpoint exactly when the Senate Finance Committee would introduce a health care reform bill. Despite the vague response, Amy articulated her preference to the Senator as being “a bill that can be read and easily understood by everybody.” She placed emphasis on rare, chronic disorders during the question and answer session, but also felt it was necessary to share her personal story. Understanding the meetings would be well attended by hundreds of constituents, Amy brought her type-written personal story. She had the opportunity to pass it to one of the Senator’s legislative aides who assured her it would be given to the Senator. At the end of a long journey, Amy felt the trip to both meetings was worthwhile. She encourages everyone to take an opportunity to share their story. Members of Congress really do listen!

Sign up to share your VOICE! Please visit <http://hemophiliafed.org/advocacy/voices-campaign/> for more information. 



## IN MEMORIAM

The HFA extends sincere condolences to all family members and friends of Joyce Anne Taylor Donlan. Joyce was born on December 27, 1934 and passed away on July 10, 2009. Joyce taught for 20 years at the University of Nebraska-Lincoln in Human Development and the Family, and at Ruth Staples Child Development Lab, and retired from Bryan Hospital Child Development Center. She was a Charter


Member and Past Board Member of the Nebraska Chapter of the NHF and Past Board Member of the Hemophilia Federation of America and numerous other local organizations. Joyce, a dedicated volunteer of the HFA Annual Symposium was fondly referred to as Granny Good Food. Joyce served as the HFA Symposium Children's Committee Co-Chair for numerous years. Her true love of children was evident each year as she donned her chef hat and taught them the value of creating and eating nutritious snacks. She had the uncanny ability to connect with each child, she brought out the best in them and she will be missed tremendously. The HFA appreciates and honors her service to the organization and the community.

## IN MEMORIAM

The HFA extends condolences to the family, friends and colleagues of Julie Frankel who passed away on July 17, 2009. Julie was the Program Coordinator/ Assistant Executive Director of the Hemophilia Association of New Jersey (HANJ). In her role at HANJ, Julie worked diligently on political and insurance issues, as well as constantly advocating to improve the circumstances for all people with bleeding disorders in New Jersey. She worked side by side with the Elena Bostick, Executive Director, HANJ, in securing state monies to subsidize health insurance policies, and negotiated an exception to the statute of limitations after tainted blood products made community members ill so they could bring legal actions when that option was inconceivable to community members elsewhere. Julie made a sustained contribution to the bleeding disorders community in Jersey and nationally. Her work was appreciated and she will be both remembered and missed.

## MASS IN ACTION

*Continued from Page 9*

State Administrative Agencies, like the state department of insurance or public health. Steve graduated with a Masters degrees in Political Science from the University of Rhode Island and Social Work from the University of Vermont. Immediately before coming to HFA, Steve worked for the New England Hemophilia Association in Dedham, MA. Prior to that, Steve was a mental health provider in Vermont working primarily with substance abuse. Steve has run several statewide political campaigns and was the Former Vice President of the Champlain Valley Central Labor Council. 

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In order for the HFA page to get its very own URL, we need to have at least 1,000 fans! We encourage you to suggest to your friends to be a fan of the official HFA page on Facebook. It is as easy as going to the HFA page from your personal page and clicking "suggest friends." Select your friends and send the requests!

To find us on Twitter visit: <http://twitter.com/hemophiliated>

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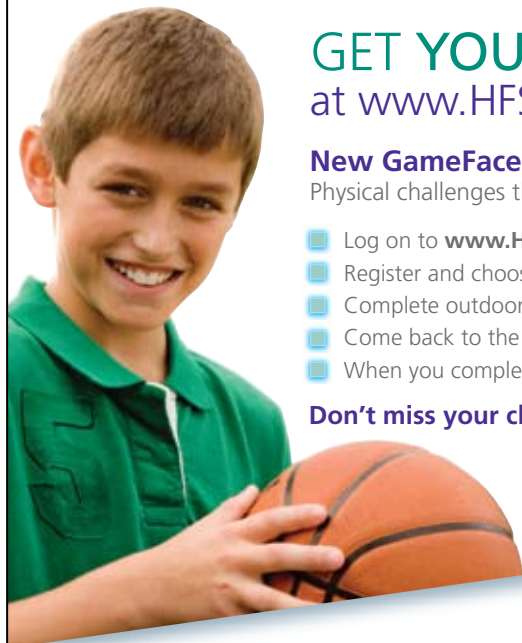
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**New GameFaces™ from Helixate® FS—**  
Physical challenges that help you get active

- Log on to [www.HFSGameFaces.com](http://www.HFSGameFaces.com)
- Register and choose your GameFaces™ character
- Complete outdoor and indoor physical challenges—even Wii™ games—on your own
- Come back to the site to log your physical activity progress
- When you complete a challenge, you will be entered in a sweepstakes to win a Wii™

**Don't miss your chance to win...register now at [www.HFSGameFaces.com](http://www.HFSGameFaces.com)!**

■ Register for a chance to win a Nintendo® Wii™!



Helixate® FS is manufactured by Bayer HealthCare LLC for CSL Behring.

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Antihemophilic Factor (Recombinant)

Formulated with Sucrose  
**Take Life On™**



When you need us,  
Baxter will be there.

### Through Therapies

Providing innovative recombinant and plasma-derived factor and inhibitor management therapies highlights our commitment to choice and illuminates our investment in research and development.

### Through Participation

In listening to your request for education programs, we've developed a range of initiatives for patients, families, physicians, and nurses. Baxter is also committed to supporting local and national organizations, community events, and volunteering.

### Through Progress

Looking to the future, Baxter is dedicated to improving current therapies. We will continue to invest in research to offer new and better ways to manage hemophilia A—innovations inspired by listening to you.

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PATIENT  
RESOURCES



COMMUNITY  
PROGRAMS



COMMUNITY  
CONNECTIONS



INSURANCE  
& ADVOCACY



CLINICAL  
INITIATIVES

**Baxter**

# COMMUNITY SPOTLIGHT

Congratulations to the Virginia Hemophilia Foundation for hosting 60 adults and 40 children at its 2009 Annual State Meeting held in Glen Allen, VA on June 20, 2009. Participants enjoyed a variety of presentations from grassroots advocacy to health and wellness.



*Marijane Valentino, Al Valentino (Board Member), Kelly Waters, Executive Director*



*VA Chapter children enjoying art activity!*

Congratulations to the Lone Star Chapter of the NHF for hosting their first South Texas Bleeding Disorders meeting August 14-16, 2009 in San Antonio, Texas. The conference had an amazing 475 in attendance. Presentations covered topics ranging from health insurance to genetics and a wide variety of breakouts.



*South Texas Bleeding Disorder General Session*



**Novo Nordisk is helping people with inhibitors realize their dreams.**

**changing possibilities in hemophilia™**

Novo Nordisk offers financial, educational, and community support programs to people with hemophilia A or B with inhibitors so they can live more normal lives.

Find out more about how you can change your possibilities by calling **1-877-668-6777** today!

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# VOICES CAMPAIGN APPEAL

## What is the Voices Campaign?

The Voices Campaign is the HFA's grassroots Advocacy initiative to drive awareness and communicate the bleeding disorder community's health issues to the public and legislatures by way of personal stories. HFA utilizes these personal stories in two ways.

1. Educate the public on the health issues, challenges, and concerns associated with living with a bleeding disorder.
2. Provide crucial "personal touches" for legislatures and federal agencies when they debate issues that impact our community.

"We know the statistics, but it is the real live stories of families across this country that motivates us by putting a face on the challenge of affording quality health insurance..." U.S. Senator Blanche Lincoln (D-AR)

What is involved? Because your VOICE is an important part of the debate surrounding healthcare reform, we

want to know YOUR stories and concerns on the issues that impact you and the community. Lifetime caps on insurance, access to public and private health insurance, availability of factor product, or the overall need for healthcare reform are just a few examples.

After recording your story, we are determined to help make YOUR story a part of healthcare reform as it relates to the bleeding disorder community.

How can I be a part of the campaign and have my Voice Heard?

1. Email [info@hemophiliafed.org](mailto:info@hemophiliafed.org) to indicate your interest
2. We will contact you to collect your story and discuss how it may be distributed
3. Be sure to also sign-up for the Legislative Action Center at [www.hemophiliafed.org](http://www.hemophiliafed.org) to receive updates about upcoming legislation that impacts our community. 

## BECOME A SUPPORTER OF THE HFA TODAY!

Membership Levels: (circle one) \$25 (Individual) \$50 (Family) \$100 (Industry Professional)  
\$500 (Corporate) Other \$ \_\_\_\_\_

Please check one:  2009 Membership  Automatically Renew Membership (annual)

Name \_\_\_\_\_ Address \_\_\_\_\_ City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_ Telephone \_\_\_\_\_ E-Mail \_\_\_\_\_

I would like to pay for my membership by:

Check: Please make check payable to HFA and mail this page to:

Hemophilia Federation of America | 210 7th St. SE Suite 200B | Washington, DC 20003

Credit Card: Check One Visa \_\_\_\_\_ MasterCard \_\_\_\_\_ American Express \_\_\_\_\_ Discover \_\_\_\_\_

Card Number \_\_\_\_\_ Expiration Date \_\_\_\_\_

Print Name on Card \_\_\_\_\_ Signature \_\_\_\_\_ Security Code \_\_\_\_\_

Signature \_\_\_\_\_

Membership Forms and Donation Opportunities available at [www.hemophiliafed.org](http://www.hemophiliafed.org)  
or contact HFA at 800-230-9797

# HEMOPHILIA FEDERATION OF AMERICA

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HFA gratefully acknowledges the generosity of all valued donors on the website at [www.hemophiliafed.org](http://www.hemophiliafed.org).



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