

## INSIDE

HFA'S PRESIDENTS LETTER..... 1 & 2

HFA WELCOMES NEW STAFF .....3

HFA WELCOMES TWO NEW BLOOD BROTHERHOOD SITES ..... 4

HIGHLIGHTS Dads in Action ..... 5 & 9

HELPING HANDS..... 6

RECOGNIZING PARTNERSHIPS & PROGRESS ..... 7

FIT FACTOR COMMUNITY HIGHLIGHT..... 8 & 9

SCHOLARSHIP WINNERS ... 10 & 11

HFA NATIONAL NOTES ..... 12 & 13

HFA VOICES COORDINATOR HEADS TO CAMP ..... 18 & 19

MEMBER ORGANIZATION HIGHLIGHT Challenge Discovery Day.... 14 & 19

COMMUNITY NEWS ..... 15

COMMUNITY ADVOCATE Nick Cady in Action ..... 16 & 17

CORPORATE SPONSORS ..... 19

BECOME A SUPPORTER ..... 20 (Back cover)

## *A Visit From*

## PRESIDENT OBAMA



*Paul & Francis Brayshaw with President Obama*

*By Paul Bradshaw*

Dear Community,

I hope this finds you well and enjoying the cool months of fall. It is hard to believe it is already September, but after many exciting events, positive experiences and educational opportunities throughout the summer I am reminded of the importance of staying engaged in all things hemophilia.

In late July, I attended the 2nd Annual American Thrombosis and Hemostasis Network (ATHN) Data Summit in Chicago, Illinois. This conference provided several new insights regarding the current state of ATHN and its

future strategic direction. As a member of the ATHN Data Privacy Committee I participated in a preconference committee meeting and other sessions involving data use, security, and privacy.

With healthcare reform, advances in healthcare delivery, and spiraling health costs, healthcare delivery will be drastically impacted by quality data. The data collection, storage, accessibility, security, and ownership are critical to the lives and livelihoods

*Continued on page 2*

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## MISSION

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

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## PRESIDENT'S REPORT



of people with bleeding disorders. Each of these components will require numerous safeguards to ensure quality data is collected and properly safeguarded.

Participating in the ATHN Data Summit provided fresh reassurance this effort involves good intentions. However, this sentiment is not shared universally among end users and others, and it will be critically important for ATHN to continue to engage and involve end users in all roles of study design, clinical interventions and project implementation. While it may be premature to exclude a type of researcher or study design, ATHN must continue to build consensus among all stakeholders to improve transparency, and ensure that the data accurately represents the end-user community.

Last, but certainly not least important, Wednesday, September 22nd was an exciting day for my wife Francis and I, and a life changing week for people with bleeding disorders. The opportunity to spend some time with President Obama and to host a town hall style meeting in my backyard was an honor and the experience offered an important opportunity to share my story regarding hemophilia as it relates to the provisions of the Affordable Care Act going into effect. The significance of this law will allow all people with high costs chronic conditions some normalcy in their pursuit of optimal health and well-being. However, much work remains.

The regulatory process will define how we all access care. HFA and its members must be ready to work with state and local officials to ensure the Health Exchanges meet our unique health care needs.

Paul Brayshaw  
Board President



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Heard the buzz?

JOIN BBS FROM ACROSS THE COUNTRY

Hosted by: HFA & the Blood Brothers  
of Lone Star Chapter

When: 7:45 p.m. – 9:45 p.m.,  
Thursday, November 11, 2010

Where: New Orleans

Program will include:

- BB Rap Session
- "How to Mentor and Be Mentored",
- Intro to New Online Community Forum
- HFA's FitFactor Program

Visit <http://hemophiliafed.org/programs-and-services/blood-brotherhood/> for details.

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## HFA WELCOMES NEW STAFF IN DC



Office Coordinator, Rosalyn Pierce

Rosalyn brings enthusiasm and experience to HFA with her professional work as an office assistant with OptiMed Services in Maryland and as an intern with Discovery Creek Children's Museum. Her volunteer activities

include service with MassEquality, Audubon Society, and the Obama for America campaign. A native of Bethesda, Maryland, Rosalyn joins HFA as a recent graduate from Boston University, with a B.A. in Political Science and a minor in History. She is looking forward to working at HFA and learning more from the community members.



Program Coordinator, Lauren Neybert

Lauren recently completed her Master of Social Work, Social Justice/Social Change at The Catholic University of America in Washington, DC. Her past experiences include a variety of nonprofit and social service

activities including work with a domestic violence program, homeless women, senior citizens and children's programs. Lauren will split her responsibilities between managing our Helping Hands Program and providing support to all other HFA programs. Lauren is excited about joining HFA and looks forward to getting to know the community through our programming.



Policy Analyst, Eboni Morris

Eboni brings to the HFA seven years of experience in government affairs with a special focus on health policy issues for vulnerable populations. She comes to us from a program manager position at the National

Association of Councils on Developmental Disabilities where her responsibilities included federal legislative advocacy. She also brings experience from the National Urban League-Policy Institute where she was a Health Policy Fellow and the National Conference of State Legislatures (NCSL) - Forum for State Health Policy Leadership. She earned her Bachelor's degree in Political Science from Siena College in Loudonville, N.Y and her Master's degree in Public Policy from the University of Maryland – Baltimore County (UMBC) in Baltimore, MD. Eboni looks forward to serving the community!



HFA WELCOMES TWO NEW BLOOD BROTHERHOOD SITES

The Hemophilia Federation of America (HFA) welcomes two new Blood Brotherhood sites, Hemophilia Foundation of Northern California (HFNC) and Hemophilia Foundation of Minnesota/Dakotas (HFMD). As of July 1, these sites join nine Blood Brotherhood Sites across the country, each of which provides educational tools and resources as well as social support to the Blood Brothers in their local communities.

HFNC held their first local event on August 7, 2010 at Fisherman’s Wharf in San Francisco, CA. The Blood Brothers who attended this kickoff event learned about the importance of financial planning. “HFNC is very excited about the opportunity HFA has given us to develop a Blood Brotherhood program in Northern California. This funding will allow HFNC to reach out to our men living with hemophilia and offer them a program that truly supports them in meeting the challenges of their everyday lives as husbands, fathers and brothers,” states Merlin Wedepohl, Executive Director of HFNC.

To find out more about the Blood Brotherhood events in Northern California, visit [www.hemofoundation.org](http://www.hemofoundation.org)

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HFMD September 4th event at Target Field

The Blood Brothers of HFMD held their first meeting September 4, 2010 in Minneapolis, MN. Jim Paist, Executive Director, HFMD comments, “The HFMD is honored and excited to be selected as a new Blood Brotherhood site. We look forward to offering the broad range of Blood Brotherhood programs and services to the men in our community. Thank you, HFA, for bringing us into the Blood Brotherhood!”

Visit HFMD’s website [www.hfmd.org](http://www.hfmd.org) to learn more about upcoming Blood Brotherhood events.

Blood Brotherhood, established in 2006, offers group interaction and health information in a safe environment for older men within the bleeding disorders community. The program is supported in part through a collaborative agreement with the Centers for Disease Control (CDC). In addition to the local site meetings, HFA leads the national effort by offering interested participants a secure on-line message board and educational webinars.

Check out the **NEW** and **IMPROVED** Blood Brotherhood chat site! This popular online forum has moved to a new address. Visit <http://community.hemophiliafed.org> to register! 🩸



Brad Nolan, a Louisiana native now resides in North Carolina. Brad works for a company based out of California in sales and marketing of medical equipment. He’s also a husband and father to three children, two boys and a girl. His sons, Alex (15) and Michael (8), have severe hemophilia Factor VIII. “My wife’s uncle Edward had hemophilia. He passed away before my wife was born. My parents knew Edward growing up and their memories included Edward missing a lot of school and on crutches because of hemophilia. They were scared for my children, their grandchildren.”

Brad’s first son, Alex, was first diagnosed when he was around 8 months old. There were warning signs, and Brad freely admits that though he and his wife tried tirelessly to get medical personnel at different hospitals to test Alex for hemophilia, the tests were repeatedly denied. Brad stated, “Alex probably had spontaneous bleeds to joints, but the bleeds must have never gotten out of control.” Finally, though, when bruising started to show up on Alex’s torso, doctors tested and confirmed his diagnosis of hemophilia. It was July 24, 1995, and as Brad recalls, “Our lives changed forever.”



Brad Nolan and Family

When Alex was a baby, Brad and his wife were regulars at their local HTC. At the time, the HTC received state and federal funding however a couple of years later the state legislature began slashing budgets, and one of those budgets involved \$1.5 million in funding for the HTC. Brad was serving in a consumer seat of the Louisiana Hemophilia Advisory Committee and quickly became involved in preserving the current funding for the program; thus, he officially entered the world of advocacy!

Other advocacy work that Brad has engaged in on behalf of his sons and the hemophilia community is speaking publicly about “navigating the emergency room.” Speaking from personal experience, Brad shares his insight about getting into a room and starting treatment faster. He has shared his unique knowledge at the HFA conference and has even participated in a webinar on the subject with the Dads in Action program.

The Nolan family refrained from community activity for several years. Brad states, “We were uninvolved, due to ongoing challenges with treatment of our youngest son. His hemophilia was very difficult to manage: he never liked needles.” Michael didn’t allowed his parents to infuse him and his bleeds were so bad that he became immobile. Brad explains, “This was a very

*Continued on page 9*

**HFA**  
 Hemophilia Federation of America

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THANK YOU FOR THE OPPORTUNITY!

by Sommer Mallow

As the end of the summer draws near and grad school is on the horizon for me, I would like to take this opportunity to say thank you to the HFA community for allowing me to serve you! I would also like to say thank you to the Helping Hands committee for giving the Helping Hands program heart and soul, and to those of you who dug deep and gave donations to keep this beneficial program afloat. Thank you, I am confident that the program will continue to thrive as I pass the Helping Hands Coordinator role to Lauren Neybert. She comes to Helping Hands with a Master's Degree in Social Work as well as a sincerity and kindness that will keep Helping Hands the special program it is.

Helping Hands changes lives daily. It helps keep the air-conditioning humming during heat waves, a roof over the children's heads, a car running back and forth to doctor appointments, a wheelchair moving down the sidewalk to visit a friend, a comfortable bed to get a good night's rest, and Christmas presents under the tree. Helping Hands gives hope, and for those that

are in emergency financial situations, a little hope is often a resource Helping Hands provides to keep a person with a bleeding disorder on the path to health and happiness.

While we near 200 applications for 2010, Helping Hands continues to open doors for applicants to the many resources that the HFA community has to offer. Upon hearing about HFA's educational symposium through Helping Hands, a single mom of three children with von Willebrand disease drove her family 20 hours in a minivan to attend. A 68-year-old man became a part of a Voices video as well as HFA's Blood Brotherhood program which he heard of through Helping Hands. A 24-year-old recently referred to Helping Hands through his Social Worker also joined the Blood Brotherhood online chat site to connect with other men with hemophilia.

Through Helping Hands, hope is contagious in this community. If you have a little hope to spare in the form of a donation, we will be able to continue to provide this resourceful program to our community, offering hope to those among us who are most in need. We can receive your donation through our website [www.hemophiliafed.org](http://www.hemophiliafed.org) or in the form of a check mailed to our office at 210 7th St. SE, Suite 200B, Washington, DC 20003. ♦

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By: Kimberly Haugstad, HFA Executive Director



We hope you are enjoying this issue of Dateline Federation. This issue in particular is a collaborative effort that illustrates the hard work and actions underway by a number of those in the bleeding disorders community. This is just a small sample of the great work being done but I hope you are as inspired as I am by the efforts described!

In particular, several articles in this issue focus on blood safety and the actions and activities that have taken place in the past few months. Numerous federal legislators in the House and Senate requested the FDA relook at the current blood donation

rules that set a lifetime deferral (ban) for men who have had sex with other men (MSM). Local and national media have picked up on the story and run articles and editorials, taking views for and against changing the deferral status. In June, the Advisory Committee on Blood Safety and Availability (ACBSA) met to discuss this issue in depth, ultimately voting to recommend further research before any change is made. At present, the National Institute of Health (NIH) is actively formulating this research agenda.

In a recent staff discussion on blood safety, a long-time HFA staffer and current Director of Development, Susan Swindle reinforced a reminder of HFA's beginning and it resonates. HFA founded in 1994 as an organization devoted exclusively to the individuals and family members of those with hemophilia at a time when there was an intense passion and perception of the need for purely community representation. HFA began as an organization distinct from the medical community that serves patients and we remain independent as a community voice of the people with bleeding disorders today. However, a favorite word of HFA's current Policy Director, Kisa Carter is collaboration and 2010 has proven to be a year filled with collaborative teamwork across agencies.

It has been rewarding to support and see emerging community leaders and advocates like Nick Cady attend and speak his view at the Product Advisory Committee meetings (BPAC). It has also been inspiring to be a part of the strategic conversations, teaming HFA up with the World Hemophilia Federation (WHF), the Committee of Ten Thousand (COTT) and the National Hemophilia Foundation (NHF) to form the bleeding disorders community position around blood safety issues. Mark Skinner (WHF) and Corey Dubin (COTT) demonstrated their long-time community leadership in bringing the American Plasma Users (APLUS) Coalition together and in preparing and presenting a 20-plus page presentation that ultimately became the foundation of the research recommendation ACBSA called for in June.

It really does seem to be a time of partnerships and progress across organizations. HFA has actively supported NHF's Medical and Scientific Advisory Committee (MASAC) in its efforts to establish guidelines and treatment standards. We also deeply value the ongoing work of COTT as an ever-vigilant watchdog for blood safety for our community. It isn't the "spirit" of working together these days, it is the practice! ♦

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[www.facebook.com/  
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We are connecting people all over the world who are a part of the bleeding disorder community! Here you will find legislative updates, press releases, HFA program information and much more!

Welcome to the inaugural Fit Factor Community Highlight section. Getting fit is important to all of us and we are excited to highlight community members who are doing just that! Congratulations to Michael Forbes on his accomplishments and thank you to Jane and Michael Forbes for sharing their son's story.



Michael Forbes

## CALIFORNIA SWIMMER WITH SEVERE HEMOPHILIA PLACES FIRST IN INTERNATIONAL SWIM MEET THIS SUMMER

By Jane Forbes, R.N. and Michael Forbes, Ed.D.

Michael Forbes placed 1st and 3rd in his team relays at the North American Cup Challenge and 4th and 9th in the individual 50-meter freestyle and the 200-meter freestyle in early August, 2010. In the relay that he placed first, Michael served as the anchor, and in most exciting fashion, he moved his team from second to first place with his best swim to date [55.80 seconds in the 100 meter freestyle].

Fourteen-year-old Michael, who has severe hemophilia A and who also had a high-titre inhibitor, is now seeded 4th in California [in the 50-meter freestyle] and 5th in California [in the 100-meter freestyle] for Competitive Swimming for his age. Recently he travelled with the Southern California swim team to compete in an international competition in Santa Clara, California. He competed against teams from Canada, Mexico, and the Pacific States. This was the first time Michael competed in an international swim event, representing the United States of America. He was thrilled to be chosen for this team. It was the first time that he travelled by airplane with his new team to attend such a high-level swimming competition. It was also the first time he stayed in the dormitories of a leading California university. Overall, it was a fantastic experience for a 14-year-old boy and all of his teammates.

Michael, along with his three brothers and two sisters, started swimming about 4 years ago. Michael's three brothers, Raphael, Gabriel, and Emmanuel also have severe hemophilia A. Two of Michael's brothers and one of his sisters are swimming at the Junior Olympic level. Swimming is a non-contact sport and also low in impact. It is a highly recommended sport for children with hemophilia by hematologists and hemophilia specialists throughout the world.

Exercise builds healthy bones, muscles and joints. It also builds lean body mass, self-esteem, and self-confidence. It decreases weight, feelings of depression and anxiety, and helps to decrease the risk of spontaneous joint bleeds. Swimming is rated No. 1 for safety for children with hemophilia, and it allows many children with hemophilia to actively compete in a recognized international sport.



Studies have shown that swimming is also beneficial for children with Attention Deficit Disorder (ADD), asthma, and other medical problems. Michael Phelps and Ian Crocker, who both have ADD, benefited greatly from the therapeutic aspects of swimming. They both went on to become great Olympic champions.

Michael and his siblings train five to six times a week at the Rose Bowl Aquatics Center in Pasadena, California. This summer, Michael competed at the Junior Olympics and placed 3rd and 4th in the 50- and 100- meter freestyle. His relay team did exceptionally well - placing 2nd and 3rd - and broke two Rose Bowl Team records. He also earned two sectional times, and has been promoted to the National Team at Rose Bowl Aquatics.

Swimming is highly competitive and we do not know what Michael's swimming future will hold for him, but for now he sure is having tons of fun and lots of great experiences. ♦

Brad Nolan...Continued from page 5

difficult time for my family. We were somewhat in denial about everything, and we just wanted to be away from anything to do with the hemophilia community. Eventually, we sought out in-home care and now I'm back involved after a six-year hiatus."

While there have been many challenges for Brad as a dad of two sons with severe hemophilia he truly believes that his life has been improved by these experiences.

He is especially proud of his son Alex, now a role model for their younger son and to kids at the Paul Newman "Hole in the Wall" camp. He is also extremely proud of Michael, who has learned to not only live with his hemophilia but also to embrace it, and even love it! ♦

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## FEATURE ARTICLE SCHOLARSHIP WINNERS

### 2010 HFA SCHOLARSHIP AND GRANT WINNERS!



#### Abby Sloan

I recently graduated from Bothell High School as the Valedictorian of my senior class. While in high school, I enjoyed competing in National Science Olympiad competitions. In my freshman year, I won the national Anatomy and Physiology event. I also enjoyed contributing articles to the school paper where I served as Editor-in-Chief. In the fall, I will attend Whitman College, a small liberal arts school in Walla Walla, WA. I plan to study pre-medicine, and I ultimately hope to become a pediatric cardiologist.



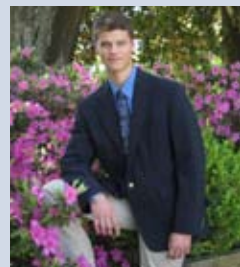
#### Flicsha Roberson

I am thirty-nine years old, have been married for nineteen years, and have three children. I am currently in the nursing program at Metropolitan Community College of Kansas City. I have von Willebrand's disease as do my children. I grew up with von Willebrand's disease but was not diagnosed until my mid-twenties. Prior to my diagnosis I was always reassured by my doctor, "Some people just bleed more than others." I know better now and know that other people, especially girls, suffer with this disease unknowingly. This is why I want to become a nurse. I have always had a strong desire to help others and now I tend to focus my help to those of the hemophilia community. Once I receive my nursing degree I hope to work within our local hemophilia treatment center. (HTC)



#### Gina Olzowski

I'm an artist and author from the Chicago suburbs. In addition to drawing cartoons for the local newspaper and creating murals out of home-made sidewalk chalk, I also wrote a book about urban sprawl and its affect on nature and community, inspired by my childhood on the edge of suburbia. The book, *Now Coming to a Town Near You*, was published through an environmental grant from The Wild Gift. This fall, with the support of an HFA educational scholarship, I will begin my MFA in Creative Writing at Chatham University, where I will continue to write about social and environmental issues.



#### Jacob Kerr

My three brothers and I are homeschooled and live in a rural town in northern Florida. My youngest brother and I are severe, Type A Hemophiliacs. I am homeschooled and graduated from high school this year while working part-time at a small-engine repair shop. My hobbies include reading, writing, hunting, fishing, and building household wood items. I have written three books, and am preparing the third one, *Man Without a Cross*, for publishing. The prospect of publishing my own book is very exciting, and I am very grateful for the Artistic Encouragement Grant that the Hemophilia Federation of America has awarded me. I have decided to publish *Man Without a Cross* through the Westbow Publishing Company, and hope that it will be a successful venture!



#### Kristina Lebron

I am 18 and currently live in Orlando, Florida with my parents and my 14-year-old brother, who has severe Hemophilia A. I love to play tennis and in my spare time I enjoy writing poetry, drawing, and reading. I am very outgoing and make friends easily. I am privileged to be a part of the bleeding disorders community, which has given me the opportunity to make lasting friendships and partake in leadership roles that have inspired me as an individual. I'm looking forward to attending University of Central Florida this fall majoring in accounting.



#### Kyle Davis

I have always felt connected to the medical community after being diagnosed with Hemophilia A at a young age. I first knew I wanted to pursue a career in medicine after spending my elementary school's 4th Grader Shadowing Day with my hematologist, Dr. Ruymann. From my experience that day, I knew that I too wanted to be a hematologist and care for patients with bleeding disorders. I recently graduated cum laude from the Ohio State University with a major in Biology and a minor in Psychology. During that time I was the president of a pre-health organization, captain of a NHF Walk team, and involved in volunteer activities through the university hospital. At the beginning of this I was accepted into medical school at the Wright State University Boonshoft School of Medicine. In August, I will begin my challenging and rewarding journey to medical school, as I work to live out my dream and become a hematologist.



#### Patricia DeRatto

I am on track to graduate in May 2011 with an associate's degree in Human Services. I will be graduating at the same time that my daughter earns her bachelor's. As she considers a post-graduate degree I will be contemplating moving forward to earn my Bachelors degree. This is something that I had never dreamed I would ever accomplish and am so happy and proud of myself for persevering. In addition to the education, the confidence I have gained from this endeavor will help me achieve any goal I set in my future.



#### Perseus Patel

My personal drive to help others combined with my academic interests in science and mathematics culminated in a pursuit of a career in hematology. I look forward to beginning my junior year at the University of California Los Angeles (UCLA) this September. I enjoy playing basketball and remain heavily involved with the Hemophilia Foundation of Northern California, my local chapter. Apart from volunteering at various fundraisers for the chapter, I am an Assistant Counselor at Camp Hemotion and will soon begin the programming internship for summer camp. I look forward to being an integral part of the bleeding disorders community for a long time and thank HFA for helping defray my college expenses so as to help achieve this goal.



#### Ryan Shorosky

My name is Ryan Shorosky, and I am 21 years of age. Currently I attend School of Visual Arts in New York City, in pursuit of a BFA in photography. I am pursuing photography not only as a career but also as a lifelong obsession in hopes of continually exploring the vast parallels of human nature. I also want to be able to wake up every single morning knowing that I am doing something I love. Besides photography, I enjoy spending time experimenting in other medias of art, riding long distances on my bike, exploring nature, and skateboarding.



#### Veronica Idoate

I'm a seventeen-year-old that has a big dream to be a film producer and look forward to attending Columbia College in Chicago. This year I take one of the most important steps to fulfill my goal of going to college. With my determination and with the help of the Sibling Continuing Education Scholarship, this very important first step will be possible.

## ON THE ROAD: DIARY OF SUMMER TRAVELS

by Kisa Carter, HFA Public Policy Director



Summer of 2010 has been eventful. The signing of Public Law 111-148 and 111-152 mixed with the extraordinary weather has made traveling

across the nation very interesting. The summer presentations kicked off in early June at the Nebraska Chapter of the NHF Educational Conference. June travels took me to the Oklahoma Hemophilia Foundation and in July, I presented at the Arizona Hemophilia Foundation.

The presentations revolved around one central topic of discussion, Health Care Reform: What the heck does that mean for me? The presentations highlighted key provisions within the new law, steps in the regulatory process, state activity and Medicaid challenges in each state.

The meetings presented an exciting opportunity for community members to learn, connect and share experiences with other people in the bleeding disorders community. Likewise, I had an opportunity to hear their questions and concerns about the new law. A few of the most common concerns shared are:

- Immediate and long-term benefits and challenges of the new law
- The new law's impact on access to treatment
- The cost of insurance coverage
- Effective date of the elimination of lifetime and annual caps
- Coverage concerns and the individual mandate

In between travel to state annual meetings, Susan Swindle and I traveled to Kentucky to exhibit at the National Conference of State Legislatures (NCSL) Legislative Summit. The NCSL is a "bipartisan organization that serves the legislators and staffs of the nation's 50 states, its commonwealths and territories". With well over 5000 members in attendance, legislators come together to attend hundreds of sessions and vote on policy positions that guide their advocacy efforts before Congress and the administration.

Although summer draws to an end, HFA's outreach to its members does not. A component of our mission is to "foster community dialogue, action, education and information services to the bleeding disorders community". As a team member, it is an honor to continue to do my part to uphold our commitment to the community through outreach and education. Look for HFA to be actively involved in the early fall meetings in New Mexico and Ohio.

To read more about the issues referenced in this article, please visit the Advocacy section of the HFA website. ♦



## SO WE PASSED THE LAW, WHAT NEXT? A SUMMARY OF THE REGULATORY PROCESS

by Kisa Carter, HFA Public Policy Director

The federal regulatory or rulemaking process, like the legislative process, can be lengthy and complicated. The rulemaking process is "the process by which federal agencies develop, amend or repeal rules". Shortly after passage of Public Law 111-148 and 111-152 (the Patient Protection and Affordable Care Act & the Health Care and Education Reconciliation Act), various federal government agencies began publishing interim final rules often referred to as regulations. Ultimately, the interim final rules will become the final rule or regulations that enforce the law authorized by the health care reform legislation. A number of federal agencies will participate in the federal regulatory/rulemaking process. These agencies include, but are not limited to:

- Office of Consumer Information and Insurance Oversight
- Centers for Medicare and Medicaid Services
- Food and Drug Administration
- Internal Revenue Service
- U.S. Department of Labor

A number of interim rules that enforce the new health law have been published. Regulations are published in the Federal Register, "the official daily publication for rules, proposed rules, and notices of Federal agencies and organizations, as well as executive orders and other presidential documents". Many of the rules are listed on the relevant agency's website.

The public has an opportunity to comment on the regulations before the regulations become final. Comments can be submitted to regulations.gov, the online source for U.S. government regulations from nearly 300 federal agencies. Regulations.gov asserts their commitment to "improving your access to and participation in the federal regulatory process". As such, the website

allows you to search for a regulation, submit comments on a regulation, and sign up for alerts about a specific regulation.

Over the summer HFA, the American Plasma Users Coalition (A-PLUS) and the National Organization for Rare Disorders (NORD) have written joint comments in response to proposed rules (interim regulations). The first set of comments, were submitted in response to the Interim Final Rules for Group Health Plans and Health Insurance Coverage Relating to Status as Grandfathered Health Plan under the Patient Protection and Affordable Care Act. The groups also submitted joint comments in response to the Interim Final Rules for Group Health Plans and Health Insurance Coverage Regarding Preexisting Condition Exclusions, Lifetime and Annual Dollar Limits on Benefits, Rescissions, and Patient Protections under the Patient Protection and Affordable Care Act.

As the interim regulations are released, HFA will continue to participate in the rulemaking process. All comments will be posted and can be read on the HFA website under the Advocacy tab. HFA encourages individuals and organizations to participate in the regulatory process. Interim regulations have been published for the Pre-Existing Condition Insurance Plan Program (temporary high risk pools) and comments have been requested for the types of standards the health insurance exchanges should be required to meet.

For more information about regulations and the regulatory process please visit the following websites:  
[www.hhs.gov/ociio/regulations/index.html](http://www.hhs.gov/ociio/regulations/index.html)  
[www.gpoaccess.gov/fr/](http://www.gpoaccess.gov/fr/)  
[www.regulations.gov](http://www.regulations.gov) ♦

*Copeland, Curtis; CRS Report for Congress: The Federal Rulemaking Process: An Overview; August 28, 2008*

CHALLENGE DISCOVERY DAY

By: Axel Freese

Usually the toughest challenge in the area of Doswell, Virginia, is to find where the line ends for the biggest Roller Coaster at Kings Dominion. Not so on April 10, 2010! On that day the challenges were of much greater significance and allowed for personal growth and improvement.

The Virginia Hemophilia Foundation (VHF) in conjunction with Factor Support Network Pharmacy (FSN) brought a diverse and fun group together to go through the Challenge Discovery Program (CDP), just outside the Kings Dominion park boundaries. The day dawned cool and bright. As the day progressed, the sun provided a dappled



VHF Challenge Participants prepare for ropes course

and pretty palette along with the green of all the leaves. In no time, it was short-sleeve weather – what a setting!

Following arrival and lunch, our first Challenge was to take our group of nearly 30 and organize ourselves by birth month – January to December – all without saying a word. Next came the “Alaskan Football” challenge - it required

teamwork which helped us prepare for the challenges ahead.

Our first “Woods Challenge” required us to cross a river of molten lava and safely reach the other side. By placing boards into notches in stumps everyone had to make it across by handing the

*Continued on page 19*

UPDATE BY PAUL BRAYSHAW ON CITIZEN PETITION TO FDA SEEKS EARLY/EXPANDED ACCESS TO INVESTIGATIONAL NEW DRUGS FOR THE TREATMENT OF CHRONIC HEPATITIS C (CHC)

Earlier this year, I helped submit a “Citizen Petition” to the FDA to request access to promising new direct-acting antiviral (DAA) drugs for the treatment of chronic hepatitis C (CHC) for people with bleeding disorders. In my estimation, there may be approximately 7000 people with bleeding disorders who remain alive after injecting contaminated anti-hemophilic clotting factor prior to 1985.

While a small percentage of individuals fought off their hepatitis C early after infections, most did not; and therefore have lived with CHC at least 25 years (often with HIV coinfection). Amazingly, many of us are hanging on, but with advanced infections our medical options are poor.

The Citizen Petition proceeds from a couple of verifiable recognitions. Specifically, recent studies are now concluding that success with Standard of Care (SOC) therapy (pegylated interferon/ribavirin) drops off rapidly with advanced disease (see for example “Fibrosis Stage Predicts SVR Rate: Cirrhotics have 10% SVR rate in Chariot Study,” [www.NATAP.org](http://www.NATAP.org), dateline August 6, 2010). Furthermore, current testing is not set up to encourage testing combinations of DAA, but rather seems to be focused on short therapy with single DAAs followed by the SOC therapy that many people with bleeding disorders cannot tolerate.

With some promise we eagerly anticipate the results of two DAA combination studies which separately challenge that barrier, including:

1) The Genentech consortium test with RG7128 and RG7227 breaks the intra-company wall that has so far prevented combining ‘best of class’ DAA agents;

2) Vertex, in testing Telaprevir and VX222, has developed a concept of “Response guided” dosage that will allow continuing treatment with DAA combinations where sensitive tests indicate viral elimination.

When the FDA Citizen Petition effort began, the intent was to urgently seek good medical options, access to new drug regimes, and a somewhat normal life expectancy. To succeed, people with bleeding disorders/CHC must have a DAA combination drug regimen to beat HCV. The FDA must encourage tests as discussed (Genentech and Vertex). If the private sector does not respond to this urgent need, we call on FDA to work with the NIH to commence further studies. It is our hope that people with bleeding disorders and CHC will gain early/expanded access to promising combinations while we are still alive. I’m proud that the Hemophilia Federation of America is supporting this effort.

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VOICES CAMPAIGN APPEAL

The Voices Campaign is HFA's grassroots advocacy initiative to encourage community members to **share their story**. Your story will increase public awareness of our community's everyday healthcare challenges.

*"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)

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P.S. Don't forget to sign-up for HFA's Legislative Action Center at [www.hemophiliafed.org](http://www.hemophiliafed.org) so you receive updates about upcoming legislation that impacts our community

# COMMUNITY ADVOCATE, NICK CADY IN ACTION

By: Nick Cady

I spent some time at the Advisory Committee on Blood Safety and Availability (ACBSA) and Blood Products Advisory Committee (BPAC) meetings this summer—never heard of them? Neither had I. (Thomas Jefferson wrote that “governments are instituted among men to secure certain unalienable rights,” but did he also mention to create confusing acronyms?) These two particular committees advise the Department of Health and Human Services (HHS) and the Food and Drug Administration (FDA) on blood safety issues.

As people with hemophilia, we are among the most vulnerable to blood-borne pathogens. In 1983, at the beginning of the AIDS epidemic, the FDA began deferring men who have sex with men (MSM) from donating blood. For several years, some organizations

have been requesting this policy be overturned. When I heard the ACBSA was holding a hearing on this issue in Rockville, MD, I felt I should attend.

Like many other people with hemophilia, I contracted HIV through blood products in 1987, when I was three years old. My first reaction to the thought of lifting the ban was one of fear and anger. It seemed the FDA had forgotten about the thousands of people with bleeding disorders who had died of AIDS. It bothered me that the issue had been politicized, with several prominent senators lobbying the FDA to overturn the policy, when there was very little scientific evidence indicating that lifting the ban would not increase risks to the blood supply. But as I researched the issue, I came to a more nuanced opinion. The current policy likely excludes some candidates who are low

risk, but includes some who are higher risk. The system needs to evolve, but not before there is research to help us determine the best way to proceed.

At the ACBSA meeting in June, during a presentation made by those supporting an end to the ban, something struck me. They said that lifting the ban would increase risks, but only by a small amount. This is one of the great traps of statistics: you can focus so intently on the numbers that it is easy to forget that the “one” in “one in ten-thousand” is a real person.

As I listened to the presentation, I felt obliged to speak on behalf of all those in my community who had died, so I signed up to make a public statement at the FDA’s Blood Policy Advisory Committee meeting a month later. Standing before

the microphone, I had not felt that nervous since my wedding day, when I was terrified I would forget the vows I was reciting from memory. I did not speak much about the science behind the issue. The people I was addressing had more PhDs than I could count, and I am not an expert on biomedical statistics. But I am an expert on what happens when the system fails, and so I recounted my experience with HIV. I urged the committee to proceed cautiously and to never forget that their decisions would affect real people: brothers, mothers, and friends.

HFA Note: Following these meetings, NIH has begun to actively define research to investigate and provide the data needed to make recommendations based on science and research. There is no doubt that Nick’s voice, and the voices of other end users was heard. 💧



Nick and Taylor Cady

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## HFA VOICES COORDINATOR

# Heads to Summer Camp

### FINDING INDEPENDENCE IN THE TREES - A PEEK INSIDE A WEEK AT SUMMER CAMP

By Katie Whittle

I believe we all could use a bit more positivity in our life, a break from the daily grind and a chance to let loose. One week a summer, I pull out my grungy clothes and put away my somewhat serious self for an unforgettable week of summer camp. I just returned from Oregon's bleeding disorders camp and have a refreshed sense of why I work in this community.

A week at camp for these children with bleeding disorders is priceless. Camp is about building self-confidence and leadership skills. Every



Katie baiting the hooks for campers!

time a camper infuses himself/herself for the first time, an excited announcement is broadcast through camp's radios. These campers receive a Big Stick Award—a celebration of their

achievement and their big step toward independence. Camp provides an environment where kids can try new things beyond their comfort zone, without the threat of failing.

I watched my campers grow during the short time at camp. At the beginning of the week, the campers arrive timid and unsure of what lies ahead, but by week's end they all come out of their shells and can be seen swinging tree to tree on the camp's elaborate high ropes course.

On the last night of camp the oldest girl campers had a special get-together at the campfire to reflect on their week. It was at that gathering I realized what makes camp so special. One 15-year-old said it perfectly; "I had the opportunity to try things here

at camp that would not be possible in the 'real' world." With the support of a strong medical staff, the children's bleeding disorders do not define them and their limits, but rather, it helps them fit in.

Describing camp in a few paragraphs is close to impossible; I hope every child with a bleeding disorder has the opportunity to attend a summer camp with other kids who manage the same obstacles. I am grateful I had the chance to witness the growth and joy experienced by all at camp. Here's to 51 more weeks until we can do it all over again! ♦



Kelle Carthey and Katie getting in touch with nature!



telephone pole. At the top was a small platform that would hold 4 people. Following an elaborate ceremony groups then jumped.

The day was an unqualified success and no one wanted to leave! Everyone attempted to get 'outside the comfort zone', and we all tried new experiences at Challenge Discovery.

Challenge Discovery, FSN and VHF gave our group a terrific opportunity to meet and get to know a wider group of people in our community. This day and these challenges made us all better acquainted, and hopefully better equipped to face our own challenges with a better understanding of how to approach and overcome them.

An additional bonus was that the Hemophilia Federation of America (HFA) brought a film crew to Challenge Discovery. The video effort is a part of the "Fit Factor" program which launched in April, 2010. The program tries to encourage our community to get out and be active, and to try things (safely) that you might not have ever considered doing before. The film crew was able to get shots of everyone participating in all the challenges I have described, and there were even a few short interviews with a few members of the team at the conclusion of the day. Look for the "Fit Factor" videos to become available soon. ♦



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Challenge Discovery Day...Continued from page 14

boards back and forth – all while balancing on precarious perches. Our take-away lesson from this challenge

was one of teamwork, perseverance, and working together to find a model that worked to allow us all to make it to safety. All great life lessons, and all are something we can use in our daily lives.

The next challenge had us balance the entire group on the pallet, while NOT letting it tip or touch. After nearly 20 minutes loading the pallet with team members, we had 4 more people to get on the pallet, and one by one they joined the rest of the team. We did it! In celebration, we sang a rousing couple of verses of "Row, Row, Row your boat"! Lots of laughter and high fives all around! The lesson we all took away from this exercise was that simply not giving up on a challenge, even if there are setbacks, is the best way to overcome it. Also listening and trying others ideas/solutions often is key to building a team. In fact, the CD team said they had never seen the solution we came up with work – but we made it happen! Remember, our community RULES!

Our last challenge was a safe and yet exciting climbing adventure that takes participants to the top of a 35-foot-tall

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