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
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 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 end-user community.

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 normalcy in their pursuit of optimal health and well-being. However, much work remains.

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To find us on Twitter visit: http://twitter.com/hemophiliafed
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 joined 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.

HFA AWARDED CDC COOPERATIVE AGREEMENT FOR BLOOD BROTHERHOOD PROGRAM

The Hemophilia Federation of America (HFA) welcomes a collaborative agreement with the Centers for Disease Control (CDC). In addition to the local site meetings, CDC will allow HFA to reach out to our men living with hemophilia and brothers, “states Merlin Wedepohl, Executive Director of HFNC.

The Blood Brothers of HFMD held their first meeting September 4, 2010 in Minneapolis, MN. Jim Paisit, 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 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 online 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.

HFA Programs

Dads in Action

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.”

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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 allow his parents to infuse him and his bleeds were so bad that he became immobile. Brad explains, “This was a very...
Hemophilia Health Services
...for the human factor*

BEYOND PHARMACY SERVICES.
We believe pharmacy services reach beyond our ability to accurately fill prescriptions. That's why we provide dedicated care teams to help you manage your therapy from the time medication arrives on your doorstep.

Our registered nurses can walk you through the infusion process, including how to self-infuse, so you can become empowered in your care.

A personal touch from people who know bleeding disorders.

CONNECT WITH HFA ON FACEBOOK

www.facebook.com/hemophiliafed.org
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!

1 800 800-6606

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.

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 or in the form of a check mailed to our office at 210 7th St. SE, Suite 2008, Washington, DC 20003.

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.

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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 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.

By: Kimberly Haugstad, HFA Executive Director

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 (PAC). 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!

* Hemophilia Health Services

Hemophilia Foundation

Recognizing Partnerships & Progress

By: Kimberly Haugstad, HFA Executive Director

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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 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.

Studie$s hav$e sho$n th$at swimmin$ is als$o ben ficai$ for c,hildren w$ith Atten$ion Deficit Disorder (ADD), asthma, and othe$ medi$cal probl$ems. Michael Phelps and Ian Cracker, who both hav$e 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.

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.

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

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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! 🌟
**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.

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**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.

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**Mrs. 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 the local hemophilia treatment center. (HTC) 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)

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**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 parttime 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.

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**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.

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**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.

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**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 mediums of art, riding long distances on my bike, exploring nature, and skateboarding.

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**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.
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 Regarding Pre-Existing Condition Exclusions, Lifetime and Annual Dollar Limits on Benefits, Rescissions, and Patient Protections 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 Pre-Existing 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/oci/_regs/index.html
- www.apaaccess.gov/fr/
- www.regulations.gov


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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.
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 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

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Voice 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.

“While we know the statistics, but it is the real life 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 so you receive updates about upcoming legislation that impacts our community.
By: Nick Cady

I spent some time at the Advisory Committee on Blood Safety and Availability (ACBSA) and Blood Products Advisory Committee (BRAC) meetings this summer—never heard of them? Neither had I. (Thomas Jefferson wrote this summer—never heard of them?"

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. And when there was very little scientific evidence indicating that lifting the ban would not 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.

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Visit www.advate.com for more information.
**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 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 I would 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.

For more information, please visit ChangingPossibilities-US.com.

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