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Kansas City



HERE WE COME!

If you haven't been to Kansas City, you are in for a surprise! The area is filled with a wealth of attractions in every direction to include beautiful parks, fantastic architecture and more than 200 fountains. The city's central U.S. location makes either air or car travel easy; and reasonable prices make education and fun affordable.

to Crown Center, featuring Coterie Children's Theatre, Kaleidoscope, and the Hallmark Visitors Center.

The conference offers presentations and interactive sessions on legislative and social advocacy for adults, and entertaining, age-appropriate programs for children and teens.

HFA will host its community-centered educational event at the **Westin Crown Center, April 23-24, 2010.** The hotel is directly connected

We invite YOU to pack your bags and join the bleeding disorders community as we discover something unique and unexpected in Kansas City, Missouri! ❄



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EXECUTIVE'S REPORT

By Kimberly Haugstad

Can 2009 already be at an end? My first full year as your Executive Director at the HFA has absolutely flown by! On a thoughtful note, the end of the year is often a time of reflection for me and I've been asking myself many questions. Did we meet our mission at HFA this year? Did I meet my personal goals? Did you?

I hope you did and we can report that HFA stretched and grew this year! We've expanded our services and connected with more individuals than ever. The community-based, grassroots organization founded in 1994 with a "family" feel is still here and our family is growing.

Do we have work to do? Absolutely! Are we continually looking to improve? You bet! Can we do it alone? No way! Our biggest avenue of success is with the involvement of you, our family.

I was inspired recently at a national meeting when I ran into a mom I met several years ago. We had spent an hour or so communicating as new parents, admiring our babies and trading homemade family business cards. Afterwards we returned home with great intentions of keeping in touch with each other, but neither of us did and years went by.

This mom made my heart smile when she said she'd run across my name in the HFA newsletter a while ago and she watches out for things we are doing now. Honored, I had to step back and say, "Wow". She said she'd keep reading and we laughed about not following up before. However, the thought sticks with me. Why didn't we stay connected?

Roads are paved with good intentions and I'd like to encourage each of you to be accountable for a specific goal. Symposium is coming up in a few months and this issue is filled with information you need to get you and your family there. If not Symposium, try this at a local chapter meeting in your state. While there, I challenge you to follow through in making three connections and make them last.

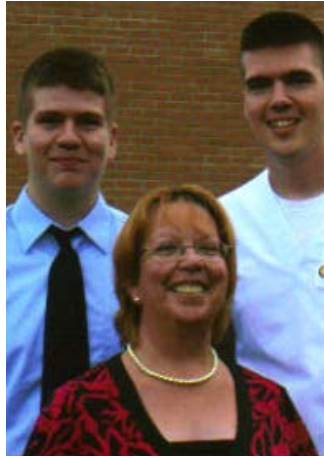
I ask you to commit yourself to follow up with each of them when you get home at least three times and see what magic happens when you add to the HFA family and support each other. Email, phone, letters, Facebook... it doesn't matter. Just Do It!

I look forward to seeing you at Symposium or beyond in 2010!
Happy holidays, ❄️

Kimberly H. Haugstad



Conventions and annual meetings are always filled with wonderful educational sessions and a variety of learning and networking opportunities, but how often do we actually "pursue" what we learned? I attended my first HFA Symposium this past March, and it turned out to be the best meeting I have ever attended. I took the information presented, followed the resources given, and managed to obtain my oldest son Joshua the tools he needed to more accurately perform his duties as a (new graduate) nurse in a busy emergency room. Joshua, who along with his younger brother Thomas, has Hemophilia B, was plagued in his childhood by recurring ear infections. Numerous ear tube placements, followed by several ear reconstruction surgeries related to an insufficient eustachian tube, resulted in an overall hearing loss. Because of the hemophilia, his ENT suggested hearing aids; however, devices such as those are not only costly, but are rarely (if ever) covered under one's health insurance plan. I tried to contest the insurance company's rules that hearing aids would not be covered. Joshua's physicians (ENT and Hematology) wrote letters stating that hearing aids would be beneficial, less costly in the long run, and less invasive to the patient than surgery, but the insurance company held steadfast to its decision. I was at a standstill...Joshua would



By Pam Williams

be graduating with his nursing degree soon, and he needed a way to better his hearing.

Enter Jeff Hughes, Coordinator of Training and Professional Development for Vocational Rehabilitative Services for the state of Indiana. Jeff's discussion about vocational rehabilitative services and the processes necessary to obtain those services made me realize that perhaps this was where I needed to go to get Joshua the help he needed. Jeff told me that hearing aids were probably the easiest benefit to obtain, and often, the Bureau would cover the entire cost of them. I was armed and ready now to seek out the Bureau. I returned home to Ohio, and while recuperating from surgery, I contacted the Bureau of Vocational Rehabilitation in my county. I explained what Joshua needed, gave a brief explanation of hemophilia, and was given an appointment time for Joshua to meet with the counselor. In the meantime, I had to contact Joshua's hematologist and obtain a letter from him detailing

hemophilia and what hemophilia meant to Joshua. I also had to obtain a letter from his ENT stating that hearing aids would benefit Joshua a great deal, and that surgery should only be considered as a last resort for someone like him.

Joshua met with the counselor a month later, and was sent home with paperwork and an assignment to obtain further information before the next meeting: tax forms for myself and him, a copy of the denial letter from the insurance company, a hearing test and audiologist's recommendation for hearing aids, and any literature which would support that hemophilia would limit him in some activities (i.e., certain sports, etc.) for the rest of his life, thus documenting his "disability." Plus, because the audiologist recommended that Joshua also obtain a specialized sound-magnifying stethoscope to adequately perform his duties as a nurse, we were required to present the counselor with prices of stethoscopes normally purchased by nurses. At his final meeting with the counselor, he was granted the specialized stethoscope (fully paid), and hearing aids that the Bureau paid all but \$1000. This was great news, and although the counselor said she would have liked to have been able to offer him everything with no outside costs, their funding was limited. Joshua has had a difficult time adjusting to the hearing aids... all of a sudden he

Continued on Page 12



Hemophilia Federation of America (HFA) has been awarded funding for a cooperative agreement from the Centers for Disease Control and Prevention (CDC). The award supports a program aimed at providing social support, health information and skills to improve the health of older men with hemophilia and von Willebrand disease.

HFA launched the program in 2006 and was awarded its first CDC cooperative agreement in support of the Blood Brotherhood Program in September of 2007. The program expanded by two additional sites in the initial two-year funding cycle to include a total of eight sites across the United States. It seeks to provide fourteen sites by 2014.

Blood Brotherhood activities occur via multiple program and communications tools. A variety of activities are offered consisting of webinars, an online chat site <http://hemophiliated.net/hfabb/>, online podcasts, exercise programs and monthly face-to-face sessions occurring at HFA member organizations.

To learn more about activities of the Blood Brotherhood Program, check our website at www.hemophiliated.org/programs-and-services/blood-brotherhood/

HFA BLOOD BROTHERHOOD PROGRAM POSTER ABSTRACT RECOGNIZED AT NHF



Kudos to Axel Freese, Online Coordinator and Michelle Burg, Program Director, who both lead HFA's Blood Brotherhood Program across the country!

Michelle Burg at NHF Poster Reception

Their hard work and the work of 8 local Blood Brotherhood sites was recognized at the NHF's Research Poster Reception on October 30, 2009 during the Annual Conference. The poster abstract highlights the impact of peer support on the overall quality of life for aging adult men with hemophilia. To view the poster go to HFA's website at <http://hemophiliated.org/2009/11/06/hfa-poster-abstract-recognized-at-nhf-research-posters-reception/>

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Hemophilia Federation of America
FOCUS ON THE FEMININE™

LENDING A HELPING HAND

A couple of youngsters from El Paso, Texas have warm, cozy beds to sleep on this holiday season thanks to the Helping Hands program. Their mom applied for assistance after experiencing some personal and financial difficulties that resulted in a move. The move left four-year-old Nathan and six-year-old Isabella without beds to sleep in. "The children love their new beds," comments Mom.

Over 200 families like this one have received assistance from the HFA Helping Hands program in 2009. Many of our community members are in need this holiday season. You can make a difference by donating to the Helping Hands program at <http://hemophiliafed.org/programs-and-services/helping-hands/>. ♦



THE HEMOPHILIA FEDERATION OF AMERICA (HFA) CONGRATULATES THE COMMITTEE OF TEN THOUSAND (COTT) FOR A TERRIFIC TWENTIETH-ANNIVERSARY CELEBRATION AND SURVIVOR REUNION!

The HFA provided 33 travel scholarships for members of the Blood Brotherhood Program to attend the celebration held at the Liaison Hotel in Washington, DC on October 2-3, 2009. The HFA is grateful to Baxter and CSL Behring for offering support to cover the cost of the travel scholarships. Check out COTT's recent post about the event at www.cott1.org. ♦

HFA AWARDED CDC COOPERATIVE AGREEMENT FOR FIT FACTOR PROGRAM

Hemophilia Federation of America (HFA) has been awarded a multi-year cooperative agreement from the Centers for Disease Control and Prevention (CDC). The award supports a program aimed at promoting physical activity and maintaining a healthy weight in individuals with hemophilia.

Proper nutrition, combined with safe and effective exercise, is especially important to facilitate good health in people with hemophilia. The program, Fit Factor: Strength, Flexibility and Wellness, offers services designed to improve health, fitness, and quality of life through regular physical activity and proper nutrition. The program will offer video podcasts, support in tracking physical activity, and dietary meal plans based on age, weight and medical complications secondary to hemophilia for those unable to afford health club memberships or have personal or travel constraints due to physical limitations or rural locations. ♦

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SINGLE ADULT/FAMILY REGISTRATION

Hemophilia Federation of America
Annual Meeting and Symposium
The Westin Crown Center - Kansas City, MO
April 23-24, 2010



To Register: **(Registration Deadline - April 9th, 2010.)**
Mail: Hemophilia Federation of America 210 7th Street SE Ste 200B, Washington, DC 20003
Fax: 202.675.6983 Questions call 1.800.230.9797 or 202.675.6984

To register children 18 and under, complete a **SEPARATE** Child/Teen registration for for **each** child you have completed **THIS** form. Feel free to duplicate any form. *Young adults (ages 18-21) living at home with parent(s) may be included as part of the family registration.*

Section 1: Payment Information

Payment information must be received before we can process your registration.

Check the registration method: _____ \$25 Individual _____ \$50 Family (Parents & Children)

Payment Method: _____ Check _____ Money Order _____ Credit Card (VISA, MC, AMEX, DISCOVER)

Credit Card Number _____ Security Code _____ Expiration Date _____
(Visa/MC on back, AMEX on front)

Name on Credit Card _____ Signature _____

Other Payment Arrangements (Explain): _____

Section 2: Information (please print neatly, or type.)

Section 2: Information

Your Name: _____
(Last Name, First Name, MI)

Address: _____

City: _____ State _____ Zip: _____

(Please list at least one contact phone number below.)

Home Phone: () _____

Work Phone: () _____

Cell Phone: () _____

E-mail Address: _____

Relation to Hemophilia/Other Bleeding Disorder (Circle)

Factor VIII | Factor IX | other Factor _____

vonWillebrand's | Family Member | Friend of Family

Carrier | Inhibitor | Other _____

Breakout Session Choice for Saturday, April 24

Please Choose one below.

HFA Dads in Action _____

HFA Focus on the Feminine _____

HFA Blood Brotherhood Session _____

Spouses Name: _____
(Last Name, First Name, MI)

Work Phone: () _____

Cell Phone: () _____

E-mail Address: _____

Relation to Hemophilia/Other Bleeding Disorder (Circle)

Factor VIII | Factor IX | other Factor _____

vonWillebrand's | Family Member | Friend of Family

Carrier | Inhibitor | Other _____

Breakout Session Choice for Saturday, April 24

Please Choose one below.

HFA Dads in Action _____

HFA Focus on the Feminine _____

HFA Blood Brotherhood Session _____

Do you authorize the use of photographs or videos for HFA use only? _____ Yes _____ No

Are you registering any children/teens? _____ Yes _____ No (If yes, please list below.) You will need to complete a separate youth/young adult for each, and send all with this form.

Children/Teen:



(Name and date of birth for each child list above) (Must fill out separate child/teen form for each child)



CHILD/TEEN REGISTRATION
Hemophilia Federation of America
Annual Meeting and Symposium
The Westin Crown Center - Kansas City, MO
April 23-24, 2010



To attend Symposium 2010, all individuals under age 18 MUST be accompanied by a responsible adult.
To Register: **(Registration Deadline - April 9th, 2010.)**
Mail: Hemophilia Federation of America 210 7th Street SE Ste 200B, Washington, DC 20003
Fax: 202.675.6983 Questions call 1.800.230.9797 or 202.675.6984

This registration form is intended for children and teens living at home with parent(s) / guardian(s). It must accompany an Adult Registration form.

Please complete a form for each child attending.

Indicate the type of registration below.

____ Child (infant - 2 years) ____ Child (3 - 4 years) ____ Child (5 - 8 years)
____ Child (9 - 12 years) ____ Teen (13 - 18 years)

Section 1: ALL REGISTRANTS

Parents Legal Guardian:

Address: _____

City: _____ State _____ Zip: _____

Cell Phone: () _____ Home Phone: _____ Pager _____

Child's Last Name _____ First Name _____ Nickname _____

Date of Birth (required) _____ Age _____ Male ____ Female ____

Child's Relation to Hemophilia/Other Bleeding Disorder (Circle)

Factor VIII | Factor IX | other Factor _____

vonWillebrand's | Family Member | Friend of Family

Carrier | Inhibitor | Other _____

***Please be advised that some activities planned for Friday & Saturday, April 23 & 24th for both Children's and Teen Programs may take place offsite. Do you grant permission for the child in your care to go on a chaperoned fieldtrip? (Please circle your choice) YES NO

Please list ALL medical conditions, and include ALL medications (including FACTOR), as well as any other information necessary to ensure your child's safety.

***The undersigned parent/legal guardian hereby consents to their child, _____, participating in the activities of the Hemophilia Federation of America's HFA Kids/Teen Connection program at its Symposium 2010 event in Kansas City, MO. The undersigned parent/legal guardian does hereby release, hold harmless and agree to indemnify, the Hemophilia Federation of America from any and all liability resulting from the participation of said child in the activities sponsored and conducted by the Hemophilia Federation of America's Children's/Teen's Programs.

Parent/Legal Guardian Signature _____ Date _____

Do you or your spouse have health/accident insurance? ____ Yes ____ No If yes, please supply the following:

Company Name _____ Company phone number _____

Company Address _____ Policy Number _____

Policy Holder _____





Thursday

April 22, 2010

1:00 PM	Exhibitor & General Registration Children's Registration & Pictures Exhibitor Set Up
5:30 PM	Exhibitor Welcome
6:00 PM	Exhibit Hall Opens

Friday

April 23, 2010

9:00 AM - 12:00 PM	Registration
9:30 AM - 11:45 PM	Exhibit Hours
10:00 AM	HFA Capturing Community VOICES
10:45 AM - 5 :30 PM	Childcare & Childrens Programming
11:00 PM	First Time Attendee Reception
12:00 PM - 1:00 PM	Welcome / Award Luncheon HFA welcomes, recongnizes and honors its volunteers
1:00 PM	Infusion Suite Open
1:00 PM	Keynote Speaker
1:30 PM - 7 :30 PM	Wii Competition
2:00 PM - 2 :30 PM	Federal Advocacy Update
2:30 PM	State Town Hall Meeting
3:45 PM	Break
4:00 PM - 5 :30 PM	Breakout Sessions 1 - 4
5 :30 PM - 7:30 PM	Exhibit Hall Open

Breakout 1

Navigating The Twist and Turns of Insurance

Obtaining and maintaining insurance has become increasingly difficult with job loss, increases in premiums, and restrictions to state run programs. Topics to be discussed in this session include COBRA, Private Insurance, Public Insurance, etc.

Breakout 2

What Is In It For Me - A look at Healthcare Reform

Taking a closer at federal health care reform and how changes to the health and insurance system will impact individuals and families in the BDC.

Breakout 3

Hemophilia by the Numbers.....

Datamining is the process by which personal health information is bundled together by health insurance carriers and others and licensed for commercial gain. Some states have passed laws to prohibit the sale of confidential prescriber data for marketing purposes. Session will focus on what this means to you.

Breakout 4

Mission Critical: State Assistance programs in dire financial times

State budgets in crisis..session offers update on assistance programs (GHPP, Children's Programs, Premium Assistance Program)

PRELIMINARY SYMPOSIUM AGENDA

April 22 - 24, 2010

Saturday

7:00 AM - 8:30 AM	Continental Breakfast Member Organization Executive Director/Chapter Staff Breakfast
8:00 AM - 5:30 PM	Childcare & Children's Programming
8:15 AM - 9:15 AM	FitFactor "Healthy Community in 2010" Community members and topic experts pair up to present practical how to's of getting and staying healthy.
9:30 AM	Blood Brotherhood Track Separate agenda coming soon!
9:30 AM - 10:45 AM	"Get What YOU Need! Navigating the ER!"
11:00 AM - 12:00 PM	UDC Genotyping project/CDC Project
12:00 PM - 1:30PM	Exhibit Hours "Box Lunch in Exhibit Hall"
1:30 PM	"Advocates in Action! Meeting the President and being heard."
2:15 PM - 2:45 PM	ADVOCACY Tools You Can Use Telling your story-How to use the Legislative ACTION Center - Contacting congressional representatives
2:45 PM	Break
3:00 PM - 5:00 PM	Breakout Sessions 1- 3
5:30 PM - 6:30 PM	Memorial Service
7:00 PM	HFA Final Night Event Join us for a Boot Scootin' Boogie good time! DJ, Dinner, Line Dancing, Activities for Children

Saturday, April 24, 2010



Breakout 1

DADS IN ACTION - Get in the Zone at the Collegiate Basketball Museum

Experience and practice role-playing, free play, practice skills, shoot baskets or participate in a pick-up game, skills necessary in the important role of a Dad!

Breakout 2

BLOOD BROTHERHOOD - Join the Team

The Collegiate Basketball Hall of Fame will offer a close up look at the corridor of history and mentors circle. Visitors learn about the reverence and respect elders have earned through their challenges and realize the rewards of mentoring.

Breakout 3

FOCUS on the FEMININE

Opening Reception followed by Breakouts of interactive discussion of issues affecting you! Learn from one another and share your stories.

MOMS - Hear Our Voices!

WOMEN with Bleeding Disorders

S.O.S. Spouses and Significant Others

HFA NATIONAL NOTES

by Kisa Carter, HFA Public Policy Director, Federal Affairs



HEALTH CARE REFORM: AND THE SAGA CONTINUES...

It is winter and we are a long way from completion of a final bill to be signed by President Obama.

On November 18, 2009, the Senate received a Congressional Budget Office (CBO) score outlining the cost of the Patient Protection and Affordable Care Act. At \$849 billion, this bill will cover about 94% of the uninsured, approximately 30 million Americans. Uncertain when a final bill will be completed in the Senate, Majority Leader Harry Reid made progress November 21, 2009 when a major procedural obstacle was overcome just a few days before Thanksgiving. In a 69-30 favorable vote, the Senate moved to bring the bill to the Senate floor to begin debate.

The House of Representatives passed its version of health care reform on November 7, 2009 with a favorable vote of 220-215. The Affordable Health

Care for America Act is 2,016 pages. Despite progress in the House and Senate, both chambers have a long road ahead to see a final bill.

The legislative process for health care reform is complicated. Debate of the Patient Protection and Affordable Care Act could last for weeks. When the Senate passes its version of health care reform, the House of Representatives bill and the Senate bill must somehow merge. The merger occurs during a House-Senate Conference Committee where a conference report will be produced. The conference report must then be taken back to the House and the Senate for debate and ultimately a vote from both chambers. A favorable vote from both chambers must occur prior to placement of a final bill on the President's desk for signature. Simply put, the process to pass a bill through Congress and then receive a signature from the President is not straightforward. In reality, health care reform could drag on until Spring.

To see a tutorial of the health care reform legislative process, please visit the Kaiser Family Foundation's Process of Health Care Reform at <http://www.kaiseredu.org/tutorials/reformprocess/player.html> 

YOUNG ADVOCATES IN ACTION: TWO TEXAS STUDENTS LEAD THE WAY

by Christian Rodriguez and Robert DeForde



In early October, we had the opportunity to travel to Washington, DC, for HFA's first Advocacy Intensive. The intensive program is designed to equip bleeding disorders community

members with the tools to become stronger advocates. We agree it was possibly the single most amazing experience of our lives. There was a total of seven participants from various places in the US. Our days began at 5:30 A.M. and

the intensive program started promptly at 7:00 A.M. Our meetings continued through the early evening over the course of the week. Throughout the intensive we began to notice the development of a brotherhood and that we were all focused on the same goal: strengthening our skills as advocates. By the end of the week we found ourselves staying up until 2:00 A.M. discussing different health care policies and ways we could work to improve the current and proposed systems. Christian and I both agree that the brotherhood we formed in DC is one that will continue.

The overarching theme from our experience in DC was that we are our own advocates and together we can



DEATH BY A THOUSAND CUTS...

*An Open Letter to America's Bleeding Disorders Community
by Steve May*

As I sit down to write this letter today, 48 of the 50 states are running budget deficits. (Consider yourself lucky if you live in Montana or North

Dakota.) The 2010 Fiscal Year is not six-months old, yet state lawmakers will be returning to work facing a growing mountain of debt. This bleak financial reality comes on the heels of 2009's deep cuts in funding to high risk pools and support for premium assistance programs. It is equally likely that efforts will be made to curb access to clotting factor. In all, the financial circumstances facing local and state governments are dire.

Hemophilia has always been a favorite target of political leaders in difficult economic times. The primary reason for this is that the community is small in numbers and its needs are resource heavy. In other words, properly treating hemophilia and von Willebrand patients is expensive. Focusing cuts on populations where the effects will be "localized" and not ripple across the entire electorate is highly desirable.

With an eye towards the 2010 legislative session, we as a national community will be forced to fight hard and to stave off efforts to roll back access to programs and products. This may take a variety of forms including formulary restrictions like prior authorizations, preferred drug lists and step therapy. As noted above, the programs which help sustain this community also will be heavily threatened due to fewer revenue dollars entering into state coffers.

In an effort to better serve our member organizations around the country, the HFA Advocacy Committee and Executive Committee have identified a series of legislative approaches to best serve the bleeding disorders community during this difficult time. Almost all of the measures identified are policy driven in scope as the financial environment makes spending outlays difficult to justify. Two measures in particular have been identified as national priorities due to their potential importance for the community. They are tier IV drug pricing and treatment standards legislation.

National priorities are measures which we believe every chapter organization should bring to its state lawmakers. In addition to these two national priorities, another series of proposals has been identified for further

Continued on Page 13

make our voices loud enough to reach inside the halls of Congress, state and local legislative offices. Now that the two of us have arrived back in Houston we have, with the approval of the Lonestar Chapter Board, organized the creation of an Advocacy Committee in Texas. Our goal is to develop an agenda and assist committee and bleeding disorder community members with their advocacy efforts. We started drafting an agenda for the next few months and for the following years.

Our community still faces many issues such as access to health insurance, affordability issues, lifetime caps, pre-existing conditions, out-of-pocket costs (Tier IV), and challenges due to co-morbidities (HIV and Hepatitis C). We encourage any Texans reading this to contact us and sign up to join the advocacy committee. All of us with a

bleeding disorder must remember to be vigilant in getting our VOICE heard!

About the Authors

Christian Rodriguez is a 23-year old who was diagnosed with severe Hemophilia A at the age of three. He currently resides in Spring, Texas with his Mom, Dad, and three siblings. He is a full-time student at the University of Houston.

Robert DeForde is a 20-year old who currently resides in Friendswood, Texas. At 15, he was diagnosed with von Willebrand's Disease. He is currently a student majoring in political science and hopes to one day work in politics and eventually run for an elected office. ♦

Continued from Page 3

was hearing things around him that the rest of us had taken for granted. At times, it became overwhelming, and he experienced headaches from the new sounds called "noise." His stethoscope, however, has been a godsend.

When I began this process, I wondered if Joshua was "entitled" to pursue such avenues. After all, I worked full-time, I had good health insurance, Joshua was about to graduate with a nursing degree...I didn't think we "fit the profile," but my nurse manager at my job said "you should go for it...you work, yes, but sometimes a little extra help is needed when certain things aren't covered by working." So, I went for it...sometimes as a single mom, you have to pursue avenues you previously assumed were closed to you because you were employed. I'm really glad I went to HFA's symposium, met Jeff Hughes, and was guided in the right direction to get my son the tools he needed to pursue his career more effectively. 💧

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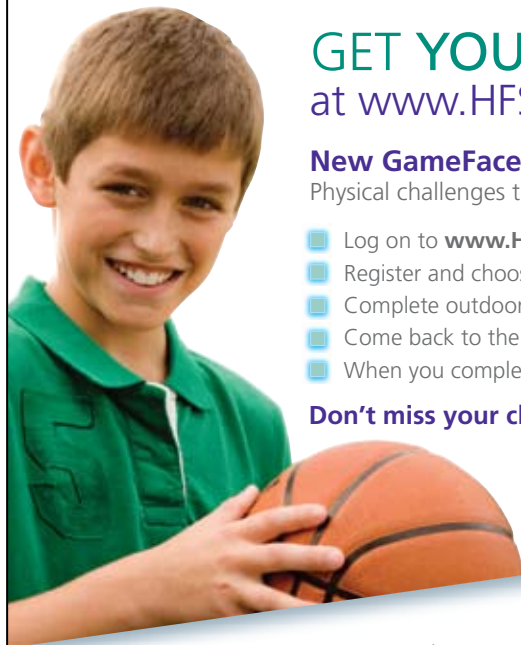
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- Complete outdoor and indoor physical challenges—even Wii™ games—on your own
- Come back to the site to log your physical activity progress
- When you complete a challenge, you will be entered in a sweepstakes to win a Wii™

Don't miss your chance to win...register now at www.HFSGameFaces.com!

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



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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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HEMOPHILIA
THERAPIES



PATIENT
RESOURCES



COMMUNITY
PROGRAMS



COMMUNITY
CONNECTIONS



INSURANCE
& ADVOCACY



CLINICAL
INITIATIVES

Baxter

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action. These proposals include efforts to increase access to health coverage for people under the age of 29-years old, Protections against Data Mining, and creation of Hemophilia Advisory Committees. For more information on all these measures, follow this link to the advocacy section on the HFA webpage at:


<http://hemophiliafed.org/advocacy/issues-and-positions/2010-state-legislative-agenda>.

As we move forward over the course of this legislative year, we at HFA's Office of Public Policy commit to making the often complicated and difficult political environment accessible to community members through our outreach efforts. These include the Friday Update, a weekly briefing intended to give readers a sense of what has happened in the week prior or what will be happening in the week coming. Kisa and I keep blogs which can be found on the

Continued from Page 11

HFA webpage where we discuss emerging political and legislative issues on a regular basis. Please consider HFA's Office of Public Policy to be a resource available to you in addressing concerns and questions in this period of great upheaval.

In solidarity—

Steve May, Director of Public Policy – State Affairs,
Hemophilia Federation of America 

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2010 FANS TO CELEBRATE SYMPOSIUM 2010

ON HFA'S OFFICIAL FACEBOOK PAGE

www.facebook.com/hemophiliafed.org

**HFA has set a goal to have 2010
Facebook FANS by 4/25/2010
We need your HELP!**

We encourage you to suggest to your friends to be a fan of the official HFA page on Facebook. Go to the HFA page from your personal page and click suggest friends. Select your friends and send the requests!

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!

To find us on Twitter, visit:

<http://twitter.com/hemophiliafed>

Visit our Voices page:

<http://voices.hemophiliafed.org/>

CONGRATULATIONS TO PARTICIPANTS WHO COMPLETED THE FIRST HFA ADVOCACY INTENSIVE, OCTOBER 2-5.

The program is a best practice model for bringing HFA social advocacy programs full circle and encouraging members of the bleeding disorders community to reach their full potential through role modeling and self advocacy. The program is delivered during an intense four days of experiential learning where participants engage in a variety of hands-on activities including team building and communication exercises, special projects and training on the legislative process. The participants also authored their own "Personal Story" and delivered it to legislators on Capitol Hill. 🩸



*(Top left) Katie Whittle,
Justin Lindhorst, Aaron
Anderson, Paul Cobb*

*(Bottom left to right)
Chad Blair, Christian
Rodriguez, Robert
DeForde*

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