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## HELLO FROM *Kansas City*

Dear Community,

This year's HFA Symposium was held in Kansas City, Missouri on April 22-24, 2010, amid the beautiful backdrop of the Westin Crown Center Hotel. With people traveling from all over including, as far west as California, Arizona, and Montana, those from the Midwest, also Boston and New York in the east, and states like Tennessee, Georgia, and Florida in the south, the theme of this successful meeting, "Uniting Our Voices Across the Country" was very befitting.

The Symposium offered a comprehensive agenda with carefully targeted break-out sessions in an effort to accommodate specific networking groups, such as men, women, teens, and young adults. The meeting began

with a keynote address from Jerry Holmberg, Senior Advisor for Blood Policy at the U.S. Department of Health and Human Services. With updates on federal and state legislative affairs, and tips on navigating a new health care system, it is clear that states have their work cut out for them.

Attendees were presented with a lot of critical information, including: ensuring access to appropriate emergency care; the latest on the genotyping project at the Centers for Disease Control and Prevention, which helps us understand how data impacts health outcomes; and how a new fitness program, Fit Factor, helps encourage fitness and wellness within our community.

*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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Hemophilia Federation of America

Community advocates were on the scene and shared their personal success stories. They encouraged participants to play an active role in the way health care will be defined. While it may be as small as making good choices about the foods in your diet, no tactic lacks value in the overall scheme. Policymakers and regulators must understand the unique needs of people with bleeding disorders. As data will drive much of our ability to access health care, it is up to each one of us to positively impact data to ensure its patient-centric quality.

In addition to the great topic sessions, there was a selection of fun networking opportunities, including the Wii competition, Poker Night and the trip to the Collegiate Basketball Museum. All-in-all, it was an exceptional educational experience as well as a great time for attendees to make lasting friendships and connections with others.

Every year at Symposium, the HFA Board of Directors conducts an election for its executive committee. Several members of the bleeding disorders community were elected to leadership positions. As the new HFA President, I am honored to be elected to this position, and I look forward to engaging in an organization comprised of so many great programs, opportunities, volunteers as well as an amazing staff.

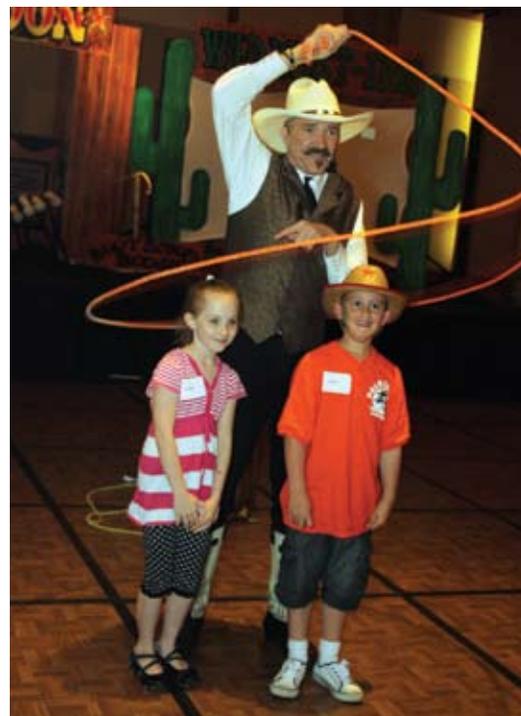
I look forward to working with all of you as we work to confront and solve the challenges ahead; including working with all stakeholders to ensure the needs of the bleeding disorders community are met. The Board of Directors and staff of HFA would like to thank everyone who made this a wonderful event!

Warm regards,



Paul Brayshaw

Board President





*Randi Clites, Community Activist*

Last fall several Partnership for Advocacy and Communications Training (PACT) grants were awarded to state chapters around the country, and one hard-working mom from Ohio, Randi Clites, was responsible for securing the grant for her local chapter. The purpose of the PACT grant is to strengthen and encourage consumer voices in the advocacy process for the purpose of protecting access to quality hemophilia care and therapies. Randi decided to focus her advocacy efforts on developing and maintaining relationships with the administrative staff of the Ohio Department of Insurance and the Department of Health, including the Medicaid Pharmacy Director.

Last November, she was invited by a Baxter representative to attend the PACT training. It was announced at this meeting that there was some extra money for chapters to get more involved with advocacy by bringing a train-the-trainer type program into their state. Those interested would need to submit a grant proposal. So, with the help of one of her chapter/board members, Randi set out to write a proposal for a grant. In February, she learned that she secured the largest amount, \$4,500, in a PACT grant for her state of Ohio.

The grant money will be used to “Create a training module for families throughout all of Ohio in which I will teach families how to advocate at the state capital.” This will involve making appointments with key people around the state. Randi just secured her first appointments. She stated, “HFA has been a huge help directing me to the key people in the state to talk to about hemophilia issues.” The meetings that will take place are opportunities to educate health care decision makers. Three other families will help Randi deliver the key messages to administrators and others.

Randi told Dateline that the reason she is so heavily involved in the hemophilia community is because of her son, and “the advocacy portion, this is the driving force for me getting involved because this is where I feel I can contribute the most.” Randi is a past board member of FAMOHIO, current Board Treasurer and Advocacy Chairperson of the Northern Ohio Hemophilia Foundation, and a consumer member of the Ohio Bleeding Disorder Council.

Because Randi has already participated in Washington Days and helped to organize the past three Annual Statehouse Days in Ohio, she has a great foundation to draw upon for her upcoming work. ♦

“SOME PEOPLE FEEL LIKE THEY DON’T HAVE POWERFUL ENOUGH STORIES IN OHIO, AND I WANT TO REASSURE FAMILIES THAT THEY DO; THAT JUST BECAUSE THEY ARE NOT DEALING WITH GETTING HIV FROM A BAD BLOOD SUPPLY, OR RECEIVED HEP C, THAT THEIR STORIES ARE SOMEHOW LESS IMPORTANT.”

Hemophilia Federation of America  
**FOCUS** ON THE *Feminine*™

Focus on the Feminine (FOF) - This year's FOF session was held on the last day of the conference, late in the afternoon, purposely around the time of a traditional "tea time." In keeping with past tradition, chocolate-covered strawberries, mini-sized chocolate éclairs, mini-bars and petit fours were readily available to the FOF participants. The FOF breakout session - only for ladies - was started in 2003 and continues today as one of the Symposium favorites. It provides women the opportunity to connect, discuss issues that impact only women, and as importantly, to support one another.

The session was kicked-off by an inspiring speaker, Usha Parthasarathy, a qualified national leader of an India Outreach program. Usha is a mother of a son with severe Hemophilia A. Her son is currently enrolled in college in the United States and she was visiting him, which is why she was available to speak at the conference. Usha also had a second son who died from hemophilia.

Usha currently is based in Chennai, India and is a former board member of the Hemophilia Federation of India. In October 2009, Usha launched her outreach program and traveled to eleven partners over two months. The organization helps bring beneficiaries



Nikki Murry, Usha Parthasarathy, Kimberly Haugstad

to the partner-sponsored locations for treatment for their bleeding conditions. She spoke eloquently and passionately about her ties to the hemophilia community, and also about the miraculous work that is being done globally by Save One Life. After a standing ovation, Mrs. Parthasarathy departed and the room was divided into three sections, so that women could move to participate in one of three sessions: Partners; Women with Bleeding Disorders; or Moms. The Partners breakout was facilitated by Linda Wyman-Collins (Lew) and Eric Johnson and was for both men and women. Their session touched on nutrition and co-infections. Jill Williams and Laveane Lovelady led the Women with Bleeding Disorders group, informing women as to the things they need to know about symptoms, treatments, and taking care of and advocating for themselves. The Moms' breakout focused on giving moms the tools to help them to know how to talk to their child's school, how to have a voice and advocate for their child, and networking. Niki Murry, RN facilitated this breakout.

This was another successful women's event. What's next for FOF? They are focused on continuing their educational focus of bringing information to women everywhere and hoping to be able to do this through webinars and other media sources. Another goal is to make sure that women receive helpful information on where to secure treatment after they have been diagnosed. ♦

An advertisement for AHE Homecare. The headline reads 'The Homecare That Cares!'. Below this, it says 'AHE's® homecare pharmacy works exclusively with bleeding disorders. We operate on two principles...'. The ad lists 'Superior Service' with 'Nearly a 100% Client Satisfaction Rating' and 'Community Involvement' with 'Returning Approximately 80% of Our Proceeds Back to the Community'. It also states 'AHE's personalized care and attention to detail is what has made AHE the leaders in pediatric care.' The contact information is '800-243-4621', 'AHE@AHEInfo.com', and 'www.AHEInfo.com'. There is a photo of a young child in a red shirt and the AHE logo at the bottom right, which includes the text 'The Bleeding Disorders Homecare Company'.

# HIGHLIGHTS



While many of us are enjoying our air-conditioned homes during the hot weather, many families in our community cannot afford that luxury. Instead they are left to worry about what is more important—a cool, comfortable home or a vehicle filled with enough gas to transport their child to doctor appointments. It is not a choice anyone should have to make; yet with the loss of jobs in this tough economy and the unpredictability of a bleeding disorder, many of our friends and community members are left with no choice.

Luckily there is hope for these families through Helping Hands. In 2010, Helping Hands has already taken 115 applications from families for emergency financial assistance. This year, Helping Hands has helped many community members keep their electricity on, pay their rent, feed their children, fix a roof, repair cars, purchase a mattress and much more.

Helping Hands recently helped a disabled 67-year-old gentleman get a better night's rest with the purchase of a mattress. When we first spoke with the applicant, he was sleeping on a worn out, uncomfortable mattress donated to him by a family member 30 years ago. It was hard on his joints and so worn it was difficult for him to get out of bed safely. Being a self-described frugal person, he said he always finds ways to put food on the table but has never had enough money to put aside for a new mattress. With funding from Helping Hands, he was able to pick out a brand new twin-size mattress from JC Penney that was delivered to his door within two weeks. Recently when Helping Hands spoke with him, he excitedly thanked us for the assistance and offered to send us his favorite chocolate chip cookie recipe.

In 2010, Helping Hands has seen a drastic increase in applications. With this increasing need, we need your help now more than ever. With your donations we can continue to help our friends in the community. You can make a difference by donating to the Helping Hands program at <http://hemophiliated.org/contact-us/donate> ♦



Fit Factor - HFA highlighted one of its newest programs during the Fit Factor: Strength, Flexibility and Wellness session. HFA was excited to share the announcement of a recently awarded five-year cooperative agreement from the CDC. The grant supports a program aimed at promoting physical activity and maintaining a healthy weight in individuals with bleeding disorders.

During the session, video clips were shown demonstrating the different exercises that can be learned and performed. There were leg extensions, hamstring stretches,

and breathing techniques that were highlighted. In addition, practicing yoga was discussed as a good exercise for all people; and at the end of the session, the speaker had attendees perform some of the good breathing techniques she espoused.

Every exercise that was discussed and shown during the session will eventually be a part of the online format. Furthermore, there will be guidelines and age-appropriate suggestions on which exercises a person should perform based on their specific challenges and needs. Look for the three-minute clips and there will be thirty minute videos to be posted on the HFA website soon. ♦



*Derick Stace-Naughton*

A new breakout session was offered at this year's symposium titled, Young Leaders At this session, young adults came together to share their stories with their peers and their connection to the bleeding disorders community. They also willingly shared what activities they have been involved in within their own states. Lucky for HFA, these young, active and enthusiastic adults are contributing at all levels and are truly making a difference.

Take Derick Stace-Naughton for example. In high school, Derick first got involved with the bleeding disorders community by writing a newsletter for teens. As a person with a bleeding disorder and an undefined platelet disorder, he has had an interest in educating people about the painful symptoms of von Willebrand's Disease, and how these symptoms go undiagnosed for millions of Americans.

When he entered Georgetown University in Washington, DC, he continued to talk and educate friends, students, and even random people about the plight of people with bleeding disorders. As his message resonated with more people, a core group of active peers materialized. These peers were not only interested in the issues, but they had an interest, like Derick, in public policy.

"I started approaching congressional offices about our bill and honed in on U.S. Congresswoman McCarthy (D-New York) because during the 105th Congress, she had a concurrent resolution on bleeding disorders, which demonstrated she had an interest already."

Derick began talking and working with Representative McCarthy's staff on drafting a bill. His primary focus was screening and education. He wanted to make sure that the undiagnosed individuals get some relief by being accurately diagnosed and treated. One such example is von Willebrand Disease, which alone affects as many as one in every fifty people. A very small portion of those with the disease have received an accurate diagnosis, leaving the vast majority either under diagnosed, misdiagnosed or completely undiagnosed from the disease and not able to take the appropriate steps to protect against

the symptoms of the disease, which may include swollen and painful joints, gastrointestinal bleeding, excessive bruising, postoperative bleeding, menorrhagia (excessive menstrual bleeding), bleeding from dental procedures, and other health problems.

H.R. 4846, the Screening, Awareness and Further Education (SAFE) Act is the result of the work Derick and others have done. Representative McCarthy is the chief sponsor in the U.S House of Representatives. There are currently seven co-sponsors. In short, the bill would:

- Provide grants for programs to increase physician awareness of bleeding disorders; and
- Provide grants for programs aimed at screening adolescents for bleeding disorders; and
- Enhance surveillance and reporting of bleeding disorders across the country, which can lead to improved, targeted research efforts. 💧

"I STARTED APPROACHING CONGRESSIONAL OFFICES ABOUT OUR BILL AND HONED IN ON U.S. CONGRESSWOMAN MCCARTHY (D-NEW YORK) BECAUSE DURING THE 105TH CONGRESS, SHE HAD A CONCURRENT RESOLUTION ON BLEEDING DISORDERS, WHICH DEMONSTRATED SHE HAD AN INTEREST ALREADY."

# MAKING A DIFFERENCE

The following pages describe just some of the learning and fun had by all in Kansas City, MO!



*Chad Blair*

IT'S CLEAR THAT WE HAVE A FRIEND IN U.S. CONGRESSMAN OWENS, WHICH CAN BE DIRECTLY ATTRIBUTED TO THE FOUNDATIONAL LEGWORK DONE BY CHAD BLAIR.

## YOUTH LEADERSHIP

While all the young adults at the young leaders' focus group have been participating at their own state level, Dateline spoke with Chad Blair from New York on his outreach efforts.

According to Chad, there are numerous chapters in New York. Chad is active in the Binghamton, New York chapter. His involvement in the bleeding disorders community has been a lengthy one. He has gone to summer camps since he was seven. He has also lobbied in Washington, DC during the National Hemophilia Foundation's Washington Days. He had such a great experience advocating and building relationships in DC that he set out to do something similar back in Albany, NY. He and several community members organized a coalition of chapters with the idea that they would organize a lobby day at the New York State Capitol. It was the Binghamton chapter that led the efforts in carrying the message about the bleeding disorders community to legislators in New York. The lobby day in New York was a great success.

Chad has a great relationship with both his state House and Senate legislators, but equally as important, he has developed a strong relationship with U.S. Congressman Bill Owens, who was elected in a special election in 2009. Congressman Owens, a Democrat, was so impressed with Chad that he invited him to his district office to give a presentation on hemophilia. Chad has also met with the Congressman's chief of staff, and has been told that the Congressman would like to "spotlight" the hemophilia community. While all the details on this have not been finalized, it is clear that we have a friend in Congressman Owens, which can be

directly attributed to the foundational legwork done by Chad Blair.

When Dateline asked what was next for Chad, he replied, "Tier 4 drug pricing." Tier 4 drug pricing occurs when insurance companies require an individual to pay 20 to 40% of the drug cost of their prescription medication. According to Chad, some states have already implemented Tier 4 drug pricing. Chad is working with, and monitoring activity on, this issue in New York because there is a bill to prevent Tier 4 pricing. In Chad's view, Tier 4 drug pricing is the new way for insurance companies to drop people with chronic conditions.

Tier 4 drug pricing is yet another reason why we all have to stay vigilant and have to be willing to advocate for the change we need as a community. 💧



*Patrick Haggerty and Josh Lunior discussing the issues.*



## THE KEYNOTE ADDRESS

Jerry Holmberg, Ph.D, Senior Advisor for Blood Policy, Department of Health and Human Services, gave the keynote address. Mr. Holmberg works for the U.S. Assistant Secretary of Health, who is considered the Blood Safety Officer for the nation. As such, he is responsible for coordinating activities related to the safety, availability and access to blood products for all Americans. Mr. Holmberg, the Assistant Secretary, the Surgeon General of the United States, and many others work to coordinate research and development, biovigilance, donor eligibility, and reimbursement, with stakeholders both inside and outside this enormous and hugely complex department.

In his remarks, Mr. Holmberg spoke about having the best system in place to look for, detect and respond to the next infectious disease when it is discovered. He emphasized that one of the United States Department of Health and Human Services' (HHS's) driving principles is to create a better system of prevention through the collaboration of various agencies such as the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Food and Drug Administration (FDA), Centers for Medicare and Medicaid Services (CMS) and the Institutes of Health (NIH) working together. He also mentioned that it is in their purview to make sure the blood, organ or tissue that is used

by people with bleeding disorders for transfusions or transplantations is safe. The overall mission is to make evidence based, prevention-centered, cost-effective science and health care widely available.

To continue with this work, funding is critical. In the health care reform bill that was signed by the President, there was \$500 million in FY 2010 and \$750 million in FY 2011 for prevention. According to Mr. Holmberg, "There are many challenges, yet great opportunities for all of us to share in this reform. Looking ahead, the department is looking into webcasting so people across the country can watch and hear the Advisory Committee meetings." To read more about the blood safety and availability committee, please visit [www.hhs.gov/bloodsafety/advisorycommittee/](http://www.hhs.gov/bloodsafety/advisorycommittee/).

## UDC GENOTYPING PROJECT/CDC PROJECT

Sally Owens McAlister, Team Leader, Prevention Research Team, Division of Blood Disorders presented at the session on the Universal Data Collection (UDC) program, which is an important program that exists at the CDC and Prevention. The purpose of the study is to monitor blood safety among recipients of blood products, monitor the extent and progression of joint disease, and identify issues for further study. The UDC study has been in effect since 1998 and thousands





of people from Hemophilia Treatment Centers (HTCs) across the U.S. have been enrolled and contribute to the success of this project.

The UDC collects data from people with bleeding disorders of all ages to better understand issues across the lifespan. For example, genes are studied to help research better clotting factor. Inhibitors are studied so that scientists can verify the acceptable number of inhibitors allowed for a product that is used for a bleeding disorder to be deemed safe. For more information on the study, please visit [www.cdc.gov/ncbddd/blooddisorders](http://www.cdc.gov/ncbddd/blooddisorders).

facebook

CONNECT WITH HFA ON FACEBOOK

[www.facebook.com/hemophiliafed.org](http://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!

**HEALTH CARE REFORM OVERHAUL Bill** - Every President has one...a vote, a decision, or a bill that marks his presidency. For President Obama, many will agree that the approval and passage of, followed by the eventual signature on, the health care reform bill could very well be the issue for which his administration and party will long be remembered. Realizing that Obama is still in the early stages of his tenure as president, it is nothing short of a miracle that he was able to get the health care overhaul bill passed. Congress dedicated most, if not all of 2009, to this issue without any success of passage, but once the 2010 calendar was flipped, the bill passed in just 61 days. Now comes the heavy lifting—determining just what was passed and how to implement its directives and mandates. For the hemophilia community, this simply means: VIGILANCE.

*Continued on page 17*

I ATTENDED MY FIRST MEETING IN INDY  
LAST YEAR, AND WAS SO IMPRESSED.  
NOW I'M HOOKED WITH HFA!  
I ENJOY THE HFA CONFERENCE...  
IT'S MORE FAMILY AND CONSUMER ORIENTED.  
HFA IS PERSONABLE...I'VE MET THE DIRECTOR,  
AND THE PRESIDENT, AND PAST PRESIDENTS...  
THAT MAKES A DIFFERENCE TO ME."

PAM WILLIMAS



*Katie Whittle, HFA Voices Coordinator chats with  
Community Member, Pam Williams*



MEET SAM CIERI

One of the more unique and compelling presentations at the conference was displayed not by someone who stood on a podium and spoke into a microphone before an audience. Instead, it was provided by 17-year-old Sam Cieri who sat on a chair outside the main ballroom with guitar in hand strumming and singing.

Sam has entertained attendees at the HFA Symposium for two years. This year he was invited to play his guitar and sing during the Remembrance Ceremony on Saturday afternoon.

Sam is from Celebration, Florida and he traveled to the meeting with his mom and siblings. I also learned that Sam and a number of his family members all have severe von Willebrand Disease. Sam stated, "When I was younger, I participated in

'The Hole in the Wall' summer camps," which ironically were sponsored by none other than former actor Paul Newman.

As one child of several with a bleeding disorder in a single-family unit, I wondered if his mom was more protective of him. He added that, "When I was younger she was; but now that I am older, she's a little less so." I posed that question to him after I learned that Sam is about to embark on an exciting, once-in-a-lifetime adventure. In June, he will fly to London, England, and meet up with a buddy who works in a pub. Sam will play his guitar and sing for a living. He suspects that he will have to do some bartending, too, to help him earn a living wage, so that he can motorcycle around Europe for five months. 📍

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## FIRST TIME ATTENDEE ENERGIZED AFTER SYMPOSIUM



*Community Advocate, Lisa Maxwell*

Lisa Maxwell may be a first time attendee at Symposium, but she is no stranger to the hemophilia community in her state. Lisa is a mother to a 14 year-old son with severe hemophilia. She also is the current vice president of the Rocky Mountain Hemophilia Bleeding Disorder Association (RMHBDA) for Montana and Wyoming, a camp director and a member of the RMHBDA advocacy committee. She states that, "Our board is a small working board with members from both states." Back in the fall, Lisa was fortunate to be able to attend a workshop sponsored by Baxter, that allowed her the opportunity to learn first-hand about advocacy, and it was at this fall meeting that she also heard about HFA's annual Symposium. When I asked her why HFA, she stated, "I had never attended and wanted to see what this conference could offer both me and the RMHBDA."

Lisa admits to learning a lot at the conference and found a number of the sessions very helpful particularly the sessions about the new health care law. "The Symposium was consumer friendly and everyone made you feel so welcomed. All programs were very helpful and not too many as to be overwhelming."

In particular, Lisa was excited about the contacts she made; and with a newly hired Executive Director at RMHBDA, she is bringing back a lot of good information

to share. "I thought there was amazing energy from other members of the bleeding disorders community! Talking with others that have 'been there, done that' is always helpful. Networking, sharing information, and solutions is what makes this community so awesome." Randi Clites, also an attendee, and someone Lisa met in the fall, introduced her to Kim Bernstein, HFA policy advisor and advocate). "Immediately, the energy and information we shared was worth the trip, and I have forwarded the contact information to our new executive director."

"I was so thankful to receive a grant which allowed me to attend!" When I asked her what was next, Lisa stated, "[We are] working on starting our own State House Day in Montana and expanding into Wyoming." Quote: "Networking, sharing information and solutions is what makes this community so awesome!" ♦



*Levert Conway & son enjoying the final night event.*

A SMALL GROUP OF THOUGHTFUL PEOPLE  
COULD CHANGE THE WORLD. INDEED,  
IT'S THE ONLY THING THAT EVER HAS

MARGARET MEADE

At this year's Symposium, there was a lot of talk about taking action, getting involved, staying abreast of the issues, and keeping an eye on what's going on in Washington, DC and within a person's own home state, and for good reason. Individuals can and do make a difference every day in state capitols across this country, and in Congress.

Community action does work, and on Saturday during the afternoon presentations, attendees heard from two families who shared their first-hand experiences about Washington, DC, meeting with federal lawmakers, and how they had the opportunity of a lifetime - meeting with the most powerful and influential man in the free world, President Barack Obama.

Mr. Michael Forbes was the first to share his family's compelling story. He, and his wife Jane, have six children, five with hemophilia. Mr. Forbes started his talk by mentioning his book titled, *Surviving the American Medical System in the 21st Century*. Because of his family's personal struggles, going through at least "\$12,000 worth of medicine each week and racking up to close to \$1 million in drug costs each year," Mr. Forbes works hard to carry the message about hemophilia to anyone who will listen.

It is a story like the Forbes' that demonstrates an urgent need for an overhaul of our current health care system. We don't have to imagine why this family was invited to visit with the President about their health care situation. In their meeting with President Obama, Mr. Forbes stated that the President was "very gracious, definitely intelligent, a keen listener and well aware of the antics of the insurance industry. However, he didn't know a lot about hemophilia." The Forbes had about 15 minutes with him and in the end, the President said, "Your the kinds of

families we want to help." The President's words should give the hemophilia community hope as Mr. Forbes stated, "We're a vulnerable group of people."



*Michael Forbes*

The second story that participants heard was from Nathan and Sonji Wilkes of Colorado. They have a young son with hemophilia who has inhibitors. Their family's struggles were also the catalyst for Nathan to first take action or as he sees it, engage in "my mission of personal advocacy."

Like many other families and individuals, the Wilkes were dropped from their health insurance provider when they quickly reached their cap. Their son's medicines became prohibitive when a daily dose of what he needed cost \$1,000 a day, or \$30,000 a month. Because of their dire situation, Nathan took matters into his own hands and wrote an essay to the Governor of Colorado, in which he pleaded his family's health care case. He never heard from the Governor. But, when he sent his essay to a friend in California who had some connections, the next thing he knew he was being asked to speak at the National Press Club in Washington, DC. What followed was nothing less than a tsunami of opportunities in which to share his compelling story. The Wilkes' story showed up in a number of publications, including *Newsweek*, a national nursing magazine, a Japanese magazine, and even on *MSNBC*. The couple was also invited to speak at a committee hearing in Congress where they testified about their insurance challenges. 💧

At the close of their talk, they wanted everyone to know how easy it is to get involved and suggested the following tips:

## “Wilkes’ Recommendations”

1. Start locally. Develop relationships with people on the local and state levels
2. Donate \$5 to their re-election campaign
3. Show up at your local house and senate representative’s town hall meetings

Other ways to get involved:

1. Call your legislator
2. Write or email him or her on your issues
3. Visit them at their offices

Remember to do the following:

1. Explain your problem (make numerals line up with the above numerals)
2. Offer a solution
3. Tell them how your solution would improve lives



*Sonji & Nathan Wilkes*

## WE APPRECIATE THE FOLLOWING ORGANIZATIONS FOR THEIR GENEROUS SUPPORT OF SYMPOSIUM

### PLATINUM \$75,000+

Baxter  
Bayer HealthCare

### SILVER \$25,000 - \$49,999

CSL Behring  
Novo Nordisk Inc.  
Octapharma  
Pfizer

### BRONZE

\$5,000 - \$24,999

Accredo, HHS  
Grifols  
Hemophilia Alliance  
National Cornerstone  
Walgreens

---

We also thank our many Symposium Exhibitors!  
See complete listing on HFA's website for details

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## DID YOU KNOW...

Things to Bring with You  
When Going to the ER

1. Clotting factor and infusion supplies
2. Insurance card
3. Icepack
4. ER Packet

that includes the following:

- a. Emergency care letter from HTC provider
  - b. MASAC documents
  - c. Treatment Guidelines
  - d. ER articles
5. HTC contact information
  6. Toys (e.g., books, crayons, stuffed animal)
  7. Snacks/drinks

**\*\*Don't forget to contact your HTC on the way to the ER.\*\***

# ADVOCACY NEWS

by Kisa Carter, HFA Public Policy Director



## EDUCATION IS FUNDAMENTAL TO DEVELOPING STRONG ADVOCATES

As you read through the Symposium-related articles, you will find a common thread:

education is a key element to developing strong advocates. Education and advocacy are part of the core mission of HFA. Throughout the HFA Symposium, individuals and families recognized the importance of taking newly acquired information back to their

respective states. Attendees consistently acknowledged the importance of sharing information with local community members, especially information about the new health law. Acquiring and distributing knowledge of the issues is one of the first basic steps to advocacy. Education begets action and action begets solutions. Individuals empower themselves with a crucial tool just through educating themselves and others. As you continue reading the remarkable stories from Symposium, think about how you can educate yourself and TAKE ACTION. You can start by visiting the HFA Advocacy section of the website to look at the blogs, Friday Updates and other helpful documents and information.

Never hesitate to reach out to a member of the HFA team to learn more about policy and advocacy. Visit the Advocacy section of the website at [www.hemophiliafed.org](http://www.hemophiliafed.org).

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# GRIFOLS

## “TREATMENT FOR ALL” - IT GOES BEYOND OUR BORDERS

As we each know, one of the main reasons for attending the Symposium is to mingle and network with people. So is the case with Michael Rosenthal. I met Mr. Rosenthal on my ride to the hotel. I was sitting next to him on the shuttle we were sharing. We were wet from the rain, and hot, because there was no air on in the shuttle and we were all sitting very close to one another. Thus, I struck up a conversation with him and learned that this was his first time, like me, at Symposium. I also learned during our ride that he writes a newsletter for an organization. I was naturally intrigued, since I was going to be contributing articles to this edition of Dateline. It wasn't until later at the conference that I learned more about him and what he did.

Mr. Rosenthal is a consultant with the World Federation of Hemophilia (WFH), USA Division. The Mission of WFH is “treatment for all.” According to Mr. Rosenthal, there are approximately 400,000 people worldwide with hemophilia and only 25% of them are being treated. Poverty is so widespread in most third world countries, that for the people who live in these countries, the challenge of finding food and clean water is an everyday exercise in survival. Comprehensive health care isn't even something they think about. Yet, comprehensive health care is what is being offered to international governments and hospitals by the United States through WFH's “Twinning Program.”

The Twinning Program will match a hemophilia treatment center in say, Texas, with one elsewhere in the world. This means doctors in the United States will work with doctors in developing countries like Peru, Argentina, Istanbul, or Poland on setting up comprehensive treatment centers, so that people will be able to come to a treatment center and be treated for hemophilia. Some people in Peru will travel for up to a week to get to a treatment center.

The clinics in the United States currently donate factor to aid in the treatment of these individuals. Mr. Rosenthal believes that this program is a win-win situation, “a two-way street” as our HTC doctors learn from the doctors in developing countries and those doctors learn techniques, education, medicines, and treatments from our doctors.

When I asked Mr. Rosenthal, why HFA's Symposium? He stated, “It is the spirit and companionship of this organization; it's like a family - how could you not want to be a part of it?” 📌

“IT IS THE SPIRIT AND COMPANIONSHIP  
OF THIS ORGANIZATION; IT'S LIKE A FAMILY -  
HOW COULD YOU NOT WANT  
TO BE A PART OF IT?”



*John Jarratt, Blood Brother & Stanford Murry,  
HFA Executive Board Member*

## LAURA FENSTERMAKER'S BIO

Hi, my name is Laura Fenstermaker. I had the pleasure of attending HFA's Symposium this year and contributing a number of articles to this issue of Dateline. This is a wonderful opportunity for me. My past work includes 18-years' experience in communications, government relations (i.e., lobbying), media relations, and management. My professional work has been in Minnesota, where I have worked for a number of nonprofit organizations including: the Minnesota Certified Public Accountants (MNC-PA), The Minnesota Dental Association (MDA), The Brain Injury Association of MN (BIAMN) and several other nonprofits in Florida.



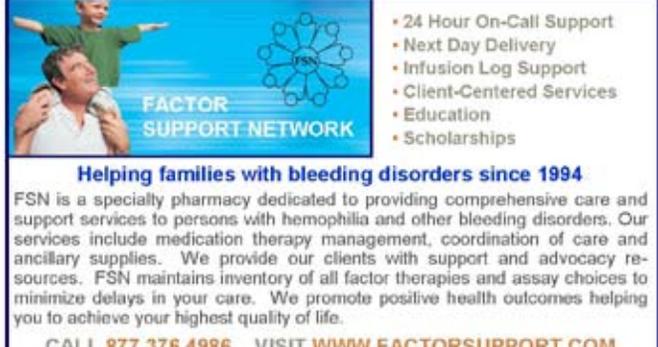
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*Continued from page 9*

Jed Perry, the Director of Legislative Affairs at Baxter who spoke to Symposium attendees, recommended that everyone pay close attention to what happens next, and to get involved at every level of government—local, state and federal.

As importantly, he drew participants' attention to a single significant section—Comparative Effectiveness Research (CER). CER studies are used to examine the relative value of treatments on a certain disease or condition. Rare diseases, such as hemophilia, may not be adequately understood by individuals conducting the studies. The good news is that the new health care law requires that CER studies of rare diseases must have an advisory panel including patients (or caregivers) and clinicians with specific knowledge of the disease. 



*Symposium Attendees*

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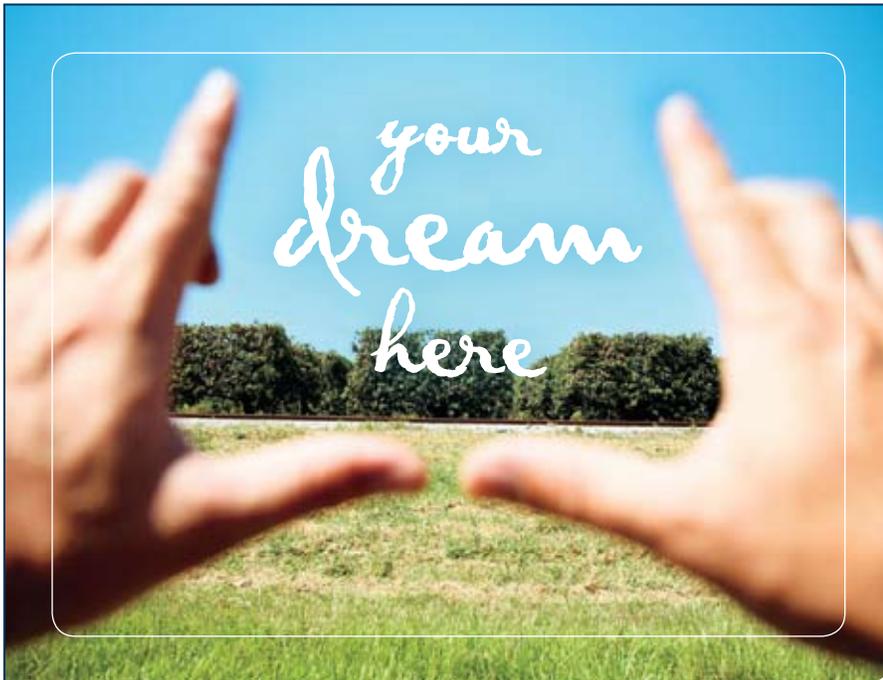
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## HONORING OUR COMMUNITY RECOGNITION AND AWARDS

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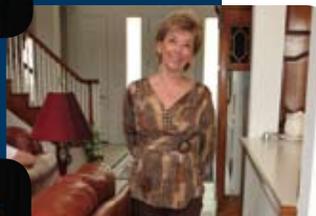
for extraordinary service to the community via one's professional service and work - *Mark Zatyрка*

**Service Award** - for service to the community via one's volunteerism and charitable giving - *Dan LiVolsi*

**T.E.A. Award** - Teach, Educate, Advocate  
(Women's Advocate Award) - *Kathy Gerus-Darbison*

**Volunteer of the Year** - *Margie Yancey*

**The Charles Stanley Hamilton Lifetime Achievement Award** - for extraordinary lifetime service that encompasses volunteerism, professionalism and leadership - *Joyce Donlan* (posthumously awarded).💧



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