

Newsletter of the Hemophilia Federation of America

dateline

FEDERATION

Issue 19 Volume 10 • Spring 2009



Symposium 2009

HFA on the Right Track



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Dateline Federation is published four times a year by the Hemophilia Federation of America, 210 7th St., Suite 200 B, Washington, DC 20003 Toll Free 800-230-9797 202-675-6984 Fax: 202-675-6983 Requests for permission to translate and/or reprint contents of Dateline Federation should be directed to the Editor at info@hemophiliafed.org. Dateline Federation is available as a PDF file from the HFA web site at www.hemophiliafed.org.

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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.

Vision The vision of the Hemophilia Federation of America is that the bleeding disorders community has removed all barriers to both choice of treatment and quality of life.

Educational Symposium 2009

Front Cover: HFA symposium attendees of the kids program join Sam, community member, for a musical performance and lesson in Indianapolis.

Dear Friends of the HFA,

The 2009 Educational Symposium validated to our Board, our staff and me that the HFA is "On the Right Track." This Symposium was held in Indianapolis, IN and was a celebration of the HFA's 15th anniversary. Well over 500 members of our community, member organizations' leaders and the hemophilia community at large came together for an educational, fun-filled weekend. The added fun of the Wii Tournament and Poker Tournaments provided entertainment and connection opportunities for our community members.

The HFA Board met on March 11, prior to Symposium. Important program and administrative issues were decided and the future of HFA is bright! Stay tuned as we are actively introducing a new look, new programs, expanding our offerings to our member organizations and consumers and... we want to hear your Voice as we move forward! Let us know how we are doing!

More information about the individual sessions and news from the symposium can be found throughout this issue of Dateline Federation. I would be remiss in reflecting on the 2009 Symposium without thanking the generous sponsors of our sessions, the speakers, volunteers and staff who made the event happen!

Enjoy this issue!

Chad Stevens

HFA President



The 2009 HFA Board joined their families and staff following a day of Board meetings in Indianapolis.

Ladies and Gentlemen, Start Your Engines, HFA 2009

Symposium Opens with a Rousing “Be Our Guest”

After a rousing singing introduction from the Indianapolis Marriott East staff, HFA Board President, Chad Stevens, officially opened the 2009 Educational Symposium in Indianapolis. The opening provided a forum for acknowledging the outstanding work of community volunteers, generous donations of members and industry supporters.

A moving tribute was delivered in honor of Michael Morse, former HFA Board member, who passed away in 2008. Michael was awarded posthumously the Charles Stanley Hamilton Lifetime Achievement Award for extraordinary lifetime service through volunteerism. The award was presented to his parents Arlie and Ann Morse, honorary guests of the event.



Charles Stanley Hamilton Lifetime Achievement Award: Mike Morse (posthumously)



T.E.A. Award: Jill Williams



Volunteer of the Year: Susan Leffew



President's Award: Susan Swindle

HFA Educational Symposium Highlights for Friday Afternoon, March 13, 2009:

Keynote speaker, Jennifer Jaff, a lawyer and patient with two serious chronic illnesses, shared her perspective of why the fight to make the legal system more amenable to people with chronic illness, is a civil rights struggle.

Jaff established Advocacy for Patients with Chronic Illness, Inc. to assist and advocate for people like her. She has authored two books, one of which was made available to the participants of the session, “Know Your Rights; A Handbook for Patients with Chronic Illness.”

Jennifer shared important statistics and personal stories of patients she’s represented. She’s empowered the bleeding disorders community to get involved in advocacy for themselves and others. Jaff ended her session issuing a call to arms by encouraging attendees to contact their state legislators, to connect with other chronically ill patients around the world and to tell their stories to healthcare activists.

Coming Together Our Community at Work offered interactive roundtable discussions on topics of their choosing. Health Insurance, COBRA, School Advocacy, Personal Advocacy in the ER, Navigating Restrictions on Health Insurance, Standards of Service/Standards of Care and Hepatitis C. Session participants were invited to join small group discussions on a topic of their choosing and subsequently move to another topic of interest.



See page 4 for Lessons Learned from the Friday Sessions.

AT LEFT: Attendees share during a break.



Andy Matthews leads a roundtable discussion on Health Insurance during one of the Friday sessions.

Symposium 2009 - On the Right Track *Hemophilia Federation of America*



Saturday Kisa Carter, HFA Public Policy Director, joins Bill Speirs, PPTA, and other Federal and State advocates to share advocacy issues and strategies.

HFA Educational Symposium Lessons Learned for Friday Afternoon March 13, 2009:

- 1. Consumers beware** - Insurers can change formularies by moving prescriptions into tier 4 and up, and change specialty pharmacies. In addition, prior authorization has to be obtained periodically; you start all over again any time you change specialty pharmacy.
- 2. Career selection and education** are imperative for obtaining and keeping health insurance.
- 3. A key point of standards of care**, clinical, is significant when discussing standards of service, home care service and dispensing. Because there are various ways to provide service (i.e., home care, specialty pharmacy, 340B) developing a minimum standard which can be assessed and accounted for is essential.
- 4. Education, communication and collaboration** between parents, school officials and health care professionals who understand bleeding disorders is essential in developing an appropriate 504 plan for your child.
- 5. Effective communication and proactive personal advocacy** are essential to getting what you need in the Emergency Room as a patient and/or parent of a child with a chronic condition.

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Saturday at Symposium, March 14, 2009:

Does taking ginkgo biloba improve your memory? What is a Medical Health Care Directive? Why should you be concerned about health care changes in New England? These are only a few of the probing questions discussed in the Saturday educational sessions at Symposium.

In the opening session on "Financial Health in Tough Economic Times," Larry Counen, a Senior Wealth Consultant with Robert W. Baird & Co., Inc., gave attendees a compact synopsis of our current financial market. While Counen acknowledged the uncertainty of our economic situation, he also stressed how there are potential signs of improvement on the horizon and how to capitalize on those opportunities by asset allocation and diversification and college saving options. The message of taking charge over personal responsibilities was further echoed in HFA General Counsel Donnie Akers' presentation on the legal tools that persons in the bleeding disorders community could employ as they age. In particular, Akers explained the proper usage of Medical Authorization Forms, Medical Health Care Directive (also known as Living Wills), and Special Needs Trust. And in the last morning presentation, Jeff Hughes, Coordinator of Training and Professional Development of Indiana's Vocational Rehabilitative Services, gave attendees a roadmap for navigating vocational rehabilitation in their state by explaining how the process works in Indiana.



ABOVE: WHF President Mark Skinner addresses the world issues important to the community, specifically with an update on vCJD.



LEFT: Community members share legislative advocacy issues in their states.

Continued from Page four.

After a short break, attendees shifted focus on some of the pressing health matters affecting our community. Mark Skinner, President of the World Hemophilia Federation (WHF), opened with the sobering statistics that an estimated 400,000 people worldwide have hemophilia, of which 70% are undiagnosed and 75% are untreated. Skinner elaborated on how "treatment" encompasses more than just factor; it involves comprehensive care by a team of trained professionals, as well as the personal connections to others in the bleeding disorders community. In light of recent events in the United Kingdom, Skinner also addressed the issue of vCJD, the human form of Mad Cow Disease. Not wanting to provide false assurances or information on vCJD, Skinner noted that the WHF continues to monitor and share information regarding the plasma product transfusion of vCJD. Following Skinner, Dr. Miguel Escobar of the Gulf States Hemophilia and Thrombophilia Center walked attendees through the often cited but perplexing world of Complementary and Alternative Medicine (CAM). As a specialist who works with patients who have bleeding disorders, Dr. Escobar cautioned that "what is on the label may not be what is in the bottle," particularly with herbal products, because they are not supervised by the FDA. Dr. Escobar then presented existing



data that purports that some CAM treatments, like ginkgo biloba, ginseng, garlic extract, curcumin (turmeric), St. John's Wort, may adversely affect persons with bleeding disorders by inhibiting platelet aggregation.

And in the last session of the day, "Legislative Advocacy Update Session," Diane Dorman, Vice President for Public Policy at the National Organization for Rare Disorders (NORD), began with an informative lecture on the legislation and issues associated with the future of health care in America. As NORD's primary liaison to the FDA, Dorman outlined her work to gain access, sustainability and affordability for all with rare diseases, hemophilia in particular. Bill Speir, Assistant Director for State Affairs for the Plasma Protein Therapeutics Association, spoke about the effect that the economic stimulus bill and the rough economy will have on the 47 states that are facing budget shortfalls. His message was supported by the mini-presentation from leaders and grass-root advocates, such as Tony Maynard of the Hemophilia Council of California, who discussed recent legislative activity in their states that relates to the bleeding disorders community. HFA Public Policy Director Kisa Carter closed the session with the request for collaboration to effectively and successfully address these challenges.

A Special Note To Those Who Have Gone Before

What always makes HFA so special to me is the feeling of old-timers and newcomers who join together to form lifelong friendships. This year was no different, especially during the Memorial Session. The session's mood was set by Sam and his beautiful guitar work which was the first thing I heard when I entered the room. The second thing that struck me was the number of people who were there. The room was literally packed with young and old, male and female and newcomers, as well as those of us who have been in the trenches for a while.

I was reminded our losses are not limited in any way but when we come together as we did here, they are shared and thus they become less than when carried alone. It seems that every year we hear of someone who has passed in the last month or so, but this year was especially sad as we were told the story of a young boy who passed hours ago! Yet somehow this pulled the room together. We shared memories of laughter and sadness, pain and sorrow, and this too pulled us a little bit closer. Some had to leave because the emotions were overwhelming, yet it seemed everyone left with a renewed sense of being a part of this big family in which no one will ever be forgotten.

As long as one of us is here to carry on the memory, we are all here! I can only imagine what someone walking past might say about what they overheard. I think some would believe it was a truly sad session because of all the crying and tears. Some would think it was a funny session because the laughter rang out. Others who saw the doors open at the end of the session would have the best description and that would be the sight of one very large family filled with love and true feelings of joy for each other. For me this was the most emotional memorial session I can remember, and I am honored to be a part of this family and be able to remember those who have gone before.

With love, "A Family Member"

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BLOOD Brotherhood

Hemophilia Federation of America

By: Jim Brown

This was my first time to attend a session of “Blood Brotherhood” in quite some time, and I must say I was quite impressed by the growth, the support and the interest.

Over 45 “brothers” attended the session facilitated by Axel Freese and John Jarratt, with an open forum and great participation. Attendees included first-timers and “old-hands,” but everyone was on an even plane. One first-timer said he learned so much more from others who were willing to share their personal experiences, etc.

The Blood Brotherhood discussion topics included:

- **CHAT SITE** - a place for “men with bleeding disorders only” to go to talk about whatever issues they have. One excellent example of the power of the chat site was a hemophiliac looking for information on elbow replacement. He had been able to find little information on elbow replacement generally and virtually none for hemophiliacs. On the Blood Brotherhood website he found five other brothers with specific information on the procedure, outcomes, etc.

- **CONNECTIONS ARE IMPORTANT** – it became clear that one of our greatest resources is the connections we have and can establish with other brothers. Mike Morse’s dad attended and said he found the group to be a close-knit family and he was proud to have gotten to be part of this event. Many need to reconnect if they had gotten burned out and dropped out for a while.



TOP: HFA Blood Brothers gather to share in the Blood Brotherhood Breakout Session on Saturday. ABOVE and RIGHT: Friday night Blood Brothers joined Dad’s in Action and others for a hand of poker!



- **SHARING STORIES** – We all have stories to share – some may be “horror” stories while many others are marvelous stories of loving and caring families, supportive brothers, successful careers, marriages and enjoyable hobbies and other interests. Sharing these stories can be a source of encouragement and positive reality for others, including families with younger hemophiliacs.

- **GENERAL HEALTH/HEMOPHILIA** – we need to take care of our general health in addition to our “hemophilia” health. With better products, care through HTC’s and home care providers, we are much less limited in what we can do in the way of activities. **WE HAVE BEEN EXCLUDED FOR TOO LONG** from athletics and other “normal” activities of daily life! It is also extremely important that all of us, especially aging and older hemophiliacs, take care of our general health. It may be that we are just as likely,

or maybe more so, to succumb to some more common illness such as heart trouble, diabetes, cancer, etc. We may be in better “blood health” than we are in some other areas.

We can all still learn about bleeding disorders, advocacy, etc. no matter how old we are. We need to continue to work for safe, affordable and accessible medications and treatment. **ONWARD and UPWARD!**

To get involved in the Blood Brotherhood Chat Forum visit: <http://hemophiliafed.net/hfabb/>

Dads in Action

Hemophilia Federation of America

By: Lance Cleghorn

Flop, straight, full house, folding, all in and bluff... poker terms to most people, but today they were all terms teaching us about being better fathers. We were very fortunate to have Mark Borowski, author of *Big Slick Daddy*, speak at the Dads in Action breakout session at this year's HFA Symposium.

Mark started with a story about sitting around a poker table and being dealt a seven and a two, the worst hand in poker. As any good poker player would do, he folded and watched the other players bet. When the flop came, he watched in disbelief as the dealer turned over a seven-seven-two, which would have given Mark a full house and the winning hand. The story led to discussions about playing the hand you are dealt. It also pertains to the family environment we grew up in and how we were raised.

Mark defines success as the progressive realization of a worthy ideal or how you handle plan "B". Being a father of a child with hemophilia was probably not the plan most of us had when we realized we were going to be a father, but now we must play the hand we were dealt.

Statistics relayed to us from the National Fatherhood Initiative's (NFI) Father Facts seemed to amaze most of the attendees:

- 24 million children (34%) live in homes without a biological father.
- About 40% of children in father-absent homes have not seen their father at all during the past year.
- 50% of children living without their father have never set foot in their father's home.

Poker terms applied to fathering included:

- "ALL IN" - a term that every poker player loves to say because it is a power move when you commit all of your chips. When a father is "All In" it shows that he has made a total commitment to his kids (i.e., helping them with their homework, playing games and going on school field trips). Fatherhood is hard work -- the payoff for an "All In" commitment may come later or may never come. The way a kid spells love is "time."

- "BLUFFING" - can work in poker, but not with our children. We need to be honest with our kids. One of the best traits we can teach our kids is honesty in any situation. By trying to bluff our kid, which may work sometimes, we are teaching them to lie to get the behavior we want.

- "DIAMONDS IN THE MUCK" - to look for the positives that can come out of any negative experience (i.e., how responsible kids with hemophilia seem to be and how they seem more caring towards others).

We concluded our session focusing on the good our kids do. We need to talk with them about the positive things they do and not just the things they do wrong. We need to show them that we have a genuine interest in them as people and that we need to make the "All In" commitment to them!



HFA Dads in Action went "All In" at the 2009 Breakout Session (ABOVE), and Friday night Poker Tournament (BELOW).

Stay tuned for Dads In Action Program updates coming your way in Summer 2009!

Hemophilia Federation of America
FOCUS ON THE *Feminine*



Focus on the Feminine Breakout Session brought together moms, spouses, caregivers and women with bleeding disorders for open discussions with fellow women.

By: Tracey Cleghorn

Moms, spouses, caregivers and women with bleeding disorders – individually, strong, together, a force to be reckoned with. That’s what HFA had at the Focus on the Feminine breakout session at the 2009 Educational Symposium.

The session started with an inspiring talk from Shelly Mattson from Milwaukee, Wisconsin. Shelly is a young lady with vWD that is an active volunteer in the bleeding disorders community. She encouraged everyone to remain involved.

We then split up into groups: mothers, spouses/caregivers and women with bleeding disorders. As a mother of a son with hemophilia, I participated in the

Mom’s group. We had an open discussion where moms were able to ask questions. Who better to get answers from than fellow moms!

Following are a few of the questions asked:

- A mom of a teenage boy asked about her son telling his girlfriend – should he, if so, when should he? Boys choose who they want to tell and when. Quite often they may date a girl in the bleeding disorder community. Encourage your child to be educated.
- A mom of a sixteen-year-old boy commented that her son is very resistant to prophylaxis treatment and asked what she could do to encourage prophylaxis treatment. Boys that are on prophylaxis don’t always know what it feels like to have a bleed and to feel that pain. Therefore, there’s no cause and effect. A mother of an adult son said, “It’s their disease; it has to be their choice. As their mother you support and love them.”
- A mother of a young boy asked if anyone else had seen a difference in their child’s behavior since starting prophylaxis. Children seem to learn at a very young age that prophylaxis ensures them to feel better.
- Know your child so that you can diagnose how severe the bleed may be and then know what course of action to take.

In closing, a mom told a great joke: “How many hemophiliacs does it take to change a light bulb? None, their mother does it for them.”



Share your Story...

FOCUS ON THE FEMININE is collecting stories of moms, women with bleeding disorders and spouses in our community. These stories will be compiled into a booklet that honors and offers inspiration to women. If you would like more information or share your story, please email info@hemophiliafed.org.

Hemophilia Federation of America Symposium Snaps



TEEN Connection

Hemophilia Federation of America

Teens Connect at 2nd Annual Overnight Camp

By: Lee Hall, Global Health Society, President and CEO

This year marked the second annual “Teen Connection Camp” hosted by HFA under the direction of Global Health Society, Inc. (GHS). We believe camp is an integral part of our bleeding disorders community and through our camp program we strive to empower our next generation with tools that will last a lifetime.

This year’s “Teen Connection Camp” reflected and expanded on last year’s camp program “All One World . . . A Herd to be Heard.” We looked to explore our own self-identity and our place in this world. “All One World” has become a theme as we think about our blood brothers and sisters around the globe. We all have individual personalities and special gifts or talents. Through camp we have the opportunity to explore those individual skills that make up an effective working fraternal organization.

CONTINUED on next page.



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TOP: Teen Connection Members gather at Camp in Indiana. ABOVE: Teens perform their dance at the final night HFA Birthday Bash. RIGHT: Lee Hall self-infuses during the Teen Connection program.





LEFT: Teen attendees tackle the ropes course at Bradford Woods. RIGHT: "It's a Wrap" teaches clinical skills to teen members.

CONTINUED from Page 10; Teen Connection.

Highlights of camp included:

- Renee Embry led a multimedia art project that explored personal identification through creative envelope art. The group developed an envelope reflective of their individual personality, passions, interest and activities. At the end of the weekend all campers wrote a letter to themselves that contained goals, dreams or lessons learned and placed it in their artistically designed envelope to be mailed to all of the participants in the future months as a reflective journey of the "Teen Connection Camp."

- Jecorei Lyons taught the ever-so-popular "Teen Connection Dance" which made its debut at the HFA Birthday Party on Saturday evening. Jecorei also shared his inspirational story about how he became involved in dance, while instructing the teens and counselors through exciting new moves.

- Irene Vlaskamp, PT, took the clinical component of our camp far beyond the confines of the infirmary and was integrated directly into the program. Her interactive sessions included "It's a Wrap" and "Stretching Your Mind and Your Body."

- Jennifer Maahs, MSN, PNP, led a very enlightened session - "You Can Pick Your Friends But Not Your Nose" - discussing valuable noninvasive treatments affective in stopping nosebleeds.

- Amy Shapiro, MD facilitated "Myth Busters," dismantling many myths about bleeding disorders and their complications. This session discussed the common and the obscure, candidly captivating the teens in her reality talk.

- Other camp activities included teambuilding, campfire, hiking, and, of course, the adventures of a forty-foot alpine climbing tower and pampered platform.

Our journey of self-actualization was a key component with global awareness. The lessons learned at camp shape our lives, nurturing our own personal dreams, talents and skills through fun and fraternal camaraderie. "The Teen Connection's goal is to help teens within our community develop leadership skills and to educate the public about the myths and realities of living with these disorders. An additional benefit of the Teen Connection goal is that it ensures future leaders for our organization." *For more information on the Teen Connection, please visit www.hemophiliafed.org.*

Kid's Corner



By: Joey Privat

Participants in the 8 to 12 year old group were excited to visit the Children's Museum in Indianapolis. The highlight of the day was the Power of Children exhibit that featured a

performance and display of Ryan White's bedroom complete with signed gifts from Michael Jackson and John Denver among many admirers of the young man. The staff, as well as the kids in attendance, felt that reaching into the personal life of Ryan was the best learning experience possible.

To learn more about the Ryan White exhibit and for lesson plans about Hemophilia and Ryan White visit www.childrensmuseum.org/themuseum/powerofchildren/html/index.html



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A Community Success Story: Advocacy for Factor I Deficiency Part II

By: **Drew Matz, Special Projects Coordinator and Kisa Carter, Public Policy Director**



Emily Bartko, now has access to a fibrinogen concentrate for the treatment of Factor I Deficiency.

Twenty years ago Jose and Linda Trujillo were told that their 18 day-old son, Michael, had Factor I deficiency. The physician relayed this information to them on a piece of paper with the instructions, read it and asked if there were any questions. “I couldn’t think or speak at that moment,” recalls Linda who also notes that at the time she had “no clue what to even ask.” With no resources and little information, Jose and Linda followed the prescribed regimen of treating

Michael’s numerous bleeds with cryoprecipitate (cryo).

Fortunately, when Michael was 4 years old, Linda was able to enroll into the “single donor cryo program,” which was initially established for Factor XIII and IX patients. The program consisted of donating her plasma through apheresis, which was then assayed and stored at home in a freezer so they could treat Michael when necessary.

However, with the advent of recombinant factor, the program closed when Michael was 8 years old. While the Trujillos had long heard of other treatments, such as Factor I concentrate, they were told that it was unavailable in the United States. Faced with limited choices, the couple decided to return to cryo treatments.

Seventeen years later, John and Alison Bartko experienced a similar dilemma when they discovered that their daughter, Emily, had Factor I deficiency. Three days after Emily’s birth, the joy of welcoming their beautiful daughter turned into fear and confusion. The Bartkos felt extremely overwhelmed and scared when the doctor said that there was no current treatment available in the United States. They worried whether she would die without treatment and how they could possibly keep her safe.

Unlike Michael, though, Emily had the opportunity to access a treatment very early in her life through a compassionate use program. Unavailable in the United States,

Haemocomplettan-P, manufactured by CSL Behring, is the preferred choice of treatment in several countries in Europe. However, it had not yet received marketing approval in the United States. In April 2007, Rebecca Berkowitz, a registered nurse at the Hemophilia Treatment Center of Las Vegas, sent an investigational new drug (IND) application to the Food and Drug Administration (FDA). On October 2, 2007, Emily received her first infusion of Haemocomplettan-P.

At the same time, Michael entered into the Haemocomplettan-P clinical trial and began treatment in November 2007 at age 17. Haemocomplettan-P was a therapy improvement for Emily and Michael. Both families remained hopeful that Haemocomplettan-P would receive marketing approval in the United States.

In January 2009, the Hemophilia Federation of America (HFA) sponsored the Trujillo and Bartko families to travel to Washington, DC and share their stories with the FDA Blood Products Advisory Committee (BPAC). The BPAC is the governing body, responsible for advising the FDA Commissioner on issues that help ensure safe and effective biological (blood) products. Rebecca Berkowitz, a registered nurse, and Doctors Jonathan Bernstein and Andra James provided an oral testimony to support the use of Haemocomplettan-P for Factor I deficiency. The HFA, NHF, and the National Organization for Rare Disorders (NORD) also testified. Each person provided a testament to the importance of an approved therapy to treat Factor-I deficiency. After the testimonies and during the BPAC open discussion, several BPAC members referred to the stories of Emily and Michael. Approval of the first factor concentrate to treat congenital fibrinogen deficiency in the United States was favorable.

On January 16, 2009, the Bartkos and Trujillos received the news they had long awaited. RiaSTAP™, known as Haemocomplettan-P in Europe, was granted marketing approval for the treatment of congenital fibrinogen deficiency in the United States. As Alison Bartko expressed, “Having access to a fibrinogen concentrate has been nothing less than life changing for Emily and our family.” Likewise, Linda Trujillo was also thrilled by the outcome.

The approval of CSL Behring’s, RiaSTAP™ constitutes a major breakthrough for individuals with Factor I deficiency. For Emily, Michael and others with Factor I deficiency, the approval of RiaSTAP™ marks the beginning of an improved quality of life and better health outcomes.

HFA remains committed to supporting the approval of safe and effective therapies to treat all bleeding disorders. If you or someone you know has a rare bleeding disorder and would like to tell your story, please contact Kisa Carter at k.carter@hemophiliafed.org.



WHAT IS THE VOICES CAMPAIGN?

The Voices Campaign is the HFA's grassroots advocacy initiative that aims to publicize the bleeding disorders community's health issues to the public and legislatures by way of personal stories. We hope to utilize these personal stories in two ways.

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

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

What is involved? Because your VOICE is an important part of the debate surrounding healthcare reform, we want to know your stories and concerns on the issues that affect our community. Lifetime caps on insurance, access to public and private health insurance, availability of factor product, or the overall need for healthcare reform are just a few examples.

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

How can I be a part of this campaign and have my Voice heard?

1. Email Info@hemophiliated.org to indicate your interest.
2. We will contact you to collect your story and discuss how it may be utilized.
3. Sign-up on our online advocacy tool, Capwiz, at www.hemophiliated.org under "Legislative Action Center" to receive action alerts about upcoming legislation that impacts our community.

Legislative Advocacy Update

Legislation Introduced for Lifetime Caps Increase

The Health Insurance Coverage Protection Act was introduced on February 13, 2009. The Senate bill was introduced by Senators Byron Dorgan and Olympia Snowe. The House bill was introduced by Representatives Anna G. Eshoo, Jim Langevin, Betty Sutton, Dale Kildee and Jason Altmire. The Hemophilia Federation of America (HFA) appreciates the leadership of the sponsors and co-sponsors on this very important issue.

It's imperative that we continue to gain support for an increase in lifetime insurance caps placed on private health insurance plans. TAKE ACTION NOW to gain sponsors and ensure that increasing lifetime caps becomes a priority on the 2009 legislative agenda!

The Health Insurance Coverage Protection Act (S. 442 and H.R. 1085) will raise the minimum level of lifetime caps to \$5 million for the first two years and \$10 million in years three and four. Annual adjustments to lifetime caps will be raised in subsequent years based on the consumer price index.

Individuals with disabilities or chronic illnesses can reach their lifetime cap within a few years. Individuals who reach their private health insurance cap are forced to pay their health care expenses out of pocket, apply for benefits through a state health program, or seek free care from hospitals or medical providers.

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Helping Hands

Hemophilia Federation of America

By: Janel Johnson-Momanyi

The HFA community has been hard-hit by the financial crisis facing the US economy. Consequently, requests for assistance to the Helping Hands program have tripled in recent months. Families are forced to balance job lay-offs and plant closings with the struggles of bleeding disorders. The hike in gas prices and the lack of affordable health care coverage has also not gone unnoticed by those affected with bleeding disorders.

In my short time with HFA, however, I have been constantly reminded of and continuously impressed by the resilience of our applicants. Their ability to overcome improbable circumstances is astounding. One family in particular is made up of a single mom with five adopted children. Three of the adopted children have a bleeding disorder, and the mom was recently sidelined by an injury which required surgery.

Yet the mom's primary focus is returning to work as a cake decorator, so she can continue to provide for her family. Amazing!

Susan Leffew, Helping Hands Committee Chair writes:

"Every scenario imaginable comes to the Helping Hands program committee for review. Serving on the committee is a challenging task and the HFA is extremely grateful to those who volunteer as well as to those who help fund the program. We currently receive funding from Wyeth, Griffols, and Accredo's Hemophilia Health Services to help offset the cost of Helping Hands. HFA is extremely grateful for this support. In addition, HFA is very appreciative of the individual donations we receive from the community for the program."

Working together - we can make a difference.

Support for this program is needed and appreciated. To discuss how you can contribute, email: info@hemophiliafed.org

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NACCHO: Making a Difference



By Bob Graham – Camp High Hopes, NY & NACCHO Planning Committee

Did you know that nationally there are over 50 camp programs for children with bleeding disorders and almost a dozen for their families? It's a large, if often overlooked segment of the national bleeding disorders community, which is why there's NACCHO to bring them together.

Now in its 7th year, NACCHO, or the North American Camp Conference of Hemophilia Organizations, is an

annual gathering for the administrators and staffs of summer camp programs serving children and families affected by bleeding disorders. Held in Tempe, Arizona NACCHO features nationally renowned keynote speakers and literally dozens of lectures and workshops.

NACCHO is the creation of the Arizona Hemophilia Association, and supported by a generous grant from Wyeth Pharmaceuticals. All of the speakers, workshops, and lectures directly address such camp specific topics as medical care at camp, camper activities, staff training, managing camper behavior, fundraising, liability, staff screening, and more. Attendees share their ideas, learn from successful programs at other camps, and work together to develop new programs everyone can bring back to their camps. The goal is to pool experience and improve the potential of all camps to better serve their children and families.

Already NACCHO has helped institute a standard of care for camp medical staff, which is critical to keeping the campers healthy. And now NACCHO has developed a complete set of Best Practices for running the rest of camp to give everyone the safest, most enriching experience they can have. Other goals include developing ongoing bleeding disorders education programs and successful teen leadership programs at the local and national level.

More information about NACCHO along with a section of camp program materials available for download, can be found at the NACCHO website naccho.com.

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The deadline for applying for 2009 HFA Educational Scholarships is April 30, 2009. You can obtain the requirements and forms necessary at www.hemophiliamed.org or by calling the HFA office at 800-230-9797.

TO APPLY VISIT:
<http://www.hemophiliamed.org>

The Latest in Industry News



Baxter Becomes an Angel Partner for 2009

At the 2009 HFA Educational Symposium, HFA President Chad Stevens and Executive Director Kimberly Haugstad accepted the generous donation of \$100,000 from Baxter in support of HFA's 2009 Programming. Baxter representatives from left to right are Jeff Beck, Michael Bradley, Janie Davis, Shannon Resitich and Meredith Zerbe. Pictured between Mr. Beck and Mr. Bradley are Kimberly Haugstad and Chad Stevens.

For information on sponsorships and gifts to the HFA, please contact HFA Development Director Susan Swindle at s.swindle@hemophiliafed.org

FDA Approves RiaSTAP™ for Treatment of Bleeding in Patients with Rare Genetic Defect

The US Food and Drug Administration licensed RiaSTAP™, an orphan drug, for the treatment of bleeding in patients with a rare genetic defect known as congenital fibrinogen deficiency. Without treatment, these patients are at risk of potentially life-threatening bleeding.

RiaSTAP™ is an intravenous fibrinogen concentrate made from the plasma of healthy human blood donors. The product is indicated for patients who have no fibrinogen or low levels of the substance, an abnormality known as afibrinogenemia, or for those patients whose fibrinogen levels are below 50 mg/dL, an abnormality known as hypofibrinogenemia. The product is not indicated for patients with dysfibrinogenemia, who may have normal fibrinogen levels but defective fibrinogen function. Patients such as these are at risk for both bleeding and clotting complications.

This information is made possible by the FDA. For more information or for consumer inquiries call 888-INFO-FDA or visit www.fda.gov.

Pfizer to Acquire Wyeth

(January 26, 2009) - Pfizer (NYSE: PFE) and Wyeth (NYSE: WYE) announced that they have entered into a definitive merger agreement under which Pfizer will acquire Wyeth in a cash-and-stock transaction currently valued at \$50.19 per share, or a total of approximately \$68 billion. The Boards of Directors of both companies have approved the combination.

This information is made possible by Pfizer and Wyeth. For more information please visit <http://www.premierbiopharma.com/Jan-26-2009.php>.

FDA Grants Full Approval of Procleix Ultrio Blood Screening Array

(San Diego) Gen-Probe Incorporated (Nasdaq: GPRO) announced today that the US Food and Drug Administration (FDA) has approved its supplemental regulatory application to use the PROCLEIX(R) ULTRIO(R) assay to screen donated blood for the hepatitis B virus (HBV). The FDA had previously approved the assay to screen donated blood for HIV-1 and the hepatitis C virus (HCV).

This information is made possible by Gen-Probe Incorporated. For more information please visit: <http://www.gen-probe.com/news/PressReleaseText.asp?compid=135117&releaseID=1187155>.

Patient Services Acquires Access Program from Accredo

(February 20, 2009) - Patient Services, Inc. (PSI), a leading health non-profit, acquired the A.C.C.E.S.S. (Advocating for Chronic Conditions, Entitlements and Social Services) Program from Accredo Health Group, Inc. in an agreement that was executed on February 19, 2009. Under terms of the agreement, Accredo Health Group will also provide PSI with a grant to help develop and maintain the program.

This information is made possible by PSI, Inc.

ARTICLE CORRECTION, page 7 of Dateline Federation (Issue 18, Volume 10, Holidays 2008). The Strap Wrap, a seatbelt I.D. strap manufactured by Rescue Facts LLC and is available via many homecare companies, not just the one indicated in the article. The editors of Dateline apologize for the error in reporting on this very helpful product. More information is available through Rescue Facts at www.rescuefacts.com.

Corporate Partners *Hemophilia Federation of America*

2009 Honor Roll of Corporate Partners

The Hemophilia Federation of America would like to recognize and acknowledge those home care providers and pharmaceutical manufacturers who have contributed financially towards the accomplishment of our mission.

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Hemophilia Federation of America **Calendar of Events**

DATE	CHAPTER	EVENT
April 2009		
4/4/09	Florida	Lighten Up Program (informative cooking & nutrition program)
4/4/09	Texas Central	West Texas Family Day - Lubbock
4/4/09	Arkansas	Bowling Bash at Bowling World Fort Smith, AR
4/4/09	Maryland	Annual Spring Bull and Oyster Roast and Silent Auction
4/5/09	Illinois	Latino Event
4/15/09	Northern Ohio	Baxter Facts First - Dave & Buster's Westlake
4/18/09	Louisiana	Annual Crawfish Boil
4/19/09	Capital Area	Tennis Tournament
4/24/09	North Carolina	HNC 5th Annual Charity Golf Tournament - The Preserve at Jordan Lake, Chapel Hill, NC
4/24/09	Florida	Volley for a Cure Tennis Tournament
4/24/09	Illinois	Advocacy Volunteer Training
4/25/09	Northern Ohio	First Step - Akron Area
4/25/09	Illinois	Statewide Weekend
4/30/09	Tennessee	Music City Golf Classic
May 2009		
5/2/09	Texas Central	Fort Worth HTC Family Day - Fort Worth
5/2/09	Capital Area	Adult Male Retreat
5/4/09	Arkansas	Hemophilia Awareness Day
5/11/09	Capital Area	Golf Tournament
5/13/09	Illinois	Women's Night Out
5/13/09	Nevada	5K BloodRun
5/15/09	Northern Ohio	Black & Blue Ball
5/16/09	Texas Central	East Texas Family Education Day - Tyler
5/16/09	BDAST	Bronx Zoo
5/16/09	Illinois	Marcus McClure Family Camp
5/17/09	Northern California	Spanish Outreach
5/17/09	Illinois	Family Camp
5/20/09	Northern California	HCC Leg Day
5/27/09	Illinois	Blood Brotherhood Meeting
5/30/09	North Carolina	HNC Annual Meeting - Raleigh/Durham, NC
5/30/09	Illinois	Krueger Bowl
5/30/09	Nevada	1 Mile Run/Picnic/ Carnival Raffle
5/30/09	Nevada	Community Summit & 50th Anniversary Celebration
June 2009		
6/1/09	Illinois	HFI On the Road
6/2/09	Illinois	HFI On the Road
6/5/09	Texas	Matthew Thomas Golf Classic & Jr. Golf Tournament
6/6/09	Maryland	2009 Run/Walk for Hemophilia
6/7/09	BDAST	Binghamton Mets Baseball Game
6/9/09	North Carolina	HNC 2009 Legislative Day - Raleigh, NC
6/13/09	Illinois	CEO/Parents' Event
6/13/09	Arkansas	Arkansas Annual Meeting, Wild River Country, North L.R., AR
6/13/09	New York	Garden Gala
6/16/09	Illinois	Healthy Bleeding 2015 Summit
6/17/09	Northern Ohio	End of School Family Event
6/17/09	Illinois	Healthy Bleeding 2015 Summit
6/18/09	Indiana	Course for a Cure (Golf Outing)
6/19/09	Florida	Swim with the Dolphins
6/20/09	Texas Central	TexCen Annual Meeting & Family Day - Arlington
6/20/09	Illinois	Camp Experience Event
6/27/09	Illinois	Blood Brotherhood Meeting
6/29/09	Tennessee	Blues on the Green Golf Classic
July 2009		
7/5/09	Illinois	Latino Event
7/11/09	BDAST	Summer Picnic - Dorchester Park
7/17/09	Florida	Swim with the Dolphins
7/18/09	Northern Ohio	First Step
7/19/09	Northern California	Spanish Outreach
7/21/09	Illinois	Hemophilia Advisory Board Meeting
7/26/09	Northern California	Speeders for Bleeders

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We welcome individual and corporate giving. Membership and Donation forms can be found at www.hemophiliafed.org.

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