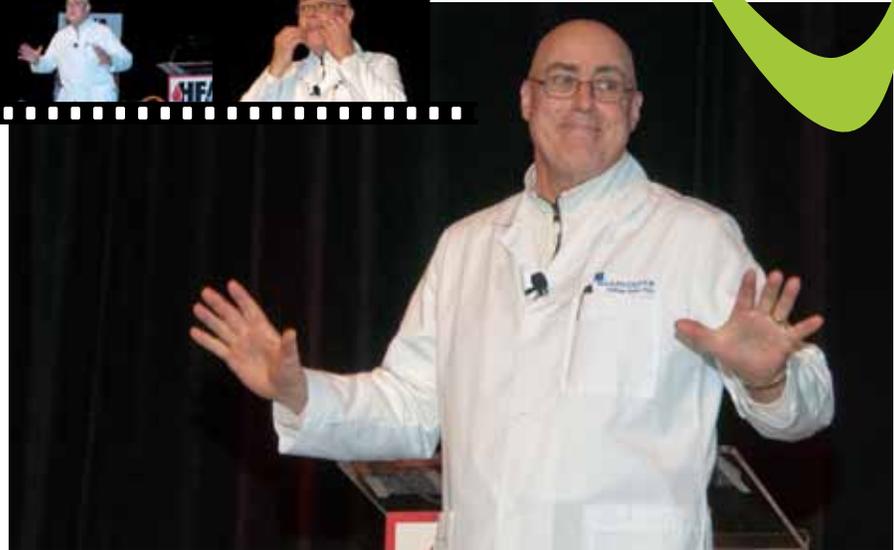


THE *Laugh* DOCTOR: *It all starts with a smile*



*"A happy heart is good medicine," says Dr. Clifford Kuhn.*

Good fun also turns out to be good medicine. So began HFA's 2011 Symposium with a kick-off luncheon and nationally known keynoter whose mantra is "it all starts with a smile."

When Dr. Clifford Kuhn arrived on stage, he brought along a scratched, well-worn satchel – his medical bag. Originally, it was a gift in his student days from his alma mater, the Jefferson Medical College in Philadelphia. Today, it holds clown noses and a collection of rubber balls that are indispensable for his brand of medicine – working with providers as well as patients who have suffered traumatic injury, life-threatening illness or chronic disease to teach them how to reduce stress, eliminate fear and achieve balance in their lives – through effective and appropriate humor.

While he no longer has a private psychiatric practice, the Laugh Doctor has built a national following by developing a methodology and life-managing techniques for intentional wellness.

**Stress an epidemic**

Stress, according to Dr. Kuhn, is an epidemic in our society. There are three reasons why, he says: the way we live, the way we treat each other, and the way we diagnose stress. Some 80% of medical problems, he notes, are stress-induced or stress-related. It's costly – some \$300 billion annually in lost productivity. And it's costly in other ways

too: We drug ourselves, we stuff ourselves, and we exhaust ourselves (in the gym). All are temporary "treatments" in trying to cope.

Dr. Kuhn asks his audience to understand that "stress is a feeling not a fact, a symptom, not an underlying cause." He says it is a perception and a reaction: we feel overwhelmed. Much of stress, he posits, comes from fear – that "I'm not good enough," or feeling inadequate in the face of challenges.

**Letting go of the fear**

Here's where juggling comes in. Out of his kit bag come three balls – and he's happy to put them in play. With one ball, Dr Kuhn demonstrates you need to catch the ball; with two, you have to watch by paying attention. With three, you must be able

*Continued on page 6*

**Humor's 12 Proven Health Benefits**

- Reduces Stress
- Boosts Immunity
- Relieves Pain
- Decreases Anxiety and Fear
- Stabilizes Mood and Prevents Depression
- Rests the Brain
- Enhances Communication
- Inspires Creativity
- Maintains Hope
- Bolsters Morale
- Sustains Resilience
- Creates a Healthy Long Term Perspective

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•• **DON'T MISS** ••

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## EXECUTIVE CORNER



Dear Members of the Bleeding Disorders Community,

Welcome to the newly designed *Dateline*, HFA's national newsletter! Inside you will notice several changes. We hope you enjoy the new features and continue to utilize *Dateline* as a valuable resource.

In this issue, there is broad coverage of the 2011 HFA Symposium in Louisville, KY. For those in attendance, there are familiar scenes and faces, and for those who could not join us, this issue will provide a summary of the information sessions and educational programming that you can use.

There is an African proverb, "It takes a village," and at HFA we say, "Yes, it sure does!" After a year of planning, individuals and families affected by bleeding disorders across the U.S. gathered for a meaningful experience in Louisville. Thank you to HFA staff and volunteers who helped make the 2011 Symposium Racing Ahead, Together We Can! a great success!

The Symposium Committee, board members, speakers who donated their time and talent, donors who supported the meeting, and all participants who came to learn and share their insights with other attendees, were integral to ensuring the value of Symposium. At the core, the April meeting met our guiding principles to educate, support and empower our community.

Symposium is one step, which can become a gait; a gait can lead to a trot (to use a horseracing metaphor), and as we Race Ahead, we must build on what we learn and apply these lessons to our everyday lives.

YOUR support, passion and the talent of the bleeding disorders community is critical, so please engage your enthusiasm and participate in your local area. The network and relationships you develop through community engagements like the HFA Symposium, as well as local programs and activities, are incredibly meaningful.

*Together We Can.*

Have a great summer!

**"Coming together is a beginning;  
keeping together is progress;  
working together is success."**

*Henry Ford*

Paul Brayshaw

Kimberly Haugstad

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### DISCLAIMER

The material provided in *Dateline Federation* is provided for general purposes only. HFA does not give medical advice or engage in the practice of medicine and recommends that you consult with your physician or local treatment center before beginning any form of treatment.

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*Thank you*

To all who donated  
time and made  
Symposium  
a success!

## Dads and Moms – A Family Perspective

As parents of an eight-year-old son with severe Hemophilia A, when we learned the topic “Parents Working Together to Make it Happen: Creating Harmony in Families with a Bleeding Disorder” was on the agenda, we were both instantly interested.

Dave Robinson, Ph.D. LIMFT, Department of Family Medicine at the University of Nebraska Medical Center, gave a fantastic presentation that reiterated what everyone in the room already knew: “All families face challenges.” With his own family-life challenges – he has two sons with a bleeding disorder – Dr. Robinson offered some great advice. He said, “Remember, working briefly on your marriage every day will do more for your health and longevity than working out at a health club.”

**“...working briefly on your marriage every day will do more for your health and longevity than working out at a health club.”**

For those of us who find it challenging to get to the gym on a regular basis, this was welcome news! He noted, “Couples with a child who has a chronic illness CAN have higher divorce rates and decreased satisfaction, BUT this doesn’t have to be you.”

Among his tips to help couples stay strong: weekly dates, remembering to say goodbye in the morning, and learning one thing that is happening in your spouse’s day. I think we all agree: These are much easier and more enjoyable than hitting the gym!

Following Dr. Robinson’s presentation, the moms and dads broke up into separate groups for a rap session. Although they were separated, the theme was common: How do we become better parents?

When the question was asked of the moms – who has caregiver burnout? – all hands went in the air! While it was comical, it was an indication of two things everyone in the room had in common: We are all moms and we are all burnt out. Facilitator Niki Murray gave the moms the title of COM: Chief Operating Mom. During the introductions, one mom concluded the list of members in her household with “... and a mom at home that keeps us all together.” Niki replied with “That’s what moms do.”

While a large part of the discussion focused on caregiver burnout, the dads were not far from our minds. Another common concern was how to get our partner/spouse more involved and make them a better parent. The dad’s rap session involved the same theme.

The dads all had similar concerns: What is the best way to allow your children to thrive while keeping them safe? In our household, as in many, it is a very delicate balancing act. Dr. Robinson reiterated a few important general guidelines:



- It is important to present a united front. It was agreed that sometimes this is easier said than done. Quite often, parents have very different opinions on safe activities for their children;
- Have clearly defined limits;
- Remember that it is easier to fix their bodies than their minds – don’t hover – allow them to learn.

Dr. Robinson offered great suggestions – some new and some that we all knew but needed to be reminded. The separate rap sessions provided a strong bonding experience for each group and for each couple. The moms and dads had similar concerns. At the end of the day, we, as a couple, realized that we had the same concerns as well. Thanks to Dr. Robinson, we now also have some great tips on how to best handle our concerns, together. ■ ■



## Beyond My Diagnosis

*The presenter for the women's breakout was Dr. Deborah Brown, Associate Professor in the Department of Pediatrics at the University of Texas Health Science Center in Houston and Associate Director of the Gulf States Hemophilia and Thrombosis Treatment Center in Houston. Dr. Brown's current research is in menstrual issues in women with bleeding disorders and thrombin generation in hemophilia and von Willebrand disease (vWD) and disseminated intravascular coagulation (DIC).*

**D**r. Brown's remarks addressed concerns of women with bleeding disorders who have hemophilia (who are also carriers); have factor XI deficiency (Hemophilia C), or have von Willebrand Disease. She provided tips and advocacy on women's treatment and pain management for menorrhagia. These tips will be available in more detail through the new Blood Sisterhood network (the online community):

- Talk to people about your experiences to "demystify" women's bleeding disorders.
- Get OB/GYNs to know more about women with bleeding disorders. Andra H. James, M.D., and Barbara Konkle, M.D., have started the Foundation for Women and Girls with Blood Disorders (FWGBD), a nonprofit 501(c)3 organization. Their vision is that "all women and adolescent girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage." This special focus to educate doctors and other medical personnel regarding women who bleed is a significant progress in treatment for women.

- Keep an accurate log of your menstrual bleeding symptoms and the type and amount of feminine products used during your menstrual cycle. Use a flow chart: there are specific ways to monitor your bleeding and provide your doctor with "objective evidence" that can be used for a treatment plan. ■■

### Tips from the Breakout

- Take your medical records to doctor visits!
- Find a doctor who will spend time with you.
- Do the research to ensure that the doctor has knowledge of your medical needs.
- Make frequent visits to get it right if necessary.
- Take the time to "train" your doctor to understand your situation.
- Always ask about alternatives/other options for care and treatment.
- Find out if your doctor is willing to e-mail. Ask, because they can check e-mail from the road, and be responsive.

## Blood Sisterhood Rap Session

**T**he kick-off of the Blood Sisterhood network at Symposium – a women-only rap session – was designed to introduce the new online community available through the HFA and the opportunity to join the network (see p. 21). Women who decided to join during the rap received a welcome packet.

Blood Sisterhood focuses on the needs of the woman beyond initial diagnosis and her need to seek adequate treatment; e.g., the needs of women planning surgery, medical testing, childbirth, etc. The online community allows women with bleeding disorders to network privately with counterparts around the country, share their stories and receive information to help advocate for themselves and others. To



aid in program development, the women were asked for their input on topics for future webinars and resources. HFA's Voices campaign has videos to view and share on women's issues and personal stories of women affected by a bleeding disorder.

Blood Sisterhood Chair Linda (Lew) Wyman-Collins, RNC-NIC, gave an overview of the Victory for Women Program through the National Hemophilia Founda-

tion. That program focuses on awareness and education for the 18-25 year old population. (Patrice Flax, MSW, director of the Victory for Women (VfW) program with NHF attended Symposium this year to learn more about our Blood Sisterhood and to share about their program.)

Dr. Sue Fletcher from the Hemophilia of North Carolina member organization,

*Continued on page 6*

“If you meet a hemophiliac with gray hair, you’ve met a survivor.” That’s what one brother remarked at HFA’s Symposium in Louisville – the largest Blood Brotherhood rap session to date. Brothers from all over the country gathered to discuss various topics and the concerns they face on a daily basis. While the discussion took many directions, all topics were dealt with and given equal importance. Topics ranged from the “new pandemic” that is HCV, to insurance, health care reform, side effects of HCV treatment and ways to cope with them, and the weight that our stories can carry.

Other main areas of discussion found that the brothers are linked in more ways than just the blood flowing through our veins. As we get older, there are social and relationship issues that most of us must deal with. These issues are sometimes a direct result of bleeding disorders, but often they are more common problems that many guys (bleeding disorder or not) deal with at one point or another. Dealing with both types of problems at the same time requires near superhuman abilities.

The Blood Brotherhood through its mere existence provides a forum and access to the people that the brothers need to help

**“If you meet a hemophiliac with gray hair, you’ve met a survivor.”**

with these issues and more. For this reason, the online forum and the face-to-face participation are vital links for many within the community.

By the end of the session, the brothers made an unofficial pact to do something very simple and extremely important: ensure that all blood brothers are moving forward. For those who were there, don’t forget to do your part, spread the word and ask our brothers who weren’t there, to do the same. ■■



### HCV Therapy: Hopeful Waiting

*Mark Antell and Paul Brayshaw (HFA Board President) spoke with the Blood Brotherhood about advocacy for improved therapy to cure HCV.*

**H**CV (Hepatitis C) is a crisis in our community. “Chronic liver disease associated with HCV is the leading cause of death in people with hemophilia.” (\*) Almost the entire community over the age of 30 was exposed to HCV from contaminated factor; most have developed chronic, progressive HCV disease. The current Standard of Care (SOC) HCV treatment consists of a 6- to 12-month treatment with Ribivirin and Interferon. SOC therapy has high side effects and cure rates of around 50% for persons in the general population. Blood Brothers, by contrast, often have conditions that make HCV treatment more difficult and less effective. The next generation of HCV therapy — based on a protease inhibitor plus Ribivirin plus Interferon — will probably be helpful, but still will leave many uncured.



Working with a few friends affected by the HCV crisis among people with bleeding disorders, Paul and Mark initiated an informal group called People with Bleeding Disorders and HCV. Citizen activism to pressure regulators and to encourage

pharma worked for HIV, and there are excellent reasons why it should work for HCV.

Our main effort has been action before the U.S. Food and Drug Administration to lobby for development and availability of new, far better HCV therapies. On April 27-28 (post-Symposium), we testified at FDA hearings on the newest generation of HCV drugs (Telaprevir and Boceprevir). We called for approval of those drugs, but asked that drug labeling state clearly that, for difficult-to-treat populations, drug

**“HCV (Hepatitis C) is a crisis in our community.”**

benefits are less attractive and drug risks are less well understood. In our work with FDA, we have received a great deal of encouragement from HFA. NHF and COTT have also indicated general support for our activism. In addition, we have formed alliances with other patient advocacy organizations including the Abigail Alliance for Better Access to Developmental Drugs and the Treatment Action Group. ■■

(\*) Source: Konkle B, Kessler C, Aledort L, Andersen J, Fogarty P, Kouides P, Quon D, Ragni M, Zakarija A, Ewenstein B. *Emerging Clinical Concerns in the Ageing Haemophilia Patient. Haemophilia* (2009); 15 (4): 926-931.

**Learn more and get updates:** <http://sites.google.com/site/accesshcvtherapy/start>

## It All Starts With a Smile

Continued from page 1

to let go quickly to free up your hand to “be ready for what’s coming next.” It’s a great example and metaphor about letting go of fear – without losing control of the situation.

### Doctor’s prescription: HA HA HA

How we use our humor — and Dr. Kuhn calls it a resource that we can lose and also resurrect — is a prescription to get the most out of everyday life, even in tough, fearful and painful situations. He offers three HA HA’s that are simple steps which can yield many positive benefits (see the box). In short, he calls it “your brain on smile.”

Humor Attitude is not about being silly or funny – that is behavior, which provokes laughter. Humor Attitude is a focus on fun, the willingness to seek out and find the positive elements in any situation. He refers to it as “finding that pony in the pile of manure.”

Dr. Kuhn recommends reconnecting with your basic Humor Aptitude. We are all born, he says, with a natural aptitude for fun and play, “along with ‘hardwired’ skills that produce positive energy.” Babies

### Dr. Kuhn’s words to live by:

- Learn to have fun
- Use your smile
- Lighten up
- Let go
- Interact with people
- Listen carefully
- Get yourself into the moment
- Open your heart
- Express heartfelt gratitude

demonstrate it early with a smile — a natural act of reaching out and connecting. In other words, “grin and share it” has a ripple effect!

Commit an effective Humor Action and you are on the way, by deepening your connection to others and to life. Listen carefully and practice keeping yourself in the moment. It is a gift you give yourself and others. Another Humor Action is the practice of expressing daily gratitude for the things and people we value. ■■



**Want to learn more?** Dr. Kuhn’s latest book *It All Starts with a Smile* is available at [http://www.drcliffordkuhn.com/tools\\_for\\_fun.htm](http://www.drcliffordkuhn.com/tools_for_fun.htm)

**Check out The Laugh Doctor’s website**

<http://www.personal-enterprise-self-help-resources.com/support-files/be-happy.pdf>

## Blood Sisterhood Rap Session

Continued from page 4

outlined its SOAR program (support, outreach, advocacy and resources). SOAR is designed to increase knowledge and awareness among providers and the public about the symptoms, diagnosis and treatment of bleeding disorders; and to equip and empower girls and women with resources if they suspect they have a bleeding disorder, so they can better discuss it with their physician and receive proper diagnosis. Timely and proper diagnosis integrated with appropriate treatment leads to better quality of life for women and decreases chronic health-related problems.



The consensus among women in the Sisterhood rap was that having an advocate — whether a family member or a friend — come with you is helpful, especially if you are unable to advocate for yourself. Women in the session also discussed the need for a network of advocates they could call upon in an emergency.

**How to follow up:** contact HFA’s Blood Sisterhood Network and let us know your needs. ■■



Chef Graham began his demonstration with chocolate-dipped strawberries. The key to creating a chocolate-dipped strawberry with a design is the use of a transfer strip. Once the berries had hardened, the design came through and made a delectable treat. Other creations included a guacamole dip with crab, olive and tomato ragu, and an onion and asparagus treat. Fresh tomatoes and mozzarella cheese were another yummy treat.

we could take him home with us, kind of like a traveling chef, and when he stopped blushing, he responded with, "I don't think my wife would like that." Nice try. ■■

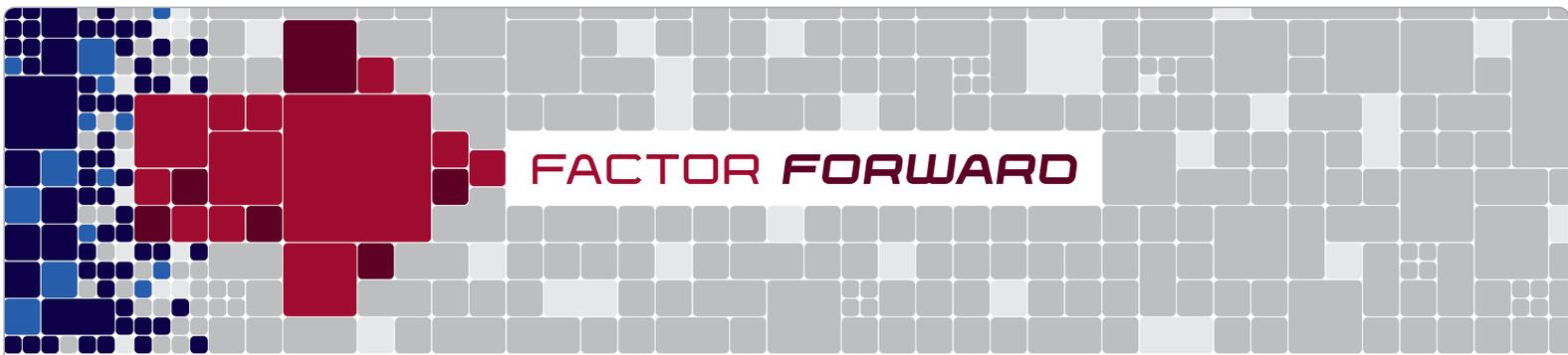
**For recipes and more health and fitness tips,** go to HFA's FitFactor website.

## Women's Health & Wellness Reception

**M**ention food and the room fills with women — 45 or 50 of them, to be exact! The Women's Health & Wellness Reception, featuring Chef Graham from the Louisville Marriott, brought hungry women to a mid-afternoon event, ready to witness the creation of easy appetizers and then taste the winning creations.



Watching the creation of these delicious treats made the women hungry, so before Chef Graham could finish his demonstration, plates were passed to everyone for a tasting. No one was disappointed – plates were "licked clean." We asked Chef Graham if



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We are currently enrolling patients in our clinical trials.



**F**itFactor — a new HFA online tool designed to promote physical activity and healthy nutrition — made its debut at Symposium. This initiative is supported by a collaborative partnership of HFA with the Centers for Disease Control.

FitFactor online includes physical activity and nutrition with exercise videos, fitness tips, meal plans, recipes and more. At the FitFactor website are resources and tools to encourage healthy eating. Starting an exercise program is key to staying healthy and protecting your joints.

**Learn more! It's free!**

**Sign up at**

**<http://fitfactor.hemophiliafed.org>**



**STRENGTH**



*The women's wellness reception featured a food demonstration – how to make delicious and healthy snacks – prepared by the executive chef at the Marriott Hotel. (see p. 7)*

**FLEXIBILITY**

▲  
Left to right;  
Faith Hunter,  
Chef Graham,  
Michelle Burg

*Kiosks were set up to go online and register for the FitFactor web site.*

**WELLNESS**

*Blood Brother Terry Lamb and FitFactor coordinator Faith Hunter talked with the Blood Brotherhood about the health benefits of physical activity and healthy nutrition.*



*Participants in Dads (and Moms) in Action discussed the importance of physical activity – it's fun, healthy and a great way to bond and connect. Check out the taekwondo demonstration!*



*Fun stretches and exercise for youngsters ages 3-12 in the Kid Care area*



CARDIO



STRENGTH



NUTRITION



WELLNESS

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Jennifer and Donovan Guerrero,  
a mom and son meeting the  
challenges of an inhibitor

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## .. LEGISLATION & POLICY ..

*“Health Care Reform: The Law Passed, Now What?”* was moderated by James Romano, Director of Government Relations at Patient Services, Inc. (PSI). The program featured presentations by Claire McAndrew, Health Analyst at Families USA; Jodi Mitchell, Executive Director, Kentucky Voices for Health; and Erin Sutton of the Pre-Existing Conditions Insurance Program at the Centers for Medicare and Medicaid Services (CMS).

McAndrew’s and Mitchell’s presentations looked at key provisions of the new law, offering both national and local perspectives. Both speakers described how some provisions, such as the ban on lifetime caps for most insurance plans and coverage for adult children up to age 26 under their parents’ insurance, have already gone into effect. They also explained how other provisions, such as the complete elimination of pre-existing condition exclusions and the creation of “insurance exchanges” will not take effect until 2014. They offered a variety of resources for more information, including the new government healthcare website, [www.healthcare.gov](http://www.healthcare.gov).

The third speaker, Erin Sutton, talked about a new coverage option known as “pre-existing condition insurance programs,” or PCIPs. They are available in every state, although the specifics of how each program is administered vary

from state to state. The advantage of the program is that it is available now to people with pre-existing conditions and it covers those conditions immediately. It also has reasonable premiums, as the program is subsidized by the federal government. The disadvantage of the program is that it is only available to individuals who have not had any insurance coverage for at least six months. More information is available about these programs at <http://www.pcip.gov>.

The consensus of the presenters was that consumers have a variety of new protections and options for health care coverage, and that more will be available over time. It is the responsibility of every consumer to stay abreast of what is available and take full advantage of every opportunity to access quality care at a reasonable cost. ■■

**“It is the responsibility of every consumer to stay abreast of what is available and take full advantage of every opportunity to access quality care at a reasonable cost.”**

### UDC: What’s Ahead in Data Collection?

Dr. Althea Grant, Chief of Epidemiology and Surveillance Branch of the Division of Blood Disorders at the Centers for Disease Control (CDC), gave an insightful presentation regarding data collection in the bleeding disorders community, the benefits surveillance brings to public health, and how the CDC plans to make changes moving forward.

The CDC began surveillance of the bleeding disorders community in 1993 with the first population-based study of hemophilia, the Hemophilia Surveillance System (HSS). Six states participated in the HSS, and final outcomes proved that people treated outside of a Hemophilia Treatment Center (HTC) had higher mortality and bleeding-related hospitalizations. Moving forward in 1998, the CDC began its Universal Data Collection (UDC) project to monitor the safety of the blood supply for people using blood products, and to monitor the occurrence of joint complications in people with hemophilia.

Over 26,000 individuals to date have joined the UDC program, and the project has continued to offer extremely valuable data and enhanced over time. In 2003, the program launched a focused initiative on children less than 2 years old; in 2005, an initiative on



quality of life as well as a specialized inhibitor pilot program; and in 2008 a focus on females with bleeding disorders.

The current cooperative agreement for the UDC expires in September 2011. In anticipation of that, the CDC has announced a revised UDC, UDC 2.0: Public Health Surveillance for the Prevention of

Complications of Bleeding and Clotting Disorders. This revised system has been devised during the past year with consultation of many stakeholders in meetings and webinars that have been open to the bleeding disorders community.

Dr. Grant noted that American Thrombosis and Hemostasis Network’s (ATHN) data set and the UDC 2.0 data are separate but indicated that ATHN could apply to be the collection entity that transports HTC-collected patient data to the CDC. The CDC is also looking to gather patient-level information from outside of the HTC network and will look for applicants that provide this information. The CDC will evaluate the forums in which information is collected to align with the goals set by the program. ■■



# BEE IN THE BUZZ!



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# faces of SYMPOSIUM

Thousands of people poured into Louisville, Kentucky, on the third weekend of April to enjoy the opening festivities in the two-week run-up to the Kentucky Derby.

Across town, hundreds from HFA's national community – families, seniors, teens, speakers and exhibitors – were wrapping up another Symposium, raising their voices and sharing advice and accomplishments that help us live the best life possible.

What's so special about Symposium? It's an annual reunion, a time for renewal, and an abundance of helpful resources – and most of all, it's people.





## Medical Advances on the Horizon

**H**FA Medical Adviser Dr. Christopher Walsh, of New York's Mt. Sinai Hemophilia Treatment Center, moderated a panel that provided a "soups to nuts" overview on the state of science and clinical care for patients with bleeding disorders. The panel featured Dr. Steven Pipe, Medical Director of Pediatric Hemophilia and Coagulation Disorders, clinician and researcher at the University of Michigan; and Dr. Margaret Ragni, Medical Director of the Hemophilia Center of Western Pennsylvania.

Dr. Pipe pointed out that the survival of hemophilia patients today is nearly that of those without the disorder, and their quality of life is virtually indistinguishable as a result of advances in clinical care, gene therapy and continuing momentum toward a cure.

Dr. Pipe presented "Themes from the Drug Development Pipeline," which include efforts to lower the costs for clotting factor while extending the half-life of

the drugs. He also discussed the current work in "transgenic livestock" and the use of animal milk as a source of clotting factor.

Dr. Ragni added to the presentation by speaking about "Medical Advances on the Horizon," beginning with a history of advances since the time of Queen Victoria. She identified ongoing studies in the treatment of hemophilia, which include

the use of prophylaxis in adults to prevent joint disease and inhibitor prevention. These challenging negative occurrences result in increased financial burdens, hospitalizations and other risks to patients.

Dr. Ragni concluded with the exciting happenings in newer, long-acting recombinant products via the process of FC Fusion technology. She demonstrated how these advances show promise in providing clotting factor with a longer half-life resulting in fewer infusions, lesser dosing requirements and safe results with few side effects. ■■



## MISSED SYMPOSIUM?

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[www.hemophiliafed.org](http://www.hemophiliafed.org)



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3. Ask your doctor to complete the form and send it in for processing.

For more information and to get started, visit [www.FactorPlusprogram.com](http://www.FactorPlusprogram.com).

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## .. THE NEXT GENERATION ..



then film actual Symposium sessions to steady their camera operating and get a feel for how the sound and picture work. On the final day, the group conceived the idea to have a YouTube.com site in which to upload individual videos while assisting others with theirs. Keep an eye out for the videos in the next few months!

Postscript: Since Symposium, the young leaders have been working hard with David Ford and each other on proposals for their video ideas. Some video topics being discussed are hemophilia myths, women with bleeding disorders, and life beyond hemophilia. They are making progress! Watch HFA's Facebook and Twitter in the coming months for their completed videos! ■■

### Young Leaders at Work

While most participants were busy in the educational and informative sessions at Symposium, a group of young people (dubbed the "young leaders") was tucked away with a few cameras, a professional cinematographer, and many great ideas. The young leaders came from almost every part of the country, ranging in age from 18 to 30, all with some relationship to the community — whether as carriers, siblings, or individuals with a bleeding disorder — to work with Cinematographer David Ford and learn how to use handheld cameras and YouTube.com as visual tools to further HFA's advocacy efforts.

Few of the young leaders knew each other at the outset, but as seems to be the standard with the bleeding disorders community, friendships soon developed, and many of the young leaders ended up spending the entire symposium attending sessions together. During their time with David Ford, the young leaders learned how to operate the cameras, conduct and film interviews, and edit them on the Internet.

Instead of having the group sit and observe, David taught the group by asking them to do mock interviews with each other and



*Tweens, teens and young adults are a valued part of the community that makes up the Hemophilia Federation of America. For families with youngsters (6 months to 12 years), **Kid Care** offered two days of fun activities using motor skills, games, stories, songs and crafts, supervised by trained professionals, under the generous sponsorship of CSL Behring.*

*For teens and young adults, special programs were developed to provide practical and inspiring tools for life.*

## Teen Adventure at Symposium

**H**FA partnered with Pat Torrey at this year's Symposium to provide the teens in attendance with an experience unique to the Louisville area and rich in challenge and learning. Pat is a facilitator and trainer known in the bleeding disorder community for his powerfully engaging programs that inspire kids to believe in their own ability to function at their optimal level and challenge them to grow into happy, healthy adults.

During this two-day adventure, the teens were challenged to venture into new territory, both physically and emotionally. Day one supported the advocacy-based mission of HFA as teens learned techniques for self-advocacy and were put into difficult situations to practice their new skills. The group was challenged first with team-building activities urging them to get out of their comfort zone, develop trust with one another, and to build communication skills needed in advocating for themselves and others. The program asked them to evaluate their own potential, take risks and think of

ways to transfer this experience back into everyday life. All useful skills needed in preparation for their caving adventure at the Marengo Caves on Saturday!

The second day required participants to bring ideas together, face fears, work together and explore personal strengths in the beautiful Marengo Caves. The group explored drier cave areas in the morning to get used to being 150 feet underground. A dark, cold, and muddy two-hour cave-exploring trip through the streams and narrow passageways proved to be an extraordinary trip in the afternoon. The cave itself is approximately five miles in length, and every teen who started the adventure was able to push through the entire underground tour regardless of the challenging temperatures and claustrophobia-inducing passages. Although there were tense moments, the teens worked together to encourage and support one another. The group interactions gave new meaning to the word "teambuilding" and provided practical and inspiring tools for life. ■■



## Today's Advocacy

**W**hat are the tools and tactics you or your organization needs to create an effective public presence? How can you develop the self-advocacy skills to tell your story and make a difference? Why are social media at the forefront of today's communications for the bleeding disorders community – but can you ignore traditional media? The how's and how to's of effective communications were featured in a trifecta of lively communications sessions at this year's Symposium.

Firespring cofounder Jay Wilkinson, who led a popular fall 2010 webinar for the HFA community, was there to share what he has learned while guiding some 3,000 clients in building an effective online presence with their web sites and a host of social media tools.

Community member Ryan Crowe, who works for CBS-TV in Texas, offered a 10-step checklist – based on his knowledge of how broadcast works – to develop effective relationships with traditional media, whether broadcast or print.

And Washingtonian Joi Ridley, principal of Au Courant Innovations, turned tables on her audience in the middle of a fast-paced half-hour presentation on “telling your own story,” and asked them to role play in a scenario that happens all too often: the Congressman or reporter is suddenly “too busy” to see you.

Her advice: Make sure you have fresh information ready for anyone with little or no time to spare (a media advisory is always good): have three bullet points ready, three things you can share very quickly, that have impact or affect constituents. Make sure you are accessible and provide written contact information. ■■

## The Firespring Approach

Firespring emphasizes five essential elements to a good website: Structure, Design, Content, Functionality, and Vitality

### Keys to a good website include:

- Content should be based on a shared vision and voice
- Tell the story in photos and headlines
- Make sure your information has relevance for browsers
- Make your website “sticky” – content, design and appeal have to keep the audience coming back (that's the “sticky” part)
- Maintain “freshness” in your content. Visitors will take less than five seconds to decide whether to go inside your site.
- Use your website as the foundation to build on: add a Facebook page, Twitter, blog and LinkedIn page.
- Use tools for content management that make it easy to link all the social media and your website, and keep the material up to date.



## Joi Ridley on Millennials and Their Media

**Y**ou are author, editor, publisher and benefactor!

“The Revolution will not be televised...but it will be Tweeted, Facebooked, blogged and Skyped!”

The Millennial generation – born between 1976 and 1996 – will be the new guard in advocacy. Millennials check their Facebook accounts an average of 12 times per day and they “tweet” incessantly.

In 2008, 9.8 million Millennials volunteered a total of 1.89 billion volunteer hours, making up more than half of all volunteer hours contributed that year.

There are 80 million potential activists, making them the largest and most diverse generation in history. Can you imagine an ally that is 80 million strong? ■■

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## Ryan Crowe's 10 Media Tips

- Keep it simple: Use the 5 W's – who, what, where, when and why.
- Keep it interesting: What's the impact or angle for your pitch?
- Know your audience: Journalists don't know much about hemophilia. Fill them in.
- Learn your contacts: Assignment desk (TV) and city-metro editors are always key.
- Do some stalking: Look for reporters who can be your champion — e.g., media sponsor/walk captain for your events.
- Stay on the radar: Check in with your contacts – do not bombard them.
- Personalize: Tell your own story. Add that vital human element.
- Know what you're getting into: You may be part of a story, not an "exclusive."
- Go beyond what's "normal": Seek out alternative press, ethnic and religious communications, public affairs programs on local TV.
- Be passionate!



### RESOURCES

If you could not attend, don't despair. Thanks to our speakers' generosity, HFA is posting their presentations on our website. [www.hemophiliafed.org/symposium](http://www.hemophiliafed.org/symposium)

## *In Memoriam*

Our thoughts and prayers are with the family and friends of:

Philip Edward Blomquist  
(Houston, Texas) Age 64

Frank C. Cadell  
(Green Valley, Arizona) Age 72

Curtis "Chris" Henderson  
(Houston, Texas) Age 50

Eshton Hewitt  
(Michigan) Age 16

Robert J. Marks  
(Alpharetta, Georgia) Age 88



# 2011



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## .. IN THE NEWS ..

### Bad Blood Airs on PBS Stations

*Bad Blood: A Cautionary Tale*, directed by nationally known filmmaker Marilyn Ness, premieres June 2 on PBS affiliate KQED public TV station in San Francisco, marking the 30th anniversary of the discovery of AIDS. Other stations in the PBS network are picking up the documentary to run on the anniversary date or other times during the summer.

Ten years in the making, *Bad Blood* documents how a life-saving treatment for hemophilia was contaminated with deadly, blood-breaching viruses – infecting 10,000 persons who had hemophilia with HIV and 15,000 with Hepatitis C. Filmmaker Marilyn Ness shares this story of the HIV/AIDS crisis in the hemophilia community, and the fight to make the system safer, through the voices of the survivors, family members, and other key players during this medical disaster.

*Bad Blood* has been edited to 53 minutes to fit the public TV format. Check local TV listings to find upcoming air dates, times, and more information.

To purchase the full-length documentary, go to <http://badblooddocumentary.com/dvd>.

**"Each of us owes a debt of gratitude," says Ness, "to the hemophilia community who unwittingly helped scientists unravel the mysteries of the AIDS epidemic by demonstrating HIV was transmitted through blood; and then rose up to safeguard the nation's blood supply for all Americans."**

On June 1, PBS Home Video is releasing the DVD on ShopPBS.org. It will also be on sale in selected retail stores beginning June 14. ■■

**For more information:**  
<http://badblooddocumentary.com>

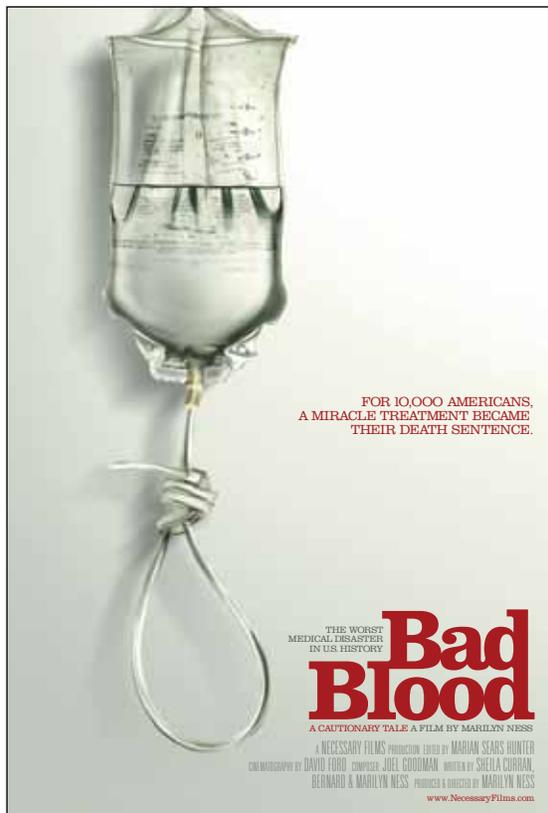
### What's Happenin'... The Online Community

HFA now offers a new way to stay connected! The "Online Community" is an interactive resource for people with bleeding disorders and their families. On this secure and private network, participants can chat with friends, stay updated on HFA news, view HFA's advocacy blog, watch community voices videos, and participate in the open forums and private groups.

HFA's open forums give participants the opportunity to speak on a variety of topics, such as advocacy issues or living with an inhibitor. There are also separate forums for moms and dads.

HFA's Online Community also hosts three private group: Blood Brotherhood, Blood Sisterhood and partners/spouses. These private groups provide separate spaces for adult men with bleeding disorders (Blood Brotherhood), adult women with bleeding disorders (Blood Sisterhood), and the partners or spouses of individuals with bleeding disorders, to join together and connect from across the country. To ensure privacy, the private groups require a separate registration process from the Online Community. ■■

**Ready to get started?** Register today at <http://community.hemophiliafed.org/>



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## .. IN THE NEWS ..



### Helping Hands at Symposium... and Beyond

Helping Hands is an emergency financial assistance program for individuals and families with hemophilia or von Willebrand disease. At this year's Symposium, HFA volunteers and staff raised funds for this vital program by selling Helping Hands supporter pins and Blood Brotherhood t-shirts. Susan Leffew, a tireless advocate for Helping Hands, who recently completed her term on the HFA Board, sported a shirt full of pins to encourage other members of the community to make a donation and show their support for others in need.

In 2010, Helping Hands distributed over \$90,000 in aid, assisting 216 households with urgent expenses such as housing, utilities and transportation. However, we cannot do this alone. We need your support to help sustain this program. Please consider making a contribution to Helping Hands. You will be helping families cope in stressful financial situations. Donations are tax-deductible and can be made through the HFA website or by sending a check made payable to Hemophilia Federation of America. ■■

Mailing address: 210 7th St., SE, Ste. 200B, Washington, DC 20003.

Website <http://hemophiliafed.org/contact-us/donate/via PayPal>.

## .. HFA HONORS ..

Awards at Symposium this year were given in recognition of four exceptional community members who always go the extra mile to share their knowledge, friendship and advocacy for those with bleeding disorders. Give them a hand!



**John Jarrett** received the *Ron Neiderman Humanitarian Award* for extraordinary service to the community via professional service and work. This is a lifetime award, in recognition of John's nearly 40 years of work in the community as a counselor, educator, writer and advocate – and a person with hemophilia (A, B and C) who has faced serious complications. He prides himself on his positive attitude, stating that he never allows hemophilia to destroy his spirit or become his identity.



*The President's Award* was made to **Barry Haarde**, a community member who has re-emerged in the past few years as a committed advocate and champion for hemophilia. HFA Board President Paul Brayshaw notes, "He is an inspiration. He keeps active and fit, demonstrating how important staying healthy is...a fellow bleeder who shares my love for the saddle and clip-on pedals... a bike rider extraordinaire." Haarde is working on a project to bring his lifetime of collection of historical hemophilia and bleeding disorders materials online.



*The TEA Award* (Teach, Empower, Advocate) this year honors **Linda Wyman-Collins** ("Lew"), a 30-year career nurse with extensive personal and professional experience in the care and management of hemophilia and other bleeding disorder patients. A frequent speaker, she has championed health care issues on the state and national level for over a decade. Today she remains active with HFA as chair of the Blood Sisterhood network, helping bring connections and support to our network of women impacted by a bleeding disorder.



A long time advocate and a hardworking volunteer, with a distinctive southern accent, **John Reed** is HFA's *Volunteer of the Year*. Currently, he serves as the chair of the Blood Brotherhood Committee and has enjoyed working with the staff, the committee and staff coordinator for the online forum. John, who is a factor VIII (severe) hemophiliac, holds a Doctorate of Pharmacy degree, is a pharmacist by trade, and owner of Cyril Home Care Pharmacy. His blended family includes 6 children and 14 grandchildren.

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Matt Igelman  
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Dr. Clifford Kuhn  
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Glenn Mones (Health Care Reform)

Joi Ridley (Telling My Story)

Pam Williams  
(Women's Wellness Reception)

Jay Wilkinson  
(Nonprofit Best Practices)

Josef Zwier (Young Leaders)

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