

Newsletter of the Hemophilia Federation of America

dateline

FEDERATION

Issue 16 Volume 10 • Fall 2008

The Hemophilia Federation of America

Goes to Washington

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Dateline Federation is published four times a year by the Hemophilia Federation of America, 1405 W. Pinhook Road, Suite 101, Lafayette, LA 70503 Toll Free 800-230-9797 337-261-9787 Fax: 337-261-1787 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.

Susan Swindle Transitions

After a myriad of accomplishments, Executive Director Susan Swindle bids farewell to her full-time role with the HFA. Susan reflects below on her time as Executive Director as she transitions to her new role as Development Director.

Dear Friends of the HFA,

Wow, it's difficult to believe that it's already September! That's what happens as you get older: years go by a little faster. I've always considered myself open to change and in the last year, my family has experienced our fair share of it: a move, a new job for my husband, and grown children moving back home, to name a few. Change is inevitable as the years fly by.

My employment at the HFA has been the one constant in my life over the last few years. In addition, I've made many friends here and have always been honored to work for the HFA. Thus, I must admit that the decision to step down has not been an easy one. Was I personally prepared for the change? Was it the right time for the organization, considering our impending move to DC? After two months of working with our new Executive Director, Kimberly Haugstad, I'm positive it was the right decision. Kimberly is an enthusiastic, energetic executive who is committed to the mission of the organization.

Kimberly has offered me a development role that I am honored to have accepted. I look forward to supporting her and to the opportunity to continue playing a role in the future of the HFA. While I will miss the daily interaction with the community, embracing change has been a positive experience for me and it can be for you too!

Susan Swindle

Susan Swindle

Development Director

The HFA offers programs and financial support to the bleeding disorders community through the generous support of its members and sponsors. If you would like to get involved, please join today at www.hemophiliafed.org.



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HFA Takes New Direction

New Director and Move to Washington in HFA Future



Hello all! It is a delight to be able to write these first few paragraphs as I take on this exciting new role with HFA. I'm honored to be here and to have the opportunity of a lifetime to serve our community nationally.

The very best part of these first few weeks as Executive Director of the HFA has been the chance to connect and listen to the needs, the opinions and the ideas of so many individuals. Reaching out to others and bringing

together the best of the community is vitally important. This is critical in an organization like ours.

Yes, some change is inevitable with new faces and new places. However, I can assure you that the bedrock of why HFA was created, to assist and advocate for individuals in the bleeding disorders community, remains firm. I was drawn to the servant leadership of the HFA family and the personal touch this organization is recognized for. You'll be happy to hear both the board and staff want to expand how we serve our community, but only if we maintain our consumer-centered focus.

Moving back to Washington is an exciting step in our future as a growing and thriving organization. How we utilize that space and continue to develop programs and services to meet our community needs are very much on our radar. We are knee deep in strategy and planning as this issue goes out!

Please stay tuned for future updates and touch base with myself or anyone in the HFA office if you have a question, idea or concern. We value your input.

Kimberly Haugstad

Kimberly K. Haugstad

HFA Executive Director

Meet Kimberly Haugstad

The Hemophilia Federation of America (HFA) Board of Directors announced that it has named Kimberly K. Haugstad as the organization's new Executive Director. Haugstad, who hails from Menomonee Falls, WI has joined the HFA prior to its move to Washington, D.C., planned for November 2008. Haugstad, with over 15 years of management and leadership experience, brings a passion for grassroots advocacy and a commitment to collaboration and results to HFA along with a personal knowledge of the hemophilia community. Haugstad's six-year-old son has severe Hemophilia.

HFA Chairman of the Board Chad Stevens says, "We are fortunate to have Kimberly lead our organization. Her commitment to bringing the organization's advocacy agenda to Washington, DC will not only bring HFA to a new level, but will bring our voice to the Capital."

Haugstad joins the HFA from her prior role as managing director of an organizational development consulting firm where she led a variety of projects as a human capital and business strategist, performance analyst and project manager. Haugstad holds a B.S. and an MBA via the University of Wisconsin system.

In addition to her corporate consulting activities, Haugstad has served the bleeding disorders community through the Wisconsin-based Great Lakes Hemophilia Foundation as a member of the board and founding chair of their advocacy committee. Additionally, Haugstad volunteers with the National Hemophilia Foundation's Public Policy Working Group and the Committee of Ten Thousand's Government Relations Working Group.

Haugstad's continued commitment to assisting and advocating for the bleeding disorders community will help fulfill the HFA's commitment to advocacy. Following a decision made at the 2008 Symposium, the HFA's offices will move from Lafayette, LA to Washington, DC.



Program Updates *Hemophilia Federation of America*



Bxter BioScience has awarded the Hemophilia Federation of America a grant for use in the HFA Blood Brotherhood Program. The HFA, in partnership with the Center for Disease Control, launched this needed program in six Pilot Sites around the country in 2007. Targeting males, 25 years-old and over, the HFA Blood Brotherhood Program provides adult men an opportunity for social support and education, both in person and online. HFA hosts national calls/webinars and chat forums via <http://www.hfab.org>.

Each group meeting will include valuable information on topics geared specifically to men - nutrition, exercise, financial planning, retirement, insurance and medical advocacy, and other issues related to aging. Each pilot site is hosted by an HFA Member Organization. Baxter's funding will help the pilot sites with the costs of hosting Blood Brotherhood support groups and events not covered through CDC funding. Janie D. Davis, Baxter



BioScience Hemophilia Programs, stated, "Baxter is proud to be supporting such a much needed resource for the hemophilia community."

Currently the HFA Blood Brotherhood program has over 75 members and is working toward the goal of having 100 active members.

The Blood Brotherhood Program provides opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. Our online forum covers everything from meds to motor sports, surviving to "Survivor."

(Left to Right) - Shannon Resetich, Group Marketing Manager, Baxter Healthcare, Chad Stevens, Susan Swindle, Dan Bond, HFA, Janie Davis, Senior Marketing Manager, Baxter Healthcare

In Memoriam

The HFA remembers Blood Brother, Board Member, Volunteer and Friend Mike Morse.



Mike embodied the spirit of the Hemophilia Federation of America (HFA). He served on the Board of Directors from 2000 to 2007. He was a wonderful friend to his fellow Board members and staff. He was a loyal dedicated volunteer who gave of his heart, time and talent to the organization and served on various committees during and after his term. Mike served on the Helping Hands committee and on the Blood Brotherhood core committee.

He was a compassionate gentle man who was always looking for a way to serve others. The Hemophilia Federation of America, Oklahoma Hemophilia Foundation, Hemophilia Foundation of Arkansas and many others from the community are honored to have been on the receiving end of his good works. Mike Morse has left an indelible footprint on all

of these organizations that will inspire others to carry on in his memory!

A memorial web site has been created by the Oklahoma Hemophilia Foundation and can be found by visiting: <http://www.mikemorse.legacy.com/LMW/Subpage.aspx?mod=1>.

Hemophilia Federation Of America
Helping HANDS
assistance for persons with bleeding disorders

The home of a 28 year-old single male with severe hemophilia and Hepatitis C was damaged in a flood. He spent all of his savings on home repairs. Shortly thereafter, he was diagnosed with cirrhosis of the liver and told he needed a transplant. He was unable to work due to poor health and numerous hospital visits. He was prescribed a new medication that has greatly improved his ability to function and is now able to return to work until a liver donor is found. Helping Hands assisted him with his mortgage payment.

Our community is extremely challenged with meeting basic needs at this time. As of August 31, the Helping Hands program assisted 85 other individuals and/or families with similar circumstances. The requests are predominantly for needs associated with housing, utilities, telephone and automobile expense.

If you know of anyone from our community in need, please refer them to the HFA for assistance. If you are fortunate to be employed and can donate to the Helping Hands fund, please do so. Your community needs your help.

The HFA offers the Helping Hands program with the generous support of community members, volunteers and a generous grant from Wyeth Pharmaceuticals.

...

HFA's goal is to provide a balanced program that evaluates and gives careful consideration to each applying individual/family with a minimum invasion of privacy. A referral to HFA's Helping Hands (HH) program must be submitted. Once a referral is made, the applicant is required to submit a written statement of need, proof of emergent situation, and complete a phone interview conducted by the HH Coordinator. The application is then forwarded to an independent committee for review.

Hemophilia Federation of America
DADS in Action
BUILDING CHILDHOOD HEROES

Today's society recognizes the psychological benefits of a positive male role model in the lives of children. Fathers of children with bleeding disorders face added challenges. The ordinary stresses of work and home are compounded by the serious economical, physical and mental concerns that surround dealing with a serious chronic medical condition. Dads in Action supplies education, support and interaction with other Dads facing similar situations.

HFA would like recognize the Hemophilia Outreach of El Paso for recently hosting a fun filled Dads event for their members. Nine fathers and ten children came together for education, support and camaraderie.

If you want to learn more about the program, please contact the HFA. The HFA Dads in Action program has recently been awarded a generous grant from Novo Nordisk in support of the Dads in Action program.

...

The HFA Dads in Action program provides training to help fathers build strong bonds with all of their children by giving dads support, a sense of belonging and keys to strengthening family ties. It includes both fathers of children with hemophilia and fathers with hemophilia who have children. Interested fathers from each HFA member organization are provided with specialized training in order to lead Dads in Action groups in their respective areas. The training is free of charge and the member organization receives a grant to help offset the costs of providing the program to their members.

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*Health care professionals are not eligible for the free gift.

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GINA: What does it mean to us?

BY: KISA CARTER HFA Public Policy Director

The Genetic Information Nondiscrimination Act of 2008 (GINA), was signed into law (Public Law 110-233) May 21, 2008. GINA will prohibit discrimination on the basis of genetic information with respect to health insurance and employment.

The provisions of the law that address health insurance will take effect 12 months after the date of signing. Eighteen months after the date of signing the employment protections will take effect. GINA should be completely in place by November 21, 2009.

Regulations must be issued within a year of signing by the Department of Health and Human Services (includes the Center for Medicare and Medicaid Services), the Department of Labor, the Equal Opportunity Commission, and the Treasury Department. Each of these agencies have jurisdiction over GINA and must provide guidance on compliance and enforcement. The public will have the opportunity to provide comment on the proposed regulations once published in the Federal Register sometime this fall or winter.

While we await full implementation of GINA, the bleeding disorders community should understand the relevance to our community. There are two parts to Public Law 110-233; Title I-Genetic Nondiscrimination in Health Insurance and Title II-Prohibiting Employment Discrimination on the Basis of Genetic Information. Under Title I, section 103, group health insurers can not require individuals or their family members to undergo genetic test, provide their genetic information for underwriting purposes, or use genetic information collected intentionally or accidentally on an individual or their family members for eligibility, coverage, underwriting and premium-setting decisions.

Title II prohibits employers from using genetic information in the decision making process to hire, discharge, promote, or compensate an employee. It also applies to an employee's terms or conditions and privileges of employment. An employer, employment agency, labor organization, or training program may not use genetic information to limit, segregate,

or classify an employee in an attempt to deprive them from employment opportunities or adversely affect the status of an employee. Genetic information on the individual or a family member can not be purchased, requested or required by these organizations.[1] Employment agencies, labor organizations or training programs may not fail or refuse to refer individuals for employment and they may

GINA is a mechanism to protect individuals from genetic information discrimination. Consumers must understand the mechanics of the law and applicable state laws to identify discriminatory practices.

If a state has a more comprehensive and protective genetic discrimination law it will not be preempted by GINA.

For more detailed information about GINA please visit the links referenced under sources.

Footnote

[1] An employer, employment agency, labor union, or training program can use information inadvertently provided as part of the individual or family member medical history or publicly available information.

Sources

- *Public Law 110-233*
<http://www.gpoaccess.gov/plaws/index.html>
- *The Genetics and Public Policy Center*
<http://www.dnapolicy.org/>
- *Coalition for Genetic Fairness*
<http://www.geneticfairness.org/ginaresource.html>
- *National Conference of State Legislatures*
<http://www.ncsl.org/programs/health/genetics/charts.htm>



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State Budgets Crisis Impacts Bleeding Disorders Community

BY: KISA CARTER HFA Public Policy Director

Twenty-nine (29) states face a combined \$48 billion budget shortfalls according to the Center on Budget and Policy Priorities. As states contend with reduced resources, health care programs will not be immune to cut backs. The Kaiser Commission on Medicaid and the Uninsured recently released a report detailing how the economic downturn has effected spending, coverage and policy changes.

Programs such as Medicaid face significant challenges. After a two month delay, California enacted a budget resulting in 10 percent cuts across the board. (The Medicaid (Medi-Cal) program will lower to a 5 percent cut in payments to pharmacies beginning March 1, 2009.)

California is not alone. State deficits hinder efforts to maintain Medicaid coverage. The Kaiser Commission reports that Medicaid officials expressed concern over serving the increasing number of people without health coverage. States lack the fiscal capability to finance Medicaid over the long haul through state revenue bases.

Chronic disease groups face detrimental health outcomes, when programs are cut. Budget reductions impact access to care, quality of care, and enrollment in state-run health programs. In fact, people with bleeding disorders face higher costs without appropriate care.

As a member of the community, it is critical to become and remain actively involved and educated on state fiscal issues. State legislatures must hear from the community as decisions are made to balance state budgets and allocate funds to health programs.

HFA continues to collaborate with chronic disease groups, COTT, NHF and state bleeding disorders organizations to contact state legislatures and state health agencies. Resources you may find valuable include:

- <http://familiesusa.org/resources/state-information/>
- <http://www.ncsl.org/index.htm?tab=issue>
- <http://ccf.georgetown.edu/index/what-s-happening-in-the-states>

Should you need assistance within your state or have questions, please consider HFA as a resource to support efforts that positively impact the community. Contact Kisa Carter, HFA Public Policy Director at k.carter@hemophiliafed.org.

State Budget Problems Worsening: 15 States Face New Shortfalls



The budget shortfall map is printed with permission from the Center on Budget and Policy Priorities.

Sources

- *29 States Faced Total Budget Shortfall of at Least \$48 Billion in 2009* <http://www.cbpp.org/1-15-08sfp.htm>
- *Headed for a Crunch: An Update on Medicaid Spending, Coverage and Policy Heading Into an Economic Downturn* <http://www.kff.org/medicaid/7815.cfm>
- *California Budget Project: Governor Signs 2008-09 Budget: Plan Includes Deep Spending Cuts, Massive Future Tax Breaks, Debt, and Budget Process Changes* http://www.cbpp.org/documents/0809_finalbudget.pdf

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Ask Jill *Hemophilia Federation of America*

Focus on the Feminine Q&As Send questions to info@hemophiliafed.org, re: FOFMQA

Dear Jill:

My 16-year-old daughter refuses to wear a Medic Alert bracelet. I find that very frightening, especially now that she's driving and I'm not always with her. She and I have had many discussions and quarrels over this topic. How can I get her to understand how important it is that she wears a Medic Alert bracelet?

Frustrated Mom
Oklahoma

Dear Mom:

First, you are not alone in facing this problem with your teenager. Teens, especially those who did not wear Medic Alert bracelets from the time they were small children, want to feel invincible. They would rather not talk about their bleeding disorder, let alone wear Medic Alert jewelry!

My first suggestion would be to see if your daughter would compromise and agree to carry a Medic Alert card in her wallet. Second, check with your local chapter. Is there a female camp counselor who could talk with your daughter? Or the social worker at your treatment center?

At this point it would be best if you don't press the issue further (beyond the wallet card). Instead, try to find a professional in the bleeding disorder community to help you communicate the importance of the Medic Alert Bracelet. Good luck!

Jill

Dear Jill:

My younger sister and I have VWD. Our grandma keeps telling us she read that people "grow out" of VWD in their late twenties. She repeats this to us all the time. If one of us has a nosebleed or a heavy period, and we're trying to treat, Grandma stands at the kitchen table and says over and over "oh, you'll grow out of it." She drives us crazy! How do we get Grandma to learn the right information?

Maryland

Dear Maryland:

Has your Grandma ever attended a VWD educational session with you? Or has she gone along with you to a Chapter event? Perhaps the best strategy would be for Grandma to accompany you to your next Comprehensive Clinic visit. Call ahead and alert them that Grandma is coming with you. Then, during your appointment, one of the staff can help answer any questions your Grandma may have, and bring up the "you can't grow out of VWD" issue as well.

Jill

Jill Williams

A woman with von Willebrand disease, Jill Williams works as a vWD Specialist for Critical Care Systems. She is a long-time advocate in the bleeding disorders community, and has authored numerous national articles, pamphlets and booklets on the medical and psychosocial issues of women with bleeding disorders.

Disclaimer

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

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Hemophilia patient Andrew Gonzalez and mother, Evelyn

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The Latest in Medical News

HHS Underscores Importance of Keeping Family History

US Department of Health and Hospitals – The U.S. Surgeon General in cooperation with the United States Department of Health and Human Services has launched a national public awareness campaign to encourage all American families to learn more about their family health history.

A recent survey found that 96% of Americans believe that knowing their family history is important. Yet, the same survey found that only one-third of Americans have ever tried to gather and write down their family's health history.

The Surgeon General has created a web-based tool to help anyone create a family medical history. The tool, "My Family Health Portrait," helps users organize family health information and print it out for presentation to the family doctor. Additionally, the tool allows saving and sharing of the family history information. The tool can be accessed at <https://familyhistory.hhs.gov/>.

This information was made available from the US Department of Health and Human Services at <http://www.hhs.gov/familyhistory>.

Research of Aerobic Capacity of Boys with Hemophilia

In June of 2008, the Journal of Pediatrics reported that a study of boys with hemophilia and their healthy peers found that aerobic capacity was lower for the boys with hemophilia than their healthy counterparts. A Reuters article about the study reads, "Compared with their healthy counterparts though, the peak oxygen capacity, heart rate, and work capacity were significantly lower among the boys with hemophilia. However, total muscle strength was normal in the patients compared with the healthy controls, and almost no joint impairment or decrease in functional ability was found."

The article referenced above comes from the Journal of Pediatrics in June 2008.

Australian Research Aims to Create Genetically Engineered Virus

The West Australian newspaper reported in June of new research that could provide hope for persons with hemophilia. The country's genetic experts studied the use of a genetically-engineered virus. That when introduced into the livers of seven male patients dramatically reduced the disease.

The article reports that, "However, the 'cure' was only short-lived, with one of the patients developing minor liver damage when his own immune cells attacked the therapeutic virus which had carried the gene into the liver cells."

The research team now aims to create a form of immune suppression that will allow the gene to become permanently established within the liver. By the end of the year a new trial with nine patients in Sydney and Philadelphia will begin. The trial patients will be followed for up to 15 years to ensure the treatment or possible cure is long-lasting.

A full copy of the article referenced above can be found at <http://www.thewest.com.au/default.aspx?MenuID=2&ContentID=79172>.



HHS Awards \$49.1 Million to States to Increase Access to Health Care Coverage

(July 21, 2008) HHS Secretary Michael Leavitt announced awards of over \$49 million in grants to 30 states that provide health insurance to residents who cannot get conventional health coverage because of their health status.

The grants will be used by the states to offset losses that they incurred in the operation of high-risk pools, which are typically state-created non-profit associations that offer health coverage to individuals with serious medical conditions. Grant funds also provide support for disease management for chronic conditions and premium subsidies for individuals with lower incomes. Enrollment in these pools is growing, with more than 200,000 individuals enrolled in state pools.

The article referenced above is credited to CMS Public Affairs and the full press release can be found at www.hemophiliafed.org.

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|--|---|
| <p>John Reed RPh Cliff Marshall RPh</p>  <p>Pharmacist's specializing In Bleeding Disorder Products</p> | <p>Cyril Home Care Pharmacy</p> <p>214 Missouri PO Box 676 Cyril, OK 73029</p> <p>Phone: 1-888-258-2453 Fax: 1-877-464-3108 Email: jbreed@tds.net</p> |
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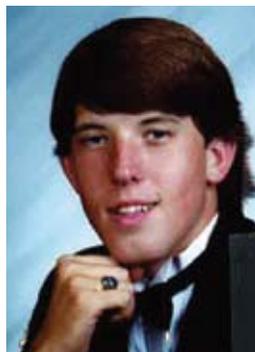
2008 Scholarship Award Winners Announced

The Hemophilia Federation of America (HFA) is proud to announce the winners of its ten educational scholarships available to members of the bleeding disorders community. Applications were received and reviewed by the HFA Scholarship Committee and were narrowed down to these ten deserving individuals listed below. To qualify, an applicant must have Hemophilia or von Willebrand (VWD) and must be seeking a post-secondary education from a college, university, or trade school. The applicant must also be able to demonstrate a commitment to improving quality of life by pursuing his/her goals with determination.



Craig Wright

Franklin, Tennessee's Craig T. Wright received an HFA Educational Scholarship that will go toward his medical education at the University of Tennessee Health Science Center in Memphis. Craig says of the honor, "The belief that your organization has in me gives me great confidence as I pursue a career in the medical field. Hopefully, I can make you and your organization proud as I proceed toward my degree in Medicine."



Jeremy Frank

Jeremy Frank, a major in Biology/Pre Med at the College of Charleston, is a young man with a bleeding disorder who would like to one day become a doctor. Frank thanked the HFA by writing, "There are not enough words to express my thanks to you and your organization for your generosity in looking out for young people with clotting disorders like myself."



Michael O'Connor

Cold Spring Harbor New York native Michael O'Connor began his studies at Amherst College in Amherst, Massachusetts this fall. As a recipient of a HFA Educational Scholarship, O'Connor says that the scholar-

ship is, "... much appreciated, and will allow me to concentrate on both my academics and athletics."

Perseus Patel

University of California Los Angeles student Perseus Patel is a 2008 beneficiary of the HFA Educational Scholarship Program. Patel is from Albany, CA and appreciates the financial assistance to pursue his educational goals.



Tristan Stoch

Keyport, Washington's Tristan Stoch was selected to receive a 2008 HFA Educational Scholarship. This fall, Stoch will attend Pacific University in Forest Grove, Oregon. His interests lie in film direction and speaking fluent Japanese. Stoch says, "This scholarship will allow me to pursue with all my heart my career goal of making movies that make people think. I will always remember that this education was made possible by the financial support of the Hemophilia Federation of America."



Eric Shepard

Eric Shepard will use his HFA Educational Scholarship for his studies at Wright State University in Dayton, Ohio. In a thank you letter to the HFA Eric writes, "I am most honored to be selected as one of the recipients of this scholarship and will work hard to be worthy of this support. I sincerely appreciate your efforts to advocate for the hemophilia and bleeding disorders community."



Left Side Pictured from Top to Bottom: Craig Wright, Jeremy Frank. Michael O'Connor Right Side Pictured from Top to Bottom: Perseus Patel, Tristan Stoch. Eric Shepard, Michelle Pascucci.

Continued on page 11

Winners Continued...

Michelle Pascucci

Michelle Pascucci was awarded a HFA Sibling Scholarship that will go toward her degree from Chapman University. Chapman is located in Orange, California. Pascucci thanked HFA and said, "I am looking forward to my senior year taking classes at Chapman and beginning my job search."

Kyle Haas

Kyle Haas will attend the University of Colorado in Boulder this fall. As a recipient of a HFA Educational Scholarship, Haas thanked the HFA when he said, "Your support demonstrates a faith in my desire to excel in a collegiate atmosphere. This funding offsets the high costs of college and allows me to reserve my time for activities pertaining to my educational and career goals. As such, I would be honored to accept this award."

Janice Cole

Janice Cole, a parent of a child with Hemophilia, is the proud recipient of a HFA Parent Scholarship. Cole will be attending Thomas Nelson Community College in Hampton, VA.

Zachary Taylor

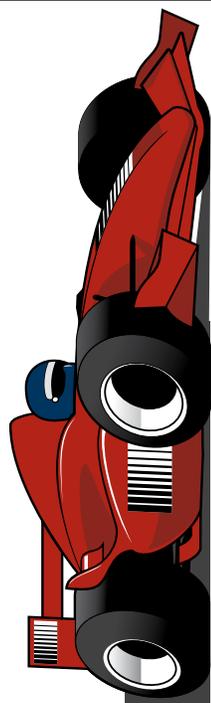
Zachary Taylor's passion is architecture. His studies in architecture will begin this fall at the Parsons The New School for Design in New York City, NY. The HFA Artistic Scholarship Taylor is receiving will alleviate some of the cost of attending Parsons. In a letter to the HFA Taylor wrote, "I have



always dreamed of going to Parsons the New School for Design and becoming an architect. Now that dream is becoming more of a reality."

Pictured from Top to Bottom : Kyle Haas, Janice Cole, Zachary Taylor.

The 2009 Hemophilia Federation of America Scholarship Applications will be available in an upcoming issue of Dateline Federation and on our web site at www.hemophiliafed.org.



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The Latest in Industry News

Bayer HealthCare Adds Terumo® SURFLO® Winged Infusion Set with filter and needle protection to Kogenate® FS with BIO-SET® Packaging

BERKELY, CA - (September 11, 2008) Bayer HealthCare announced that Grab & Go, a convenient, anti-counterfeit package of Kogenate® FS Antihemophilic Factor (Recombinant) with BIO-SET® needleless reconstitution system, now includes the Terumo® SURFLO® Winged Infusion Set with filter and needle protection. The Terumo® infusion set offers improved convenience and safety features for hemophilia A patients.

The Terumo® SURFLO® Winged Infusion Set with filter and needle protection includes a safety shield designed for the protection of accidental needlesticks following completion of the procedure, allowing for an easy, one-handed activation by the user, with an audible “click” for confirmation of the shield in lock position. In addition, the set is equipped with microbore tubing and a built-in filter, which reduces the amount of treatment lost during administration and ensures the reconstituted rFVIII is filtered prior to infusion.

This information was made available from Bayer. A full version of this press release can be found at www.hemophiliafed.org.

New Recombinant XYNTHA Now Available for Patients with Hemophilia A

COLLEGEVILLE, PA - (September 8, 2008) Wyeth Pharmaceuticals, a division of Wyeth (NYSE: WYE), announced that product shipments have begun for XYNTHA™ Antihemophilic Factor (Recombinant), Plasma/Albumin-Free, a new recombinant factor VIII product for both the control and prevention of bleeding episodes and surgical prophylaxis in patients with hemophilia A.

XYNTHA is produced using state-of-the-art manufacturing and purification processes designed to reduce the risk of viral contamination. The manufacturing process for XYNTHA is completely albumin-free from start to finish, while the purification process utilizes a unique synthetic ligand totally free of animal materials and a nanofiltration step using a 35 nanometer pore-size filter.

CSL to Buy Talecris for \$3.1 Billion in Record Buyout

(August 13, 2008) CSL Ltd., the world's second-largest maker of blood plasma products, agreed to buy Talecris Biotherapeutics Holding Corp. for \$3.1 billion cash, boosting sales by more than a third with its biggest acquisition.

CSL will raise \$1.5 billion in a share sale to help fund the acquisition, the Melbourne-based company said today in a statement. CSL will buy U.S.-based Talecris from Cerberus Partners LP and Ampersand Ventures.

This information was made available from Bloomberg and a full version of this press release can be found at www.hemophiliafed.org.

AMT Starts Collaboration With St. Jude Children's Research Hospital on Gene Therapy for Hemophilia B. Company Accesses Exclusive Commercial Rights to Final Therapy

AMSTERDAM, The Netherlands - (July, 15 2008) Amsterdam Molecular Therapeutics (Euronext: AMT), a leader in the field of human gene therapy, announced the start of a collaboration with St. Jude Children's Research Hospital in Memphis, Tennessee, USA, on the development of a gene therapy treatment for Hemophilia B. Under the deal, AMT will receive the exclusive commercial rights to the final product. The combination of this gene with AMT's proprietary adeno-associated virus (AAV) gene therapy platform could potentially cure this seriously debilitating disease with a single administration of the product.

Under the agreement AMT will sponsor research in Hemophilia B at St. Jude. Ronald Lorijn, CEO of AMT said: “The importance of this collaboration with renowned St. Jude Children's Research Hospital stretches beyond its scientific and business aspects. This collaboration will bring to these patients the hope that a real cure is on the horizon. Access to the Factor IX gene therapy program perfectly complements our gene therapy platform allowing us to develop an effective and long-lasting therapy for

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This information was made available from PR Newswire-FirstCall and a full version of this press release can be found at www.hemophiliafed.org.

CBCE Announces Adult Inhibitor Summits

The CBCE announced the dates for a new program designed to connect, inspire, educate, and empower adult patients with hemophilia with inhibitors and their primary caregivers (spouses, parents, and significant others).

Diagnosis and management of hemophilia with inhibitors can be overwhelming, and even day-to-day life can be a challenge. Many people feel they are on their own with hemophilia with inhibitors. The Adult Inhibitor Summit was created to provide an opportunity for patients and their caregivers to connect with others, discuss common experiences, and share support in the management of this difficult condition.

Currently scheduled Adult Inhibitor Summits:

Adult Inhibitor Summit I
October 17-19, 2008, Philadelphia, PA

Adult Inhibitor Summit II
November 7-9, 2008, Chicago, IL

Adult Inhibitor Summit III
November 21-23, 2008, Dallas, TX

This information was made available by the CBCE. To contact the CBCE call (888) 706-6867 or e-mail inhibitorsummits@thebce.com.

In Memoriam

HFA extends condolences to the family and friends of Jonathan Wadleigh

Of Brookline, MA. June 4, 2008. Jonathan, who passed was the beloved husband and best friend of Joanne Womboldt. Survived by niece Corinna Apellegate of Brookline and nephew Clifford MacNeil and his children, Elizabeth and Cameron all of Newton, NH. He is also survived by his half sister, Anne Gilbert Hook and her children, Steven, Clare, Julia, Deborah and Ben. A celebration of Jonathan's life was held on Saturday, June 14th in the First Parish in Brookline. In lieu of flowers, donations in memory of Jonathan may be made to COTT/Hemophilia/HIV Memorial Fund c/o Sovereign Bank, 965 Great Plain Ave., Needham, MA 02492. Jonathan was Co Founder of the Committee of Ten Thousand (COTT).

The HFA remembers Fred Hinze.

On Tuesday, July 15, 2008, Fred Hinze, a friend to many in the bleeding disorder community passed away. Fred touched many lives, in his role as a volunteer, patient advocate, legislative advocate, and dear friend.

Fred was involved with the Hemophilia Foundation of Illinois (HFI) for many years. He served on the board at HFI and served as a camp director and counselor at Camp Warren Jrych in Illinois for almost two decades. Fred also volunteered at Bleeding Disorder Camps in Oklahoma, Missouri, and Hawaii. Fred left a lasting impression on many of the younger campers. He had a special knack for being able to cure the new campers of their homesick blues. The first counselor that returning campers would seek out was Fred.

Fred was unselfish and helpful. He never complained and always gave 110% in everything he did. Fred will be dearly missed but always remembered.

Hemophilia Community Loses Dr. Margaret Hilgartner.

It is with deep sadness that we inform you that Dr. Margaret W. Hilgartner passed away on August 19. As a dedicated physician and researcher in the bleeding disorder community, Dr. Hilgartner served as the Director of the Hemophilia Comprehensive Treatment Center from 1970 to 1995, and was the Division Chief of Pediatric Hematology/Oncology from 1978 to 1992. Margaret will always be fondly remembered and revered for her inspirational leadership, for her prodigious contributions to hemophilia and other pediatric hematological diseases and for the zest with which she embraced all of her wonderfully balanced life.

Condolences can be sent to: Dr. Milton Arky and Family, 3000 Galloway Ridge Road, Apt G106, Pittsboro, NC 27312.

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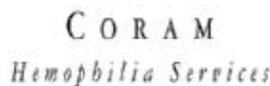
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Hemophilia Federation of America **Calendar of Events**

| Date | Organization | Description |
|----------------------|---|--|
| October 2008 | | |
| Oct 1 | Hemophilia Foundation of No. California | Volunteer Dinner |
| Oct 4 | Hemophilia Foundation of No. California | Family Information Day |
| Oct 4 | Tennessee Hemophilia and Bleeding Disorders Foundation | A Royal Gala, Crossville, TN |
| Oct 6 | United Virginia Chapter of the National Hemophilia Foundation | Golf Tournament Fundraiser |
| Oct 10-11 | Utah Hemophilia Foundation | UHF Fall Adult Retreat |
| Oct 15 | Nebraska Chapter of the NHF | Harvest Festival, Vala Pumpkin Patch, Gretna, NE |
| Oct 18 | Hemophilia of North Carolina | Hemophilia Walk 2008, Cary, NC |
| Oct 25 | Utah Hemophilia Foundation | UHF Teen Fall Retreat |
| Oct TBA | Oklahoma Hemophilia Foundation | Fall Festival |
| Oct TBA | Sangre de Oro Hemophilia Foundation of New Mexico | Family Educational Weekend, Albuquerque |
| Oct TBA | Tri State Bleeding Disorder Foundation | Annual Meeting |
| November 2008 | | |
| Nov 1 | Hemophilia Foundation of No. California | Fresno Wine Bus |
| Nov 8 | Nebraska Chapter of the NHF | Educational Conference in Western NE, Location TBA |
| Nov 8 | Hemophilia Assoc. of the Capital Area | HACA Educational Symposium and Annual Meeting |
| Nov 22 | Utah Hemophilia Foundation | UHF Family Fun Day |
| Nov TBA | United Virginia Chapter of the National Hemophilia Foundation | A Night Under the Stars Fundraiser |
| December 2008 | | |
| Dec 6 | Hemophilia of North Carolina | HNC Holiday Celebration |
| Dec 6 | Hemophilia Foundation of No. California | Fresno Holiday Event |
| Dec 6 | Nebraska Chapter of the NHF | Holiday Party, Location TBA |
| Dec 6 | Oklahoma Hemophilia Foundation | Christmas Party |
| Dec 7 | Hemophilia Foundation of No. California | Oakland Holiday Event |
| Dec 14 | Hemophilia Foundation of No. California | Modesto Holiday Event |
| Dec TBA | United Virginia Chapter of the National Hemophilia Foundation | Holiday Parties |
| Dec TBA | Sangre de Oro Hemophilia Foundation of New Mexico | Bowl-a-Thon |
| Dec TBA | Tri State Bleeding Disorder Foundation | Winter Event |

HFA member organizations are encouraged to post announcements and events by emailing the information to s.aultman@hemophiliated.org.

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