HFA Dads In Actions Training a Success!

Front row left to right: Joey Privat, HFA Volunteer Committee Co Chair, Shannon Peterkin (Hemophilia Foundation of Illinois), Scott Lovelady (Hemophilia Foundation of Arkansas), Tom Vaclavik, HFA Volunteer Committee Co Chair

Middle row: Chuck Garcia (Texas Central Hemophilia Association), Matt Igleman, Matthew Compton (Hemophilia of North Carolina), Resbe Muncy (Tennessee Hemophilia & Bleeding Disorder Association), Shawn Nease (Hemophilia Foundation of Maryland), Scott Pruitt (Hemophilia Foundation of Indiana), Lance Cleghorn (United Virginia Chapter of the NHF)

Back Row: Chris Bolls (Tri-State Bleeding Disorder Foundation), Jeff Bentley (Oklahoma Hemophilia Foundation), Craig Dubois, Sean Kaecher (Bleeding Disorders Association of the Southern Tier)

Hemophilia Federation of America’s 2006 Dads in Action (DIA) Summer Training Session was held July 21 through 23 in Lafayette, Louisiana. The Dads in Action Program provides training to help fathers build stronger bonds with their children. It includes fathers of children with bleeding disorders and fathers who have hemophilia or other bleeding disorders themselves. Thirteen dads from eleven states joined HFA Board Members and DIA Program Co-chairs, Tom Vaclavik of Indiana, and Joey Privat of Louisiana in the intensive three-day DIA training where they learned and practiced the skills necessary to facilitate DIA programs in their respective states.

HFA is very proud of this year’s graduates and know that both their respective member organizations and HFA will greatly benefit from this Dad’s participation. Thank you for sending us such great Dads in Action!
Dateline Federation is published four times a year by the Hemophilia Federation of America, 1405 W. Pinhook, Ste. 101, Lafayette, LA 70503; Toll Free: 800-230-9797; Phone 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 website at www.hemophiliafed.org

Disclaimer
This material is provided for your 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.
© Hemophilia Federation of America 2006

Mission
The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the blood clotting disorders community.

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

Officers
Carl Weixler, President
Chad Stevens, 1st Vice President
Donald Akers, Jr., 2nd Vice President
Peter Bayer, Secretary
Tom Vaclavik, Treasurer
Barbara Chang, Past President

Staff
Susan Swindle, Administrative Director
Jan Hamilton, Advocacy Director
Carole Lancon, Program Director
Sandy Aultman, Administrative Assistant
Jim Boudreaux, Webmaster
Alexis Olivier, Intern
Laurie Guidry, Bookkeeper

Publication Committee
Bob Marks, Chair
Margie Yancy
Jill Williams
HFA WELCOMES NEW MEMBER ORGANIZATIONS

The Hemophilia Federation of America (HFA) is pleased to welcome four new member organizations into our family: the Hemophilia Foundation of Minnesota/Dakotas, the Snake River Hemophilia and Bleeding Disorders Association, the Tri-State Bleeding Disorder Foundation and the United Virginia Chapter of the NHF. In its twelve-year existence, HFA’s membership roll has grown to twenty-six member organizations.

The Hemophilia Foundation of Minnesota/Dakotas (HFMD), located in Mendota, MN, defines its mission as meeting the needs and enhancing the quality of life for persons who live with hemophilia, related genetic bleeding disorders, and their complications. HFMD’s President is Aaron Reeves and its Executive Director is Jim Paist. For more information on HFMD visit www.hfmd.org.

The Snake River Hemophilia and Bleeding Disorders Association was founded in February 2005 by three families in Idaho who are affected by bleeding disorders. Located in Newdale, ID, its goals include education of families about bleeding disorders, treatment options, and patient advocacy for best care and peer support. Chad Stevens serves as Snake River’s president. For additional information, visit www.srhbda.org.

The Tri-State Bleeding Disorder Foundation is located in Cincinnati, OH. Its Executive Director is Lisa Raterman and president of the organization is Gary Dillhoff. The mission of Tri-State is to improve the quality of life for children and families living with hemophilia, von Willebrand Disease and other inherited bleeding disorders. Tri-State’s website is www.tristatebleedingdisorderfoundation.org.

United Virginia Chapter of the NHF is our newest member organization and is located in Troy, Virginia. UV’s Executive Director is Kelly Waters and its president is Kevin O’Conner. United Virginia’s Mission is to serve the needs of the genetic bleeding disorder community through education, advocacy and the support of research to find a cure. You can visit www.vahemophilia.org for more information.

For a comprehensive list of these and additional member organization’s activities, please go to the Member News section of Dateline.
GENETIC ALLIANCE 2006 ANNUAL CONFERENCE • Maria Rubin

The Genetic Alliance is a coalition of over 600 disease specific advocacy organizations working to increase capacity in advocacy organizations and to leverage the voices of the millions of individuals and families affected by genetic conditions. The Hemophilia Federation of America is one of the member organizations and this year I was glad to attend the Annual Conference on behalf of HFA.

The first day I attended a day long workshop on developing strong boards. It was coordinated by Gene Early, PhD who has worked with the Genetic Alliance over the past three years to develop its organizational incubator. Gene has authored numerous articles as well as books, the last of which is “Leadership Expectations: How Executive Expectations are Created and Used in a Non-Profit Setting”. Gene has worked with the Genetic Alliance to transform its Board from being a “working bee” board, to the current model of being a “governance” board, and continuing to their ultimate goal of becoming a “visionary” board.

The workshop gave some insight to the process that they have gone through during the last three years. In attendance were complete boards of other organizations and some interested individuals such as myself. The workshop was based on the book “Good to Great” by Jim Collins. The premise of the book is that “Good is the enemy of great”. The type of leadership in the “great” organizations made a difference. These leaders were labeled Level 5 leaders who demonstrate personal humility and professional will revealing a fierce resolve to do what is best for the organization, not the leader.

Collins identified three characteristics which executive leaders in the good-to-great organizations must have: competence, chemistry and character.

- Competence is the capacity to be the best person in the industry at the job.
- Chemistry is the depth of respect and love that allows executive team members to yell and scream, argue and debate but remain committed to one another and cohesive in what’s best for the organization.
- Character relates to the implicit values required to fit into the management team.

The organization needs to recognize what they can be best at; this is what he calls the “Hedgehog Concept”. The three elements for developing the hedgehog concept require the answer to these three questions:

1. What can you be best in the world at? The answer to this question is an identity statement defining the character of the organization and leading to strategies, goals, and intentions that express the identity.
2. What are you passionate about? The idea here is to discover your passion.
3. What drives your economic engine? The idea of understanding that drives action is one way to summarize this book.

Good to great organizations worked to understand at a deep level what made them work, and by continually looking for new answers to the question, they developed the momentum to breakthrough into greatness.

The rest of the meeting was full of interesting workshops. I attended: Parents as Advocates in the Medical Insurance Context, Maximizing Effectiveness of Voluntary Health Organizations through Coalitions, Power Up! Raise the Profile of your Organization Through Advocacy. Learning from other organizations and expanding the horizons beyond “hemophilia” made me understand that in the end we all have the same goals, the same general needs and it was great to be able to share experiences with others.

Additional information about The Genetic Alliance can be found at www.geneticalliance.org and http://geneticfairness.org

All the resources and presentations from this conference will be included in the Resource Repository at: www.geneticalliance.org/repository

4 • Dateline Federation • Fall 2006
HFA ANNOUNCES 2006 SCHOLARSHIP WINNERS

The Hemophilia Federation of America is pleased to announce the recipients of its 2006 Educational Scholarships. Beginning with a field of over fifty applicants, HFA awarded ten $1500 scholarships to the awardees listed below.

Educational Scholarships went to Nicholas P. Hilgeman, of Whitehouse, Ohio, who will be a freshman at Case Western Reserve University; Alisha Doppler of Union City, Indiana, who will be a freshman at Indiana University East; Michael D. Fitzpatrick, from Concord, New Hampshire, a senior at Keene State College; Shannon Cook from Latham, NY, a sophomore at Hudson Valley Community College; and Aaron L. Craig, Richardson, Texas, a freshman at The King’s College.

Three Sibling Continuing Education Scholarships were awarded to Rebecca Barkdull, of Orem, Utah, a sophomore at Utah Valley State College; Meaghan McDonald, of Wauwatosa, Wisconsin, a sophomore at University of Wisconsin-Madison; and Whitney Fuller, from Baldwin, New York, a freshman at Temple University.

A Parent Continuing Education Scholarship was awarded to Linda Garrett of Caledonia, Mississippi. She will begin her freshman year at Bevill State Community College. An Artistic Encouragement Grant was awarded to Collin Barkdull, of Orem, Utah, a freshman at Utah Valley State College.

Each $1,500 scholarship award was determined by HFA’s Scholarship Committee. Consideration was given to recipients who demonstrated a strong commitment to improving their quality of life by pursuing specific educational goals.

HFA was inundated with letters of appreciation from the grateful recipients of this year’s awards. “This award is an answer to prayer as it will help ease the financial strain of paying for my college education.” Another awardee wrote, “I want to thank the Hemophilia Federation of America for awarding me a scholarship . . . and I am confident it will help me succeed in achieving my academic goals.” “Thank you so much for aiding me in this chance of following my dreams”. “Thank you so very much for believing in me and my potential.”

Congratulations to all of HFA’s Educational Scholarship awardees and best wishes with your educational endeavors. For information about HFA’s 2007 Scholarships awards, visit our website at www.hemophiliafed.org or contact our national headquarters at 1-800-230-9797.

FOUR MEMBERS ROTATE OFF HFA BOARD OF DIRECTORS

The lifeline of the Hemophilia Federation of America (HFA) is its volunteers. The HFA is particularly grateful for the commitment and dedication of its Board of Directors. The Board of the HFA is a unique group of individuals representing a voice from each of its 26 member organizations and independents that share common interest in fulfilling the mission of the HFA. Four members recently rotated off the Board at the HFA annual meeting in St. Louis, Missouri on March 29, 2006. The HFA is extremely appreciative of the dedicated service of the following individuals and we look forward to their valuable continued service on its committees.

Randyl Ratcliff of Lafayette, La has served as HFA treasurer from 2000-2005 and most recently served as an Executive Committee member. Even though he does not have a blood clotting disorder, his dedication to HFA has been exemplary. Randy has also served on the Finance Committee and received the President’s Award at this year’s annual symposium in St. Louis for his generous support of the organization.
Ray Dattoli is from Plano, Texas and has hemophilia. He has devoted much time to HFA and the Texas Central Chapter. He has served on the Advocacy and Helping Hands Committees for many years. He has also played an active role in the fight to raise hemophilia awareness within government circles and the healthcare industry. He is a strong advocate of patients’ rights.

Sharen Haddad of Monroe, LA became a board member in 2000. She is one of the rare females with Moderate Hemophilia Factor VIII deficiency. She has served HFA as a member of the Advocacy, Nominating, Teen and Focus on the Feminine Committees. She has provided emotional support to other women and has increased public awareness of women affected with bleeding disorders.

Linda E. Wyman-Collins (Lew), BSN, RNC has also been a board member since 2000. Lew has been diagnosed with Hemophilia A, Platelet Disorder and is the mother of two sons with severe Hemophilia A. She is presently employed as an Ehler's Danlos Neonatal Intensive Care Nurse. She has served on the Advocacy, Nominating and Focus on the Feminine Committees of HFA. She is also on the HFA Medical Advisory Board and has devoted much time within the medical community to insure blood products are safe. Lew has volunteered as a hemophilia camp Nurse for Camp Youngblood in Virginia, Victory Junction Gang Camp in North Carolina, and, since her recent move to Texas, the Texas Hemophilia Camp. Lew has represented the Hemophilia Association of the Capital Area, Hemophilia Foundation of Maryland and finally Texas Central Hemophilia Association during her six-year HFA Board tenure.

PATIENT SUMMITS OFFER RARE OPPORTUNITY FOR PEOPLE WITH INHIBITORS

When it comes to living with inhibitors, there's a lot to learn.

This year, people with inhibitors and their caregivers are invited to listen, learn, and be heard at one of four Inhibitor Patient Education Summits being held across the US.

The Summits are one-of-a-kind learning and networking opportunities focused exclusively on topics of interest to the inhibitor community. Speaker selection and agenda development for these meetings have been directed by a steering committee composed of national and local hemophilia leaders, including physicians, nurses, advocates, patients, and representatives from physical therapy and social work.

The 2006 Summits are planned for: Anaheim (July 28–29), Dallas (August 4–5), Baltimore (September 22–23), and Chicago (October 27–28). Topics will include Basics Behind Inhibitors, Treatment Strategies, Immune Tolerance Therapy (ITT), Insurance: Changes and Challenges, Exercise and Sports, Psychosocial Issues, Joint Health, Surgical Considerations, and Pain Management. All meetings will take place at handicap-accessible facilities. On-site child care will be provided.

Travel grants will be available to eligible individuals and administered by select chapters. To register or learn more about attending a meeting, please call 1-888-706-6867 or visit www.inhibitorsummits.org.

The bleeding disorder professionals

The bleeding disorder professionals

hemophiliaoptions™

The bleeding disorder professionals

There's another way to avoid accidental needle sticks

Kogenate FS

Antihemophilic Factor (Recombinant) Formulated with BIO-SET™

www.kogenatefs.com

24/7 Availability

1-866-HEM-HERO (1-866-436-4376)

Specialized care for those with bleeding disorders

www.hemophiliaoptions.com

optioncare
The Hemophilia Federation of America was proud to announce its newly elected executive board members for 2006 at the annual symposium meeting March 31-April 2 in St. Louis, MO. The returning members are Carl Weixler (President), Donald Akers, Jr (Second Vice President), Peter Bayer (Secretary), Melinda Clark (At-Large), and Barbara Chang (Past President). Three new board members were elected to lead the organization.

**Chad Stevens, First Vice President**
Chad Stevens became a HFA board member in 2003 and served as treasurer for the HFA Executive Committee. Chad has Hemophilia B and is the last survivor of seven relatives with the disease.

Chad is an active member of the Hemophilia Foundation of Idaho and Snake River. He has worked with several community organizations, including Partners in Education, Habitat for Humanity, and Paint the Town, an organization in his hometown of Newdale, ID. He is involved with the Advocacy and Outreach Committees.

Chad moved back to Newdale from Boise, ID, where he spent eighteen years in the banking industry. He and his wife, Jolynn, have been married for 14 years.

**Tom Vaclavik, Treasurer**
Tom Vaclavik has been an active board member of the Indiana Chapter of NHF for the last eight years, and an active member of HFA's board since 2004. He is a grandfather with custody of his grandson with severe Hemophilia A.

He is very involved with the Dads In Action and Fundraising Committees. He is Co-Chair of the HFA Dads In Action Project. He has worked with several other organizations such as Moose, American Legion, Special Olympics and Eagles Baxter Hemophilia Advisory Board.

Tom lives in Hobart, IN, with his wife Linda Holliday and grandson Christopher Holliday.

**Donald Han, At-Large**
Don is the father of two young boys, one of which has Hemophilia B. In 2004, he adopted a thirty-something severe Hemophilia A with Hepatitis C +, which has shown him the challenges facing earlier generations of hemophiliacs. Don has been fully engaged in the hemophilia community since 1999, when his first son was born, and has been a board member of HFA since 2003 where he currently serves on the scholarship and executive committee. He is also an active board member of the Hemophilia Association of the Capital Area, serving as a consultant and chair of several committees.

He is currently CEO of RJ Management, Inc. and consults in the areas of organizational development, finance, strategy and leadership development. He was the founder of a premier high-tech securities trading firm in the greater Washington D.C. area, and started his successful career at the investment banking firm of Shearson Lehman Bros. He holds a Masters of Science in Leadership from the McDonough School of Business at Georgetown University, and a Bachelor of Science in Finance from the College of Business and Management at the University of Maryland, College Park.

Don lives with his three sons and his Harley Davidson in a Northern Virginia suburb of Washington D.C., and has recently forayed into advocacy and treatment for children in special education.
It took doctors diagnosing her newborn son with a genetic blood disorder for Laveane Lovelady of Greenbrier, AR to finally get the answer about her own condition. Laveane and her son, Ryan, now 16, are hemophiliacs. People with this disorder have abnormal bleeding because of a deficiency in a plasma protein that helps blood clot. Laveane, who grew up in Yell County, said she knew her grandfather was “a free bleeder. They didn’t call it hemophilia,” she said. “I had bleeding episodes all my life. If I had a tooth extracted, I usually had a bleed that day or the next day.” She still vividly remembers an incident when she was 10 and had a tooth pulled. She was staying with a great aunt and uncle in another town. “It started bleeding at 9 o’clock. ‘Bonanza’ was coming on,” she recalled. “All I had to do is open my mouth and it was like a water faucet.” Although her aunt packed it with gauze, the bleeding didn’t stop. Laveane stayed up all night, because “I was too scared to wake them up.”

When her daughter, Leigha, was born in 1987, Laveane had bleeding problems, but they went largely undetected. Almost a year later, she had an ovarian cyst rupture. By the time she saw her doctor, there was so much blood in her internal cavity that she could barely stand up. Blood tests were abnormal, but still no one mentioned hemophilia. She also was pregnant with Ryan and didn’t know it. When he was born by C-section, an IV was started in his hand “and his whole hand was black with bruising.”

Doctors at Arkansas Children’s Hospital found out when Ryan was eight days old that he was a hemophiliac, and his type was severe. It was then that Laveane finally understood that she was a carrier and a mild hemophiliac, “unless I’m in a trauma situation, and then I’m severe.” As a new mother who didn’t know much about the disorder, “I was a basket case and cried every day for six weeks.” Laveane and Ryan have hemophilia A, which results from a deficiency of the plasma protein call Factor VIII.

According to information on the WebMD Internet site, hemophilia is linked to a defective gene on the X chromosome. Men who have hemophilia do not pass the disease to their sons, because boys inherit only the Y chromosome from their father. However, men pass the X chromosome to their daughters, making them a carrier. When a female hemophiliac carrier has a daughter, the child has a 50 percent chance of being a carrier. “My mother was a carrier and passed it to me,” Laveane said, although her mother doesn’t show signs of the disorder. Daughter Leigha was tested and isn’t a carrier, much to the relief of Laveane and her husband, Scott.

Raising a rambunctious boy, knowing that he could bleed severely with any injury, was nerve-wracking for Laveane. “I worried a lot when he was very young,” she said. Even picking him up from the crib could cause bruising and bleeding. “You see those bruises and you think, ‘I’m going to be turned in for child abuse,’” she said during an interview at First Service Bank in Greenbrier, where she is an administrative loan officer. However, “God has blessed us. Ryan has not had a lot of traumatic bleeds,” she said. In fact, he hunts, fishes, plays baseball and has participated in other sports, except for football. That’s one sport the doctors
won’t let him try. He also had to stop practicing his calf-roping, because it was causing a joint in his elbow to bleed.

Four years ago Ryan had surgery on his elbow to slow the bleeds. Ryan just shrugs off the concerns about his disorder. “I don’t pay much attention,” he said. Ryan said he first realized he had a disorder “probably when I started getting out in the yard and wrestling around” as a child. “I wouldn’t even know it, and Mom would make be get a shot.” He has to give himself “shots,” which are actually the medicine Factor VIII, given intravenously, Laveane said.

“It’s a very expensive disease,” she said. The cost is $2,000 per “shot,” and she orders 10 a month. “If it weren’t for insurance, we’d be bankrupt,” she said. Laveane said they both have to be careful about what over-the-counter medicine they take. They can’t take aspirin or aspirin products or herbs that promote bleeding. In addition, she said they have to watch foods such as garlic and tomatoes, which tend to aid bleeding as well. A hemophiliac’s brain can “just start bleeding for no reason,” Laveane said. She doesn’t feel helpless, though. Laveane has been a member of the Hemophilia Foundation of Arkansas Inc. Board for 13 years, serving previously as president. “We advocate and work with people with bleeding disorders,” not just hemophilia. There is a treatment center at Arkansas Children’s Hospital. “We have get-togethers and you don’t have to explain what hemophilia is, and we know what to watch for when the kids are running around,” she said with a laugh. Laveane said there are 268 people in Arkansas affected by hemophilia. “We have Christmas parties and a family retreat. The Arkansas foundation also holds golf tournaments to raise money.

She also serves on the Hemophilia Federation of America, Board of Directors. Laveane said she and her son lead as normal a life as possible, enjoying it to the fullest. Ryan is positive about the future. “Things will probably be better when my grandkids come around,” he said, nodding his head with confidence.

Article courtesy of Women’s Inc and Log Cabin Democrat, Little Rock AR.

**MEDICARE PUBLISHES PATIENT RIGHTS ELECTRONICALLY**

Medicare is committed to helping beneficiaries get the services they need, when they need it most. The Centers for Medicare & Medicaid Services would like to announce the release of an electronic version of “Your Medicare Rights and Protections” that clearly outlines the key safeguards governing the original Medicare plan, Medicare Health plans and the Medicare Drug plans. This booklet has information that beneficiaries and advocates need to know in order to file a complaint, appeal or identify where to go to get help with questions. This easy to understand publication outlines the basic Medicare rights, including to:

1. Be treated with dignity and respect at all times.
2. Be protected from discrimination.
3. Get information about Medicare that you can understand to help you make health care decisions.
4. Have your answers about the Medicare Program answered.
5. Get culturally competent services.
6. Get emergency care when and where you need it.
7. Learn about all of your treatment choices in clear language that you can understand.
8. Ability to file a complaint.
9. Ability to appeal a decision relating to your claims for benefits.
10. Have your health information that Medicare collects about you kept private.
11. Know your health information privacy rights.

The publication can be shared electronically by going to: http://www.medicare.gov/Publications/Pubs/pdf/10112.pdf. People can get access to answers to their questions 24/7 at 1-800-MEDICARE (1-800-633-4227) or TTY1-877-486-2048.
Left to Right: Michael Bradley, Vice President Healthcare Economics and Reimbursement, Baxter Healthcare, Susan Swindle, Administrative Director, HFA, Carl Weixler, President, HFA, Peter O’Malley, Vice President of National Accounts Baxter BioScience US, Jan Hamilton, Advocacy Director, HFA.

Representatives of Baxter Healthcare, officers of HFA Board of Directors and staff gathered for a meeting at the national headquarters of the Hemophilia Federation of America (HFA) in Lafayette, LA on May 16, 2006. Baxter’s team members presented the organization a check in the amount of $100,000 in support of HFA’s mission of assisting and advocating on behalf of the blood clotting disorders community. For two consecutive years, Baxter has shown its support by donating at the HFA Angel Corporate Level (over 100,000). In addition to the individuals pictured above, Baxter Healthcare representatives in attendance were Shannon Penberthy, Director Federal Legislative Affairs and Meredith Zerbe, Manager Healthcare Economics. Also attending the meeting was Donald Akers, HFA 2nd Vice President. The Hemophilia Federation of America greatly appreciates Baxter’s continued support of its efforts.

Your Hemophilia World - We know it
You live in that wonderfully off-the-wall world of bleeding disorders, where you know the unexpected is bound to happen. So do we.
NuFACTOR’s customer care representatives know your world firsthand, and we’re committed to making it work a little smoother.

NuFACTOR
Hemophilia Homecare Services
So call us: 800-323-6832 www.nufactor.com

ARJ Infusion Services
Where caring is...
Specializing in...
- Award Winning Nursing
- 24 Hour On Call Service
- Infusion Education for Patients and Families
Toll Free 866.451.8804
www.arjinfusion.com
GENETIC ALLIANCE & PARTNERS TO ENGAGE COMMUNITIES IN FAMILY HEALTH HISTORY COLLECTION

(Washington, DC—May 22, 2006) Genetic Alliance announced today that it has received a cooperative agreement from the Genetic Services Branch of the Maternal and Child Health Bureau, HRSA, DHHS in the amount of $600,000 annually. Utilizing Family Traditions and Oral History for Health Promotion is a three year project, during which Genetic Alliance will collaborate with the Institute for Cultural Partnerships, Seattle Indian Health Board’s Urban Indian Health Institute, Intermountain Healthcare, National Council of La Raza, Appalachian Office of Justice and Peace, Iona College Social Work Department, American FolkLife Center at the Library of Congress, and American Society of Human Genetics, as well as numerous disease advocacy and community organizations.

The project, Community Centered Family Health History, focuses on family health history, folklore, genetics, and accessibility and sets a new bar for what it means to tailor health-related materials and resources to a community. "The American Indian and Alaska Native community has been using stories for countless generations to pass on history, culture and tradition," explains Maile Tauli, Associate Director of the Urban Indian Health Institute. "We are delighted to participate in a project that will support those traditions and help address the burden of disease in communities we serve."

In addition, the project demonstrates that, not only will a community-based model be effective for geographic, ethnic, or cultural groups, but it can also be applied effectively to those who share significant characteristics in common, such as a shared health condition, occupation, or life event. “Genetic Alliance advocacy organizations empower their respective member communities to take charge of their health and their future,” said Sharon Terry, President & CEO of Genetic Alliance. “Family health history is an opportunity for families and communities to take proactive steps to improve their health and to do so within the context of their lives and culture.”

The partners will further develop and evaluate the Healthy Choices through Family Health History Awareness Tool. Evaluation of family health history represents a first step in identifying genetic contributors to health and can serve as an important basis for improving health care and encouraging a healthy lifestyle. Though multiple family health history tools abound, neither the premise that they will make a difference in health outcomes, nor the analysis of their usefulness along a medical-non-medical continuum, has been validated in a systematic, evidence-based study as measured by changed behavior leading to better personal health. This project will address these issues and result in a customizable template of the Tool – information, health stories, pictures, and descriptions of conditions will be available for diverse communities. The tool will be implemented on a national scale through interested national and community-based organizations.

“Hispanics experience numerous conditions – diabetes, heart disease, obesity, and certain cancers, to name a few – that may have a genetic link. It is critical that Latinos become informed about their family health history so they can make healthier choices for their families. Thus, we are happy to partner with the Genetic Alliance in the evaluation of this tool,” said Liany Arroyo, Director of the Institute for Hispanic Health of National Council of La Raza (NCLR).

2006 HFA HONOR ROLL OF CORPORATE SPONSORS

ANGEL ($100,000)
Baxter Healthcare Corporation
Novo Nordisk, Inc.

DIAMOND ($50,000-$99,999)
Wyeth Pharmaceuticals
ZLB Behring

PLATINUM ($25,000-$49,999)
AHF, Inc.
Bayer HealthCare
Curative/Critical Care Systems
Factor Foundation of America

GOLD ($10,000-$24,999)
ARJ Infusion Services, Inc.
Factor Support Network Pharmacy
Hemophilia Health Services (HHS)
National Cornerstone
Healthcare Services, Inc.
Postitudes, Inc.

SILVER ($5,000-$9,999)
Allied Preferred Care
Axiom Therapeutics
Coram Healthcare
Cyril Home Care Pharmacy
Factor Health Management
NuFactor
Recombl
Talecris Biotherapeutics

BRONZE ($2,000-$4,999)
Atlantic Biologicals
BioRx
Caremark, Inc.
CoaguLife
Care for Life
Grifols USA, Inc.
Hemophilia Options
Matrix Health
New Life Home Care, Inc.

FRIEND (Up to $2,000)
Inax Communications
The Coalition for Hemophilia B
BAXTER HIGHLIGHTS WORK OF WORLD FEDERATION OF HEMOPHILIA IN ADDRESSING GLOBAL DISPARITIES IN HEMOPHILIA CARE
WFH's Global Alliance for Progress Continues To Impact Standards of Care in the Developing World

DEERFIELD, Ill., April 13, 2006 - In recognition of World Hemophilia Day on April 17, Baxter Healthcare Corporation has extended its commitment to the World Federation of Hemophilia's (WFH) Global Alliance for Progress (GAP), a 10-year program aimed at improving disease management for the 75 percent of the world's hemophilia population that is living without adequate care. As a founding sponsor and major contributor to GAP, Baxter applauds WFH's progress in greatly improving the diagnosis and treatment of hemophilia in developing countries. To date, Baxter has committed $1.2 million to this program.

BAXTER AND JERINI ADVANCE PROGRAM TO DEVELOP NON-INTRAVENOUS HEMOPHILIA THERAPY
Deerfield, Ill. and Berlin, Germany, May 18, 2006 - Baxter AG and Jerini AG today announced progress in their collaborative research program to develop a non-intravenous therapy for the treatment of hemophilia. Extensive in vitro and in vivo analyses have identified several synthetic lead molecules with promising pharmacological properties.

"Using our proprietary technology platform, we continue to make important progress in our collaboration with Baxter, the leader in hemophilia therapy," said Jens Schneider-Mergener, Jerini AG's chief executive officer. "We are encouraged by the identification of these molecules and the evaluation of the potential to treat hemophilia using a non-intravenous therapy with molecules that can be synthetically produced."

ZLB Behring Foundation Awards Grants to Benefit Bleeding Disorders Community
Monday June 5, 11:17 am ET
KING OF PRUSSIA, Pa., June 5 /PRNewswire/ -- The ZLB Behring Foundation for Research and Advancement of Patient Health has recently awarded funding for programs designed to benefit the bleeding disorders community. The Foundation awards grants at regular intervals throughout the year. In this cycle, nine recipients received awards. The grants support a range of initiatives, such as those that support and educate specific patient populations to research on the genetic aspect of hemophilia.

Governed by an independent Advisory Council with the sole authority to award grants, the ZLB Behring Foundation is a non-profit organization dedicated exclusively to charitable, scientific and educational purposes that advance the standard of care for persons affected by bleeding disorders such as hemophilia and von Willebrand Disease. Since its inception in 2001, the ZLB Behring Foundation has awarded millions of dollars in grants to the bleeding disorders community.

"We are confident that with our continued support, researchers and advocates will continue to advance the quality and standard of care for patients suffering from these rare and often debilitating disorders," said Paul Perreault, Vice Director of the ZLB Behring Foundation. "We strongly encourage all eligible organizations and individuals to submit grant requests for consideration."

Several of the Foundation grants awarded in this round will fund research on and educational programs for women with bleeding disorders. The National Hemophilia Foundation estimates that more than two and a half million women in the United States have an undiagnosed bleeding disorder. Women with undiagnosed bleeding disorders can often experience life-threatening complications during childbirth, surgery, accidents or injury, and are at higher risk for internal bleeding.
A grant to the Hemophilia Federation of America (HFA) will help support its "Focus on the Feminine" program, an effort to educate women across the United States on the signs and symptoms of bleeding disorders. The funding will enable HFA to participate in health fairs throughout the country.

Maxygen achieves milestone in Roche collaboration
10th May 2006, By Tom Neilsen
Maxygen has achieved a $5 million preclinical milestone in its alliance with Roche to co-develop next-generation factor VIIa therapeutics products for multiple indications of severe bleeding, including trauma and intracerebral hemorrhage. Maxygen achieved this latest milestone by developing a manufacturing process for the product candidates.

NOVO NORDISK recently announced the launch of two important initiatives that will have a positive impact on patients suffering from a rare form of the bleeding disorder, hemophilia. The programs, SevenSTART and SevenSecure, are designed to give patients with hemophilia and their families the support they need in dealing with issues around patient insurance, medical expenses and education as well as assist them in deciding how best to treat the condition.

As you may know, hemophilia is a hereditary disease caused by low or absent levels of a blood protein essential for blood clotting, and affects approximately 15,000-18,000 people in the U.S. The condition gets more complicated, however, when a patient develops inhibitors—antibodies that weaken reactions in the body that control the interruption of bleeding episodes. NovoSeven was designed to treat the population of hemophilia patients with this rare condition.

Both of these programs offer assistance and information to families dealing with inhibitors. The first program is SevenSTART. This "medical experience" program allows patients with hemophilia A & B with inhibitors to FVIII or FIX to use the treatment free of charge. Eligible patients will be enrolled in the one-time-only trial program by a physician. Enrollees will receive a comprehensive patient information starter kit with instructional DVD and user friendly directions on how to administer treatment. The starter treatment kit will arrive by mail and will include everything that the patient needs to infuse medication.

The second program, SevenSecure, is an extensive patient assistance program that offers comprehensive support to families of inhibitors patients including advice and support around insurance claims, denials and reimbursement, finding new or supplemental insurance and tracking lifetime insurance caps. Enrollment in the program may qualify participants for assistance with insurance premiums as well as certain medical and dental expenses. In addition, the program offers product assistance in the event of lapsed medical coverage and educational grants at all education levels for patients with inhibitors. Patients interested in enrolling in SevenSECURE can find more information on www.novoseven-us.com.

Wyeth Pharmaceuticals Pilots Rapid Response Service to Provide Patient Access to Hemophilia Factor VIII & IX Products in Emergency Situations
Collegeville, Pa. (July 10, 2006) — As part of its ongoing commitment to the hemophilia community, Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), announced the introduction of Hemophilia Rapid Response Service, a pilot program to help patients with hemophilia readily access clotting factor product in an emergency situation. Wyeth is the first company to provide a program that offers emergency access to clotting factor VIII and IX products, in pilot areas, 24 hours a day, seven days a week.

To help meet the needs of patients in emergency situations, the Hemophilia Rapid Response Service will provide supplies BeneFIX® Coagulation Factor IX (Recombinant) for hemophilia B and ReFacto® Antihemophilic Factor (Recombinant) for hemophilia A to approximately 2,500 hospitals via a network of 25 pharmacies located across the country. Each pharmacy provides clotting factor to participating hospitals within a 90-mile radius. Typically, the hospital will receive the product within 3 hours of placing a call to the Rapid Response Service’s toll-free number.

More information about the Wyeth Hemophilia Rapid Response Service, as well as a list of the 25 pilot sites, is available from local Wyeth representatives, who may be contacted via the Wyeth Hemophilia Hotline at (888) 999-2349.

Scoring for Care: The World Federation of Hemophilia’s Fundraising Goal To Provide Hemophilia Treatment for All: International Soccer Star, Freddy Adu, Teams With WFH To Increase Hemophilia Awareness
MONREAL, Canada, [22 MAY 2006]: The World Federation of Hemophilia (WFH) announced the launch of Scoring for Care, a soccer-oriented fundraising program made possible by a grant from Wyeth Pharmaceuticals to support those living with hemophilia in the United States and around the world. Freddy Adu, DC United soccer player and Scoring for Care spokesperson, is teaming up with soccer leagues and local hemophilia patient advocacy groups across the country to raise funds through local
soccer events. Funds raised through Scoring for Care will help people with hemophilia manage the disease, increase life expectancy, improve quality of life and raise awareness of the disease.

The soccer team that raises the most funds for hemophilia nationwide will win a training session with Adu. Other prizes include autographed soccer balls and merchandise and an all-expense paid trip to meet Adu in Washington, DC.

Scoring for Care’s Web site, www.scoringforcare.org, provides details about implementing local fundraising events, features customizable materials that can be downloaded from the site and includes hemophilia educational materials. People who are interested in learning more about this program and how to become involved can visit www.scoringforcare.org

**WYETH Pharmaceuticals Introduces the 2006 ReFacto® Antihemophilic Factor (Recombinant) Trial Prescription Program**

Collegeville, Pa. (June 12, 2006) – Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), has announced the introduction of the 2006 ReFacto® Antihemophilic Factor (Recombinant) Trial Prescription Program. In 2006, Wyeth expanded the scope of the program so that more patients may participate and is offering an informational packet and program application directly to patients. The information packet also is available from local hemophilia treatment centers.

The ReFacto Trial Prescription Program is offered to allow patients and health care professionals an opportunity to gain clinical experience with ReFacto and the ReFacto R2 Kit without incurring drug costs.

Patients in the ReFacto Trial Prescription Program will receive a one-time complimentary supply of ReFacto. There is a limited number of applications. The exact quantity of ReFacto supplied is based on the patient’s age:

- <1-5 years 5,000 IU
- 6-11 years 10,000 IU
- 12 years and older 20,000 IU

Patients should ask their health care professional if this program is right for them. More information is available by calling (800) 710-1379.

**World Federation of Hemophilia Twinning Program Receives Sixth Consecutive Year of Funding from Wyeth Pharmaceuticals; Twin of the Year Award Winners Announced and Recognized at Annual Congress**

MONTREAL, Canada, [22 MAY 2006]: Consistent with its vision to support “Treatment for All,” the World Federation of Hemophilia (WFH) announces the renewal of funding for its Twinning program sponsored by Wyeth Pharmaceuticals. Wyeth has been the exclusive funder of Twinning since 2000; the Twinning program was created by WFH in 1996. In addition, the WFH announced winners of its annual Twin of the Year Award – designed to recognize exceptional hemophilia organization and treatment center partnerships between developing and developed countries -- at its annual congress.

Through the Twinning program, treatment centers and hemophilia patient organizations in developed countries are paired with corresponding centers and organizations in developing countries to help share knowledge and best practices. The WFH Twinning Program is approaching record levels with the establishment of 11 new partnerships since February 2006. Forty-nine twins in 30 countries now belong to the program.

**Bayer HealthCare Introduces Free Product Trial Program For Kogenate® FS with BIO-SET®**

Individuals living with hemophilia A in the United States can now experience the safety, simplicity, and convenience of treatment with the first needleless reconstitution device for rFVIII treatment.

BERKELEY, Calif. (July 17, 2006) — Bayer HealthCare today announced the launch of the Kogenate® FS with BIO-SET® Free Trial Program. The Program gives individuals with hemophilia A in the United States a one-time opportunity to experience treatment with Kogenate FS [Antihemophilic Factor (Recombinant), Formulated with Sucrose] with BIO-SET, a needleless reconstitution system, as well as the accompanying support programs and services available through Bayer. Kogenate FS with BIO-SET is the first integrated reconstitution system for recombinant factor VIII that avoids the risk of accidental needle-stick injuries during reconstitution.

The Kogenate FS with BIO-SET Free Trial Program is a special one-time offer for individuals living with hemophilia A in the United States. Program enrollees will receive up to six free infusions of Kogenate FS with BIO-SET (not to exceed a program maximum of 20,000 IU) delivered to their home or location of choice within the U.S. People living with hemophilia A who are interested in learning more about the Kogenate FS with BIO-SET Free Trial Program are encouraged to visit www.kogenatefs.com.

**Grifols Acquires 15 Additional Plasma Collection Centers Through Acquisition of PlasmaCare**

With a network of over 60 wholly-owned plasma collection centers across the US, Grifols is now the second largest collector of human plasma in the world.
Madrid, March 14, 2006. Grifols, a Spanish company specializing in the production of life saving biopharmaceuticals, today announced the acquisition of PlasmaCare, Inc., a company based in Cincinnati, Ohio that specializes in plasma collection. The 15 dedicated plasma collection centers from PlasmaCare, located throughout the Mid-West and the South, will be added to the 50 plasma collection centers Grifols already has in North America. With this acquisition, Grifols will be the world’s second largest supplier of plasma. More information about Grifols can be found at www.grifols.com.

Grifols Donates $1.4 Million in Hemophilia Blood Clotting Therapies to World Federation of Hemophilia

As part of its ongoing commitment to the global bleeding disorders community, Grifols’ donation of plasma-derived blood clotting therapies will be used to treat patients in developing countries.

Barcelona, Spain (May 12, 2006). Grifols S.A., today announced that it will donate approximately $1.4 million in blood clotting therapies to the World Federation of Hemophilia (WFH). The donated products include those used to treat both Hemophilia A and Hemophilia B and will be targeted for patients in developing countries where access to adequate treatment is often lacking. It is anticipated that this donation of hemophilia therapies will be used to treat hundreds of patients. The WFH will direct the distribution of the donated products to areas of greatest need.

All HFA Industry News articles have been modified due to space limitation; to view articles in their entirety please go to the industry news section of HFA’s website at www.hemophiliafed.org.

PLEASE help put a human face on the many uninsured children in our health care system.

Families USA is part of a large national coalition that will soon launch the Campaign for Children’s Health Care: A national campaign to educate the public, opinion leaders, and decision-makers about the need to expand health insurance coverage to all children. According to the U.S. Census Bureau, more than nine million children in the United States have no health insurance. These children are at risk of experiencing irreparable health and developmental problems that could diminish their educational opportunities.

As part of this effort, we are collecting stories of uninsured children. As you may know, we maintain a database of health care stories from all over the country. This story bank is often used by reporters, policymakers, and others to help put a human face on complicated health policy issues and news stories.

We are interested in hearing from families:
- Who can’t afford health insurance for their children
- Whose children face serious health consequences because they are uninsured
- Who have seen their children’s academic achievement compromised because they are uninsured
- Who experience difficulties providing insurance for their children due to financial hardships

If you or anyone you know would like to share a story, please contact Aman Gohal, Communications Associate, toll-free at 1-800-593-5041 ext. 3621. Stories can also be e-mailed to storybank@familiesusa.org.

Families USA respects the privacy of consumers and asks for their permission before sharing their stories with anyone.
HEMOPHILIA FOUNDATION OF ARKANSAS
Upcoming Events:
September 15 – 17 - FAMILY RETREAT - Camp Winnamocka in Arkadelphia, AR.

GATEWAY HEMOPHILIA ASSOCIATION
Upcoming Events:
16th Annual Gateway Hemophilia Association Tee-Off Golf Tournament
September 25, 2006
Stonewolf Golf Course
Announcements:
The Gateway Hemophilia Association has moved into a new location at 462 North Taylor Ave.
Suite 101, St. Louis, MO 63108. The new number is (877) 623-8300.
Upcoming Events:

THE HEMOPHILIA FOUNDATION OF ILLINOIS
Upcoming Events:
August 30, 2006 Shopping Benefit, Chicago area Bloomingdale stores. Contact the HFI office for information and to purchase shopping tickets @ 312-427-1495
September 13th- 9th Annual Driving Fore Hemophilia Golf Outing, Cantigny Golf, Wheaton, IL
September 23rd- Men’s Workshop, Hyatt Lodge, Oakbrook
September 30th- Camp Reunion/Camp Superfly Celebration
October 12-14 – NHF Annual Meeting Philadelphia, PA
November 17th – Holiday Wine Auction, Chandler’s Chop House, Schaumburg Gold Club, Schaumburg, IL
November 17-19- Chicago Women’s Show, Rosemont Convention Center

HEMOPHILIA FOUNDATION OF MARYLAND
The fall season is quickly approaching, and that means it is time for HFM’s Annual Fall Bull and Oyster Roast. The Bull and Oyster Roast will be held on September 16, 2006 at the Parkville American Legion located at 2301 Putty Hill Avenue. Tickets for this event are $30.00 each, and that price includes admission to the bull roast as well as a menu of: Oysters on the Half Shell, Charcoal Top Round of Beef, Fresh Ham, Oyster Stew, Fried Panned Oysters, Beef Bar-B-Que on Rolls, Hot Dogs, Sauerkraut, Mashed Potatoes & Gravy, Greens Table, Sliced Ham, American & Swiss Cheese, Potato Salad, Cole Slaw, White & Rye Bread, Sheet Cake, and Coffee Beer, wine and soda.
Upcoming Events: GOLF BALL DROP & FALL GOLF TOURNAMENT SEPTEMBER 18, 2006 WETLANDS GOLF COURSE.
SECOND ANNUAL KAYAK REGATTA SEPTEMBER 30, 2006 11:00 TIL 3:00 THE BALTIMORE ROWING CLUB
For information on any event please call the Foundation @ 410-288-3955

HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS
Announcements: **HFMD Board of Directors Meet every third Tuesday at 7:00 pm**
Upcoming Events:
August 5, 2006 Sioux Falls Family Activity Day Hike and Butterfly House Event-Sioux Falls, SD
(Call Julie (@ 605-333-7332 to RSVP)
September, 2006 Family Fitness Event-Date and location to be announced
September 18, 2006 HFMD 10th Annual Golf Tournament Indian Hills Country Club, Stillwater, MN
October 12 - 14, 2006 58th Annual NHF Convention
Philadelphia Marriott Downtown - Philadelphia, PA (Contact the HFMD office if interested in attending)
November/December 2006 HFMD Poinsettia Sales
February 17, 2007 Hearts of Hope Gala 2007 - Downtown Hilton Hotel - Minneapolis, MN
April 6 – 7, 2007 HFMD Annual Meeting-Grand Lodge Hotel-Bloomington, MN

HEMOPHILIA OF INDIANA
Upcoming Events:
Annual Meeting Wheels for Winning
Hemophilia of Indiana has a 42 year history of providing programs and services to
over 1,050 members of the bleeding disorder community throughout the state of Indiana.
Consideration of the family unit is the driving force behind our programs and their design. Special programs include, summer camp, post-secondary scholarships, educational and therapeutic workshops, support groups, individual and group advocacy, MedicAlert® Identification, emergency financial assistance and medical advisories. Please contact our offices for more information 1-800-241-2873

LONE STAR CHAPTER OF NHF
Upcoming Events:
September 21-24, Women/Girls with Bleeding Disorder Retreat (contact Ed Kuebler 713-500-8370)
September 29-October 1, 2nd annual Lone Star Family Camp
Announcement:
April 8, 2006-The Lone Star Chapter of the NHF held a Parent Mentor Training. We had 11 parents from 5 cities come to San Antonio for a one day training session. These parent mentors are now ready to reach out to newly diagnosed families and run First Step education/support groups.

BLEEDING DISORDERS ASSOCIATION OF THE SOUTHERN TIER
Our camp affiliate Camp High Hopes is starting a new all girls' camp called Camp Little Oaks for girls with bleeding disorders being held on August 24th - 27th. For additional information about the camp, please contact Wayne Cook at 1-607-761-1665 or email weook22@hotmail.com.

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA
Upcoming Events:
September-October Golf & Tennis Tournament October 12th-14th
October 30th Golf, Shot Gun start 1:00 Arroyo Trabuco Golf Course, Mission Viejo
NHF 5th Annual Meeting, Philadelphia, PA
Regional Educational Seminars (for families with hemophilia and other bleeding disorders) will be scheduled throughout the year to be announced.

TEXAS CENTRAL HEMOPHILIA ASSOCIATION is planning an educational event to raise awareness of Women's bleeding disorders for medical personnel and the community on October 14, 2006 at the Medical Center of Lewisville (part of the North Texas HCA facilities) in Lewisville, TX at 5:30 pm-8pm. Dinner will precede the presentation. Please contact me if you are interested in tickets. Phone 410-288-3955 or email: Miller8043@comcast.net. Thank you for your support, and I hope to see you at the bull roast!

HEMOPHILIA FOUNDATION OF NEVADA
Upcoming Events:
August 18-20 Family “Camp”- Elko August 19 Patient Family Information Day- Elko
September 10 Bloodrun-Reno September 22 Art Kane Memorial Golf Tournament-Las Vegas
At Silverstone Golf Club
October 12-15 NHF-Philadelphia November 4 5K Run/1 Mile Fun Walk-Las Vegas

HEMOPHILIA ASSOCIATION OF THE CAPITOL AREA
Upcoming Events:
September 30 Blood, Sweat & Gears Bike Event 2006 Registration Form
October 28 Annual Educational Seminar

NORTHERN OHIO HEMOPHILIA FOUNDATION
Upcoming Events:
9-16-06 HHS Family Communication Workshop & Club Champs, Stonehedge Family Fun Center
10-7-06 NOHF Annual Meeting, Laureen Kelley, Keynote Speaker, Sheraton Suites, & Club Champs, Cuyohoga Falls
10-28-06 Baxter “Facts First” Program, Mapleside Restaurant, Brunswick

TRI-STATE BLEEDING DISORDER FOUNDATION
Upcoming Events:
Family Bowling Outing - October 28th
Holiday Outing - Tentative December 3rd

HFA member organizations are encouraged to post announcements and events by emailing the information to s.swindle@cox-internet.com or to sandy.a@cox-internet.com.
GRANT AWARDED FOR FOCUS ON THE FEMININE PROGRAM

The Hemophilia Federation of America (HFA) is delighted to announce that it has been the recipient of a $22,000 grant from the ZLB Behring Foundation for Research and Advancement of Patient Health. This award will help support our newest program, Focus on the Feminine, in its effort to educate women on the signs and symptoms of bleeding disorders. HFA would like to thank ZLB Behring Foundation for its generous support and confidence.

ZLB Behring, a company dedicated to helping persons with bleeding disorders, continually works to improve and enhance the quality of life for its patients. In order to fulfill its passionate commitment to care, ZLB Behring extends support to the ZLB Behring Foundation, guided by an independent Advisory Council. The nonprofit foundation is exclusively dedicated to charitable, scientific and educational endeavors benefiting the bleeding disorders community.

It is estimated that over two and one-half million women in the U.S. alone have an undiagnosed bleeding disorder which present differently in women than in men with bleeding disorders. Through Focus on the Feminine, HFA’s goal is to inform and educate this underserved group by participating in women’s expositions throughout the country. Our first Expo in Nashville in April was a huge success, with over three hundred women visiting our booth and requesting information. Next, we will travel to Dallas in August, Tampa in September, and round out this first year’s activities in Chicago.

The Hemophilia Federation of America (HFA) is proud to announce the appointment of Jan Hamilton, HFA Advocacy Director, to a seat on the Center for Biologies Evaluation and Research (CBER) Board. CBER’s mission is to ensure the safety, purity, potency, and effectiveness of biological products including vaccines, blood and blood products and cells, tissues, and gene therapies for the prevention, diagnosis, and treatment of human diseases, conditions and injury. The mission of CBER is to protect and enhance the public health through the regulation of biological and related products including blood, vaccines, tissue, allergens and biological therapeutics.

IN MEMORANDUM

The Hemophilia Federation of America (HFA) would like to extend its sincere sympathies to the family, friends and colleagues of Donald Colburn. Donald died on July 17, 2006 of lung cancer. Donald exhibited the true spirit of philanthropy through his volunteer work at the New England Hemophilia Association, National Hemophilia Foundation, Hemophilia Federation of America and the Committee of Ten Thousand. He also participated in numerous committees advocating on behalf of the blood clotting disorders community. He was the founder, president and CEO of American Homecare Federation. Donald and his wife Kathy, who passed away earlier this year, were passionate about one’s need to give back to the community. A celebration will be held at King’s Philip’s Stockade at Forest Park in Springfield, MA on September 16, 2006. In lieu of flowers, donations may be made to the Colburn-Keenan Foundation, P.O. Box 811, Enfield, CT 06083.

The Hemophilia Federation of America would also like to extend its deepest sympathy to the family and friends of Joe Holibaugh. Joe, who was 34 years old, died on June 13, 2006. He was a Regional Care Coordinator and manager for Matrix Health. Joe will always be remembered for his commitment to the hemophilia community. Donations in his honor can be made to a trust fund established for his son, Jacob S. Holibaugh at Wachovia Bank, 12314 N.W. 25th St., Coral Springs, Fla. 33065. A memorial for Joe is on the Matrix website at www.matrixhealthgroup.com
Mission Statement

The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the blood clotting disorders community.

Vision Statement

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

MEMBER ORGANIZATIONS

Bleeding Disorders Association of the Southern Tier (New York)
Florida Hemophilia Association
Gateway Hemophilia Association (Missouri)
Hemophilia Association of the Capital Area (Maryland)
Hemophilia Foundation of Arkansas
Hemophilia Foundation of Idaho
Hemophilia Foundation of Illinois
Hemophilia Foundation of Maryland
Hemophilia Foundation of Nevada
Hemophilia Foundation of Northern California
Hemophilia Foundation of Southern California
Hemophilia of Indiana
Hemophilia of North Carolina
Hemophilia of South Carolina
Hemophilia Outreach of El Paso (Texas)
Lone Star Chapter of the NHF (Texas)
Nebraska Chapter of the NHF
Northern Ohio Hemophilia Foundation
Oklahoma Hemophilia Foundation
Tennessee Hemophilia & Bleeding Disorder Foundation
Texas Central Hemophilia Foundation
Utah Hemophilia Foundation
Snake River Hemophilia & Bleeding Disorders Association (Idaho)
Hemophilia Foundation of Minnesota/Dakotas
Tri-State Bleeding Disorder Foundation (Ohio)
United Virginia Chapter
BECOME A MEMBER OF THE HEMOPHILIA FEDERATION OF AMERICA

IN ONE OF THE FOLLOWING WAYS:
Visit our website at www.hemophiliafed.org, use Paypal to send payment
or
Complete the information below and mail to address listed below.

I would like to become a partner of the Hemophilia Federation of America. Please accept my donation in the following category.

- Corporate Angel Partner ($100,000)
- Corporate Diamond Partner ($50,000)
- Corporate Plantinum Partner ($25,000)
- Corporate Gold ($10,000)
- Corporate Silver ($5,000)
- Corporate Bronze ($2,000)
- Corporate Friend (below $2,000)
- Chapters ($750)
- Individual Diamond ($1,000)
- Individual Platinum ($500)
- Individual Gold ($100)
- Individual Silver ($50)
- Individual Bronze ($25)

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Company</td>
</tr>
<tr>
<td>Address</td>
</tr>
<tr>
<td>City</td>
</tr>
<tr>
<td>State</td>
</tr>
<tr>
<td>Zip</td>
</tr>
<tr>
<td>Phone</td>
</tr>
<tr>
<td>Fax</td>
</tr>
<tr>
<td>Email Address</td>
</tr>
<tr>
<td>Work Phone</td>
</tr>
<tr>
<td>Work Fax</td>
</tr>
</tbody>
</table>

Please make checks payable to: Hemophilia Federation of America.