

KHF Hemosphere

It's a kick

2nd Annual Kick-a-thon



Kicking for a cause is the mantra of this fundraiser established last year by Nancy Cutrell. This year's event raised more than \$4,000. Nancy and her husband Bob operate a martial arts school in Evansville, Indiana. With the support of family, friends, and—foremost—their dedicated and enthusiastic students, the Kick-a-thon has been a smashing success both years.

Nancy started the event to honor the memory of her brother Terry who passed away unexpectedly last year from complications of hemophilia. The proceeds fund the Terry D. Turner Scholarship for post-secondary education; and in addition, this year, some of the money raised will also help support KHF's summer camp for children and teens with bleeding disorders and their siblings and the upcoming Family Holiday Program. The level of enthusiasm by the event's participants and the community's support for Nancy's labor of love that stands as a lasting tribute to her brother Terry are astounding.



Justin Reed, who is 10 years old, was presented with a Samurai sword by Nancy and Bob Cutrell for his achievement of most donations collected in the amount of \$517 in conjunction with the recent fundraiser. Most deservedly, Nancy was nominated by KHF as the organization's most outstanding volunteer of the year this past March for an award by Community Health Charities, and she was honored again at KHF's recent annual meeting.



Scholarships



KHF recently awarded two \$500 post-secondary education scholarships. The Terry D. Turner Memorial Scholarship was awarded to Andy Hitt of Eminence who is a freshman at Jefferson Community College's Carrollton Campus.



The Herb Schlaughenhaupt, Jr. Memorial Scholarship was awarded to Brittany Gunther of Louisville. Brittany attends Georgetown College, where she majors in Political Science. She starts her senior year this fall.



ANNUAL MEETING

KHF's annual meeting in August featured speakers on important topics for men, women, and children living with the daily challenges of a lifelong bleeding disorder, such as Planning Your Future and Sports and Fitness. Vendor exhibits offered information about available factor products, ancillary services, and home care provisions. The event took place at the Louisville Marriott Downtown, which proved to be a well-heeled and comfortable venue. 125 guests enjoyed our program, the fellowship with other attendees, and an array of tasty menu selections.

Children were entertained by George Halitzka from Drama by George and an impromptu fun activity by Accredo. During the business portion of the event, new directors and officers were elected and after the conclusion of the event, we provided tickets to our guests to the always popular Louisville Science Center and Imax Theatre.



VIP Guests

Special recognition was given at KHF's recent annual meeting to Terry and Marion Forcht of Forcht Group of Kentucky for their \$25,000 leadership gift that jump started a successful 3rd annual fund drive, which concluded in June. Both Mr. and Mrs Forcht are committed supporters of KHF, and Mrs. Forcht serves on KHF's board of directors. Also recognized was Nancy Cutrell for raising \$5,325 with her very first kicking for a cause Kick-a-thon fundraiser, which supports the Terry D. Turner Memorial Scholarship Fund that Nancy established in honor of her brother's memory. Furthermore, grateful appreciation was extended to Kentucky PGA golfer, J. B. Holmes, for his generous donation of \$5,000 and an equal amount designated to KHF via the PGA Charities Ryder Cup Outreach Program. His cousin, Robby Pelly, accepted the appreciation award on Mr. Holmes's behalf.

Board News

New directors

Newly elected directors to serve three-year terms on the KHF board of directors are Rebecca Daigrepoint, Fiducial, Louisville; Melissa Hitt-Satterly, Henry County Public Schools, Eminence; Lindsay Martin, CPA, DMLO, Louisville; and Chris Mayer, JD, Phillips Parker Orberon & Moore, Louisville. The board of directors currently has sixteen members.

Officers

Officers for the 2009/2010 fiscal year are Scott Davis, Republic Bank & Trust Company, president; Andy Mayer, Stockyards Bank & Trust Company, vice-president; Lindsay Martin, CPA, DMLO, treasurer, and Eric Marcum, RN, The Brook Hospital, secretary.



Brighten your holiday...and someone's life

Christmas will be here before you know it. Plan your holiday decorating and gift giving with our poinsettia fund raiser in mind. Plants are available in red, pink and white. Delivery may be available. Contact KHF and place your order early. (502) 456-3233 ♦ (800) 582-CURE (2873)

PLAYING A ROUND FOR A CURE

Oxmoor Country Club was again this year's venue for KHF's 20th annual golf scramble fundraiser. Sixteen teams enjoyed eighteen holes of golf, lunch, dinner, great prizes, and an ample array of giveaways. Special features were the putting contest with a \$500 guaranteed win and the ever so exciting "Ball Drop" that resulted in a \$955 win. Team winners were Walgreens Infusion Pharmacy, 1st place; KHF Team, 2nd place; and Affinity Biotech, 3rd place. The putting contest was won by Greg Browning and the ball drop by Nathan Bias. Mr. Browning graciously donated his \$500 win back to KHF, and Nathan kindly donated back \$200. Primary sponsors of the event were Accredo, Affinity Biotech, Baxter BioScience, Bayer HealthCare, Bella Grace Studios, BioRx, CSL Behring, CVS Caremark, "Fore Kids," LG&E, Medford Family Foundation, Novo Nordisk, Pepsi Americas, Publishers Printing Company, Republic Bank & Trust Company, The Brook Hospital, The Galt House Hotel & Suites, Walgreens Infusion Pharmacy, and Wyeth.



Team sponsors received a hand blown, red glass paper weight in shape of a blood drop in appreciation of their support. KHF's event raised slightly more than \$15,000, a significant drop from the prior year. We extend many thanks to all sponsors, donors, and volunteers who participated in this fundraiser during a slumping economy, and we hope that others will join in next year to boost the proceeds of this event. KHF depends on individual and corporate contributions, small local grants, and special events fundraisers, such as this one, for its funding base.



SPRING FLING

On May 23, 2009, we held our third annual "Spring Fling" family event at the German American Club in Louisville. Ninety-six adults and children attended on a balmy Saturday afternoon. While the children played carnival games, won lots of prizes, and jumped to their hearts content in the bouncy house; parents had an opportunity to gain new information from vendors regarding their products and services and chat with other parents. After a satisfying taco bar lunch; door prizes, special games, and

face-painting proved to be a hit as well. It's safe to assume that the Marcum family of Louisville gladly toted home their flat-screen tv, which they won at the event.

Support for this family information and fun event was provided by Accredo, Baxter BioScience, Coram Specialty Infusion Services, CSL Behring, Factor4Life, Matrix Health Group, and Wyeth.



Camp Discovery

I always have fun

Sean, 11

Although the memories of summer camp are beginning to fade, just taking a look at selected snapshots brings back vivid images of this year's camp activities in all their splendor and glory. Summer camp connects campers with nature and with each other. It also offers campers an opportunity to emulate adult role models who grew beyond their bleeding disorder to lead productive and independent lives.

Summer camp helps campers discover their hidden potential and their own identity. In many cases, camp provides the first setting for spreading their wings a little outside the parameters of home. Our goal for camp is to offer a traditional camp experience that motivates and empowers campers to be healthy and active, just like any other kids, while learning to manage their bleeding disorder.

The field trip to Puzzles Fun Dome started camp off fittingly with a bouncy house, tunnel, slide, putt-putt, and a challenging climbing wall. The days were filled with swimming, games, bonding with friends, and enjoying the great outdoors. Highlights were -as expected- zip lining across the lake, playing capture the flag, learning frisbee golf, and listening to stories from re-enactors of the pioneer era in Kentucky. Roasting marshmallows for smores and the annual pine box derby were eagerly anticipated as well, regardless of prevailing heat, humidity, and bugs, and the possible risk of repeat event fatigue. Not our campers – their enthusiasm was unwavering. Canoeing, sing-along music, character workshop, career exploration for the teens, and arts and crafts rounded out a full program.

I enjoyed and appreciated this camp
Desmond, 15

The foundation is amazing
Mason, 12



I love this camp
Collin, 12



Kentucky Hemophilia F

We thank all of the members of the Kentucky Hemophilia F

**Individual/Family
Membership, 10+**
Joe Berry
Pamela Kay Blevins
Sue Donahue
Ramon Dale Greene
Arthur & Terri Hackman
Barry Hatfield
James P. Huff
Frances Joyce Lewis
Mr. & Mrs. Al Loeser
Michael R. Marlier

Delores Morgan
Keith & Becky Rhodes
Carla Shepherd
Glenn A. Walker
Nita Wayne-Zehnder

Supporting Membership, \$25+
Wanda Bandy
Samuel Charas
Megan Nichole Couch
Janet & Lee Goff
Bill Griffis

Judy Hayes
In memory of Michael Jason Hayes
Josh Herring
Kevin & Becky Howard
Billie & Jeanne Hurt
April Johnson
Michael Johnson
Eric Lambing
Terry & Caroline Loeser
Mary Marasa
John & Carol Nord
Marcus E. Omer

Camp Discovery



Morning stretches, water exercises, and healthy food choices were integral daily components of the healthy living and hemophilia wellness approach that we espouse at camp.

Learning more about their bleeding disorder, how to manage it, how to stay well with it, and eventually be able to self-treat was of primary

concern and interest to kids and teens

alike. Ann Mancini, RN, with her more than twenty years experience as a pediatric treatment center nurse, led the health activities at camp and managed the infirmary with support from several infusion nurses lent to us by Walgreens Infusion Pharmacy. Campers also benefitted from her skills as an educator for Coram throughout all hemophilia wellness & self-infusion training modules. Paula Bias from Accredo served as camp director for the fifth consecutive year. She and her team of counselors ensured a seamless, safe, and fun-filled camp experience for the fifteen children and youths who participated.



The Todd M. Hurt outstanding camp volunteer award was presented to Mike Koziak this year for his leadership and commitment to KHF's camp program. Funding for camp was provided by grants from the WHAS Crusade for Children, Kosair Charities, Louisville Metro Department of Public Health & Wellness, Accredo, Baxter BioScience, Bayer HealthCare, CSL Behring, Grifols, Novo Nordisk, and Wyeth.

It's great to be here
Elijah, 8

I had a great time and can't wait to come back next year

Dylan, 12

Foundation membership

Foundation for their support during the 2008 – 2009 program year

Becky Sharp
Katie Sharp
Kim Wearsch

Royce Rogers
Betty Jo Shaak
Leeta R. Williams

Benefactor Membership, \$250+
Mr. & Mrs. Henry W. Boyd, III

Patron Membership, \$50+

Larry G. Bandy, Sr.
John & Leah Graham
Betty Meadors
Frances Mitchell
David & Terry Moore
Rondal & Linda Payne
James A. Ray

Sustaining Membership, \$100+

Bob & Diane Deitel
Barbara & Donald Grayson
Charles & Ruth Hall
Chris Nichols
Glenn & Laura Webb

Corporate Membership, \$500+

Ted & Jennifer Forcht
Terry & Marion Forcht
Medex Biocare Pharmacy, LLC



Aging with hemophilia brings other health risks

Unlike in decades past, life expectancy today for an individual with hemophilia is on par with that of the general population. Safer and widely available factor products, effective anti-viral drugs for HIV and HCV (hepatitis C), and comprehensive care provided by hemophilia treatment centers have contributed to this achievement. With increased life expectancy, however, comes a host of age-related health issues for individuals with hemophilia as it does for the general population. The co-existing medical conditions that aging persons with hemophilia appear to be at risk for are cardiovascular disease, liver disease, cancer, kidney disease, and joint disease. These findings question the previously held belief that individuals with factor VIII deficiency were protected from cardiovascular disease and moreover implicates certain coagulation proteins as possible risk factors for cardiovascular disease.

HIV, HCV, and joint disease have long been known as secondary health issues for individuals with hemophilia. Renal (kidney) disease has now been identified as a significant risk as well. Research shows a 50-fold increase in the mortality risk for individuals with hemophilia versus the general population. High blood pressure, HIV and HIV/HCV co-infection, and the presence of inhibitors are mentioned in the development of renal disease among aged persons with hemophilia. Conditions such as anemia, kidney failure, and uremia may also lead to renal disease. The good news is that better hemophilia care has resulted in increased longevity for persons with hemophilia. The obstacle that now presents itself is an increased risk for age-related health complications that was previously unknown. More research efforts are being targeted toward the development of effective treatments for co-morbidities in older persons with hemophilia.

Synopsis of article by Konkle, Kessler, Aledort, Anderson, Fogarty, Kouides, Quon, Ragni, Zakarija, Ewenstein. Emerging Clinical Concerns in the Ageing Haemophilia Patient. Haemophilia, 2009, Volume 15, Issue 4, Pages 926-931

Managing Medical Costs in a Down Economy

The economic downturn has brought with it underemployment or job loss, and thus inadequate income, foreclosure, and inability to maintain health insurance and pay for medical bills. Yet, even people with insurance are experiencing hardships because of increased out of pocket expenses passed on to the insured. People with bleeding disorders are disproportionately affected because their health care costs are greater, and they use their insurance more frequently. There are a few helpful tips for navigating these challenges.

- Have a yearly financial plan or develop a plan now for the remainder of the year for paying your medical bills.
- Project the yearly total cost, especially for factor use.
- Find out what the insurance company will pay and what you will have to pay.
- Budget on a monthly basis and make adjustments -if needed- for costs that are not covered by insurance.
- Contact patient accounts for each provider including those for homecare and pharmaceuticals and set up a payment plan if you are unable to pay.
- Find out if the provider has a patient assistance program that you can access in the event of financial hardship.
- Explore your eligibility for other types of assistance, such as your state's Children with Special Health Care Needs Program, Medicaid, and Social Security disability programs.
- Contact your treatment center, your local chapter, and other hemophilia organizations for help in accessing assistance.



Summary of article by David Linney, Hemaware, July/August 2009, Vol. 14, Issue 4

Biologics Subject to Exclusivity Debate

Congress is currently embroiled in a debate whose outcome is touted by some to help rein in the amount of money spent on healthcare in the US. At the center of this debate is the issue of exclusivity, which is the period during which brand name drugs are protected from competition by generic counterparts. For small-molecule drugs that are easily copied, this period is five years. Once generic competition reaches the market, the price for small-molecule drugs drops significantly. The current exclusivity debate, however, involves a special group of drugs called biologics that are manufactured through advanced biotechnology for intravenous treatment of rare diseases. They are expensive drugs with a complex molecular structure that is difficult to copy exactly.

On the surface, it appears that by allowing generic “copycat” versions of these drugs to enter the market, an enormous amount of money could be saved by all parties affected. Manufacturers of these drugs claim that they need 12 to 14 years exclusivity to make new drug developments financially feasible for them. Many of these drugs also have patent protection, which gives them additional time of reprieve from generic competition. At present, the Senate is leaning toward twelve years exclusivity for these drugs, the House is divided between five and twelve years, and the Administration would prefer seven.

The writer points out that the projected savings of \$10 billion from allowing copycat biologics on the market would be dwarfed by an anticipated cost of \$1 trillion for healthcare reform, nor would these savings be realized anytime soon. The savings for the consumer would average maybe half of that from generic small-molecule drugs because of higher manufacturing costs and more intense regulatory scrutiny. A copycat biologic drug would be unaffordable at \$35,000 just as the original name brand version is at \$50,000.

Compounding the issue at hand is the difficulty, if not impossibility, of producing exact copies of biologic drugs. Slight variations in the makeup of these drugs could affect the drugs’ safety and other characteristics. Therefore, these drugs are considered by many to be biosimilars. Obtaining FDA approval of copycat biologics or biosimilars, if you will, would require clinical trials, which are expensive.

Marketing these generic varieties to gain the buy-in of prescribers would add to the cost of bringing these copycat versions to market. In Europe, three biosimilar drugs are being sold at 20 to 30 percent lower cost. In Germany, they have captured 30 percent of the market and have forced a reduction in price of the original drugs sold by name brand manufacturers. It is unlikely that competition from biosimilars will drastically impede the sales and profits of name brand biologic drugs. Consequently, the biotechnology industry expects a 30 to 50 percent revenue retention once biosimilars enter the market. This is another reason as to why the opinions in the exclusivity debate range from one extreme of some Senators advocating for 12 years of exclusivity for biologics to the Federal Trade Commission saying that no exclusivity period is really needed for these drugs. Then the debate pendulum swings back toward the middle where opinions advocate five years exclusivity for biologics because of the belief that the time and cost it takes to bring them to market are not that much different from that for small-molecule drugs.

Patents may not offer any additional protection for biologics after all contrary to what was previously stated, because it could be argued that copycat biologics are not exact copies of the original drug and thereby are not infringing on the original drug’s patent. Although biologics patents have held up in court, generics manufacturers are pushing for a short exclusivity period in anticipation of that trend’s reversal.

IN MEMORY

January 1, 2009 – June 30, 2009

*Gone from our sight but never our memories;
gone from our touch but never our hearts...*

William L. Farmer, Sr.
Mrs. William L. Farmer, Sr.
Mrs. William L. Farmer, Sr.
Mrs. William L. Farmer, Sr.

Jim Gordon
for Herb Schlaughenhaupt, Jr.
Memorial Scholarship
Gail Yates

Spalding Grayson
24th anniversary of his passing
Frances Lewis

Carolyn Hall Schroering
Mr. & Mrs. Jack R. Stearns

Kermit Conrad Raydon, Jr.
E. Loyce Graff
Collista Jakoby
Joyce McGrew
George Perkins
Robert E. Riccardi
Don & Patty Staley
Don & Connie Stallard

Marjorie Sullivan Patterson
for Herb Schlaughenhaupt, Jr.
Memorial Scholarship
Flo Baldrige
The Nord & Walters Families
Karen & Randy Sullivan
Mr. & Mrs. Robert Sullivan
Mr. & Mrs. William Kenneth Wheat
Gail Yates

Dennis Wheatley
on Father's Day
Donald & Barbara Grayson



Do The Five — Follow these steps to prevent or reduce complications of bleeding disorders

1. Get an annual comprehensive checkup at a hemophilia treatment center.
2. Get vaccinated – Hepatitis A and B are preventable.
3. Treat bleeds early and adequately.
4. Exercise to protect your joints.
5. Get tested regularly for blood-borne infections.

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free **800-42-HANDI**.

KHF neither recommends nor endorses the products in this publication and does not make recommendations concerning treatment regimen for individuals. KHF suggests that you consult your physician or treatment center before pursuing any course of treatment. This publication is for general information only.

Non Profit Org.
U.S. Postage
PAID
Louisville, KY
Permit No. 883

KENTUCKY HEMOPHILIA FOUNDATION
 1850 Taylor Avenue #2
 Louisville, KY 40213-1594