

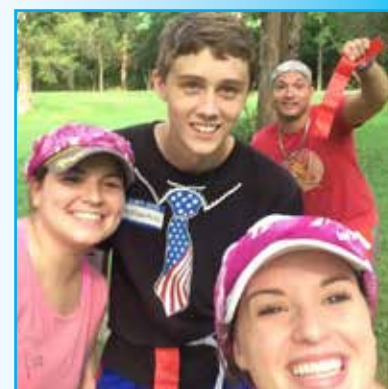
# KHF Hemosphere

## “Camp Discovery” KHF Summer Camp

Once again, the KHF Summer Camp Program for youths with bleeding disorders and their siblings was a successful, fun-filled educational and recreational experience for thirty-four children and teens from all parts of our state. Our summer camp takes place every July at Cedar Ridge Camp in Jefferson County. The focus of our summer camp is to provide an opportunity for youths who are living with a chronic condition to be 1) active in a traditional camp setting and interact with other youngsters who are dealing with the same health issues, 2) learn to manage their disorder which includes sticking themselves to administer their clotting factor replacement and develop a healthy lifestyle, and 3) have loads of fun just as any other kids would have at summer camp.

Activities included swimming and more swimming, building bird houses, zip lining, navigating the team challenge course, bowling, amazing race and scavenger hunt, and playing their favorite game of capture the flag. The cultural enrichment component featured the state of Kentucky this year complete with a fried chicken dinner, “horse racing,” and a lively performance by the Kentucky Home Cloggers.

The KHF volunteer camp staff consists of a seasoned and enthusiastic camp director and dedicated counselors, guest facilitators, complemented by credentialed and experienced nurses. We thank the camp staff for providing a safe camp environment along with educational and recreational activities that were enjoyed by all campers. Camp was made possible with support from Kosair Charities, Baxalta, WHAS Crusade for Children, Pfizer, CSL Behring, Novo Nordisk, Option Care, Bayer HealthCare, Accredo, and Grifols.



## Infusion of Humanitarian Aid to Help Sustain Hemophilia Treatment in Developing World



The World Federation of Hemophilia (WFH) and its Humanitarian Aid Program announce an international pledge of donated hemophilia therapies, which is unprecedented in size. The donation will provide 500 million international units (IUs) of critically needed hemophilia therapy over a five-year span.

This initial wave of donations, currently arriving at hemophilia treatment centers across the globe, represent the first phase of an overall 10-year commitment made by Biogen and Swedish Orphan Biovitrum AB (Sobi) to generate 1 billion IUs of hemophilia therapies for humanitarian use. The countries currently receiving aid include Senegal, Kenya, Philippines, Dominican Republic, Uzbekistan, Jordan, Egypt, Morocco, Pakistan, El Salvador, Indonesia, Ghana, Myanmar, India, Sri Lanka and Nigeria.

The Humanitarian Aid Program provide treatment and care for in the developing world, where the and sustained factor product According to WFH, of the estimated worldwide, 300,000 live in places access to viable diagnosis, treatment environment, quality of life is severely bleeding disorders and life-threatening

*...we may now be in a position to create a foundation for more sustainable and improved care in parts of the world where there is an urgent need*

was established in 1996 to individuals with hemophilia scarcity of adequate healthcare supplies is felt most acutely. 400,000 hemophilia patients where there is little-to-no and management. In such an diminished for people with situations are more common.

“The majority of people with hemophilia in developing countries do not live past adulthood and if they do, they face a life of severe disability and chronic pain,” said Assad E. Haffar, MD, WFH Humanitarian Aid Program Director. “The lack of access to clotting factor concentrates in these countries presents an urgent and important public health challenge.”

“By expanding the WFH Humanitarian Aid Program through larger and more predictable donations, we may now be in a position to create a foundation for more sustainable and improved care in parts of the world where there is an urgent need,” said WFH President Alain Weill.

To learn more about WFH’s Humanitarian Aid Program go to: [www.wfh.org](http://www.wfh.org).

Source: Joint press release from WFH, Biogen and Sobi dated October 12, 2015



## MASAC Releases New Recommendation on Inhibitors In Light of CDC Findings

The National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council (MASAC) recently issued a new recommendation concerning inhibitor testing and surveillance for patients with hemophilia A and B. MASAC Document #236, adopted by NHF's Board of Directors on October 6, 2015, was created in response to significant findings from the US Centers for Disease Control and Prevention's (CDC's) Hemophilia Inhibitor Research Study (HIRS).

A six-year-long research initiative, HIRS was designed to assess the feasibility and utility of conducting national monitoring for inhibitors among people with hemophilia living in the US. A total of 1,163 patients with hemophilia from 17 US-based hemophilia treatment centers (HTCs) were enrolled and subsequently monitored for up to 6 years to establish the optimal way to determine who was at risk for developing an inhibitor.

In light of the results, investigators concluded the following:

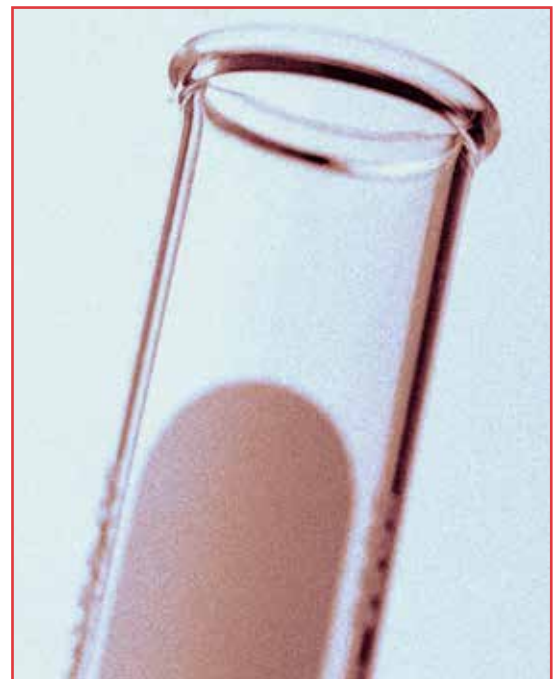
- All people with hemophilia, regardless of age, are at risk for developing inhibitors
- One-third of newly-developed inhibitors were found in people with non-severe hemophilia
- One-half were older than 5
- One-quarter had used infused factor for more than 150 days
- Six out of 10 people with hemophilia with an inhibitor had no symptoms
- Regular screening of people with hemophilia for early detection of an inhibitor by the CDC laboratory is feasible, and will inform efforts to measure rates of this complication

The results prompted CDC to enhance its surveillance system to include inhibitor testing, to address cost-related barriers to the screening process and establish a standardized testing approach to be employed by all participating HTCs.

In response to CDC's findings, MASAC created a document that includes a series of specific recommendations relevant to lab testing, standardization of an inhibitor screening method, surveillance, inhibitor prevention, research and consumer/provider education.

For details, go to: <https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASAC-Recommendations/MASAC-Recommendations-on-Standardized-Testing-and-Surveillance-for-Inhibitors-in-Patients-with-Hemophilia-A-and-B>

Source: *NHF, November 10, 2015*





# Event News

## Golf Scramble

This year's KHF Golf Scramble took place on June 29th at Oxmoor Country Club, one of Louisville's most popular golf courses. Even a robust afternoon shower did not dampen our players' spirits.

Team winners were Paragon Healthcare, 1st place; CSL Behring, 2nd place; and Octapharma, 3rd place. Brian Stentz won the putting contest, and Pamela Price's lucky ball won the Ball Drop. Our junior volunteers who sold special score boosters to the golfers in support of the KHF Summer Camp that they attend every year won the hearts of all event participants. The three young ladies raised \$463, which was generously matched by a \$1,000 donation from Kosair Charities.

Team sponsors were Accredo, Baxalta, Bayer HealthCare, BioRx, CSL Behring, Cottrill's Pharmacy, CVS Caremark, Kosair Charities, Novo Nordisk, Octapharma, Paragon Healthcare, Pfizer, and Republic Bank. Individual player and tee sign sponsors were Accredo, Amerimed, Louisville Oral Surgery and Dental Implants, and Option Care. The event raised \$28,000 for KHF's programs and services. We thank all sponsors, donors, planning committee members, and event volunteers for helping us put on a successful event.





## Summer Family Event/ Annual Education Meeting and Walk Kick-Off

The Seelbach Hilton Hotel once again proved to be a fitting venue among our attendees to enjoy nationally known speakers, who addressed hemophilia care and overall wellness topics, a lovely breakfast and Walk Kick-Off lunch, door prizes, and exhibitor product and services information. In the meantime, volunteers from Christian Fellowship facilitated the children's program. After the educational segments and a well-deserved lunch, families enjoyed interactive exhibits, a 3-D Harry Potter movie, and a greatly expanded children's play area at the Kentucky Science Center. Exhibitors and speaker sponsors who helped support this event were Accredo, Baxalta, Biogen, Cottrill's Pharmacy, Inc., CSL Behring, CVS Caremark, Grifols, Matrix Health, Novo Nordisk, Octapharma, Paragon Healthcare, Pfizer, and Option Care



## Scholarship Awards



KHF made two post-secondary education scholarship awards for the fall 2015 semester. Eligible applicants for our scholarships are Kentucky residents or individuals who receive treatment in Kentucky who have a bleeding disorder and their immediate family members. We award up to (4) \$500 scholarships per year. The Herb Schlaughenhaupt, Jr. Memorial Scholarship was awarded to Andrew Harmon of Bedford, Kentucky. Andrew is a recent high school graduate with a 3.6 GPA. Andrew has been accepted to Jefferson County Community & Technical College where he will be pursuing an Associate's degree in Education with a minor in Computer Science.

The Terry D. Turner Memorial Scholarship was awarded to Alicia Bibelhauser of Versailles, Kentucky. Alicia is also a recent high school graduate with a 3.4 GPA. Alicia has been accepted to Morehead State University, where she plans to major in psychology and work toward a Bachelor's degree. KHF congratulates both scholarship recipients and wishes them well in their educational pursuits.

**Note:** The scholarship application deadline for the 2016 spring semester is January 15, 2016. Application form and guidelines can be obtained by contacting KHF at 502-456-3233, 800-582-CURE (2873) or by sending an email to [info@kyhemo.org](mailto:info@kyhemo.org).



## Kentucky Hemophilia Foundation News and Updates



### Board Member Recognition and Welcome

Outgoing board members who were recognized for their board service were Lindsay Martin, Rebecca Daigrepoint, and Melissa Hitt. Lindsay served as President for two years, VP two years, and Treasurer for two and a half years. She also was Co-Chair of the Vegasville Planning Committee for several seasons. Lindsay's expertise, guidance, and support are appreciated and will be missed. Rebecca Daigrepoint served as Treasurer for two years and Secretary for two years. She also served on the Camp Committee. She was instrumental in securing Wetherby Park in Middletown as our Walk site. Melissa Hitt served as Secretary for one year and as Co-Chair of the Vegasville Planning Committee for several years. Melissa always offers her energy and creativity to enhance our events, especially and foremost Vegasville.

New board members elected are Barb Bitter, Sara Ceresa, and Brad Comer. Barb works for Ricoh as an Enterprise Project Manager. She has a Bachelor of Science degree in Marketing from the University of Kentucky and extensive background in finance, sales, marketing, and training. Sara is a very active volunteer and homemaker with a Bachelor's degree in Chemistry and Biology from Wartburg College in Iowa and graduate training in Genetics from the University of Iowa. She worked as a Clinical Research Coordinator for Dean McGee Eye Institute and held several positions as a Clinical Research Assistant. Her lovely twin daughters attended our summer camp this past year. Brad is a Vice President and Senior Investment Officer at Republic Bank, where he has worked for the past 10 years. He has a Master's degree in Business, a Bachelors degree in Accounting, and a Bachelors degree in Business.

## In Memory

**July 1, 2015 — October 31, 2015**

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



Sean Bennett  
Donna Fleming

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

Joe Hardman  
Debby & Robert Adams  
Teresa English  
Donald L. Mattingly  
James C. & Rev. Iva Gail McDonnell  
Allison & Ernest Noe  
James P. Pike

James & Deanna Ray  
Janet M. Young

Donald Hester  
Donna Fleming





## Kentucky Hemophilia Foundation Ninth Annual Fund Drive

*We thank the following individuals and companies for their generous support of the 2014– 2015 Annual Fund Drive*

### **Challenge Gift, \$25,000**

Forcht Bancorp,  
Mr. & Mrs. Terry Forcht

### **Fundraisers Toward Meeting the Challenge, \$10,000+**

Various Corporate Solicitations, Sales  
5th Annual KHF Strides for a Cure  
Relay Team Challenge

### **Forcht Challenge Donors, \$1,000 – \$2,000+**

Donald L. Mattingly  
Chevron Humankind  
Matching Employee Funds  
Nancy Cutrell,  
7th Annual Kickathon  
in memory of  
Terry D. Turner  
Mead Johnson Foundation Employee  
Engagement Fund  
The Community Foundation of Louisville  
Made possible by the Zoeller Company

### **Donors, \$250 – \$450**

Baxter International Foundation  
David Hasch  
Poynter Family Fundraiser  
William H. Shontee  
The Webb Family  
in honor of Isaac Webb

### **Donors, \$175 – \$200**

Biogen  
Corporate Match  
Greg Fiscus  
Pamela L. Howard  
Humana Foundation  
Kroger Community Rewards  
New Age Auto Parts  
Michael & Lisbeth Vogel

### **Donors, \$75 – \$150**

Anonymous  
M. J. & A. M. Aman  
Scott & Holly Brown  
Clark County REMC  
Jamie Cutrell  
Nan Diederich  
Forcht Bank "Hat Fundraiser"  
Sandy Franklin  
Michael A. Gatton  
in honor of John G. Gatton  
James & Tracey Gibson  
Rex Howard  
Ursela Kamala  
Paul & Amy Kilgore  
Lindsay Martin  
Vivian Marcum  
Ann Mancini  
James & Sandra Richardt  
in honor of Nancy Cutrell

Pete & Bev Slapikas  
Scott's Performance Engine Center  
Donna Steen

### **Donors, Up to \$74**

Benevity Community Impact Fund  
William Bosserman  
Nancy S. Dudley  
G. Myers Trucking  
Carol Hayes  
Jennifer Hitt  
Jessica Houchens  
Timothy & Kimberly Lawton  
Ruth Ann LeVay  
in memory of Timothy LeVay  
Cory & Whitney Meadows  
Mark & Gretchen Muchnik  
Lewis & Betty Owen  
in honor of Zak Jarrett  
Monica & Ronnie Poynter  
Gary & Jana Scarbrough  
John & Edie Shackelford  
Leeta Williams  
Women of Immanuel  
Gail Yates  
in honor of Kevin Loeser

# 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](http://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.

# Vegasville

**Mark your calendar,**

**March 5, 2016,**

**Vegasville Event.**

**You won't want to miss it!**



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