Fall 2008

llie Deitel is aptly described as a very inspiring and awesome young lady. She is a senior at St. Francis High



School in Louisville, and she is very active in sports. Her favorite sport is biking followed closely by basketball and field hockey.

KHF hamos

Allie discovered in 2006 after a biking accident that she has von Willebrand disease, a bleeding disorder

similar to hemophilia that affects both males and females. This diagnosis led her to take more precautions now when biking or pursuing her other sports but it did not stop her in any way from being as active as she was previously in all her sports activities that she is so passionate about.

A school project assignment prompted her to decide that she wanted to raise money for the Kentucky Hemophilia Foundation to help carry out its mission. She single-handedly came up with the idea of Allie's Ride, a fundraiser that would take Allie from Louisville, KY to Nashville, TN. She put together a brochure, developed a web site, and started to ask for pledges.

**Allie** 

Allie's four-day bike ride accompanied by her road crew of two close friends became easier by the day and the hills along the way less daunting. Allie only suffered one flat tire close to Nashville, mostly enjoyed the scenery, and is proud of having accomplished her goal. KHF is proud of Allie as well. We commend her for her leadership and her compassion for helping others. Allie raised a total of \$1,765 with Allie's Ride.

Find out more about Allie's Ride on page 3

### VIP Guests

KHF's annual meeting in August featured speakers on important topics for individuals living with the daily challenges of a lifelong bleeding disorder, such as Aging with Hemophilia, Adolescents and Transitioning Issues, and Elective Orthopedic Surgery. The event took place at the Galt House and was well attended by more than 125 people. BioRx's "BioBuddies" children's program educated and entertained the little ones throughout the morning. During the business portion of the event, new directors and officers were



installed and those individuals rotating off the board of directors were thanked and recognized for their service. Special recognition was bestowed upon Terry and Marion Forcht of the Forcht Group of Kentucky for their \$25,000 leadership gift that blazed the trail for a successful 2nd annual fund drive that concluded in June. Both Mr. and Mrs. Forcht are long-standing supporters of KHF. Mrs. Forcht also serves on KHF's board of directors.

From Ursela

After a summer brimming with activities – golf scramble, summer camp, annual meeting – fall has arrived all too soon and will be commemorated by our Fall Family Fun and Information Fest with the poinsettia sale fundraiser and our annual Holiday Party close on its heels. We move from one event to the next, alternating between service and fundraising activities, without taking much time for reflection. It's a sign of the times, I hear myself say as we forge ahead. What does it mean you may ask? Although we continually strive to upgrade and improve upon our existing programs and services to assist our constituency in a viable and beneficial manner, there are three significant challenges to our efforts. One, our revenue has plateaued during the last few years; two, the time and energy we must spend raising needed funds has increased markedly; and three, the costs of service activities that we offer to the bleeding disorders community continue to go up every year.

If you're not quite convinced why you should help us help others, I want to give you a couple of facts that may compel to sway you. We are so proud that our summer camp for children with bleeding disorders now also serves siblings who do not have a bleeding disorder to help them better understand the trials and tribulations their brothers and sisters face. We aim to strengthen the sibling bond within the family unit that is raising a child burdened with lifelong health issues, and to improve communication and interaction within the family. The goal is to lessen those burdens experienced by all members in the family, individually and collectively. Secondly, we have stepped up our focus on the overall health and well-being of children with bleeding disorders and have developed educational modules and hands-on activities that promote healthy living, such as making wise food choices coupled with sports and exercise. Healthier children will grow up to be healthier adults that will be able to manage their bleeding disorder and lead productive and fulfilling lives! Please help us with the means to that end and give us your support.

Thank you.

# **Board News**

#### **New directors**

Newly elected directors to serve three-year terms on the KHF board of directors are Kevin Howard, Guston; Chad Johnson, ADP, Louisville; Mary Marasa, RN, Louisville; Janet Shearn, UPS, Sellersburg, IN; Pete Slapikas, Moreno Express, Louisville; and Miguel Zamora, LINAK-US, Louisville. The board of directors currently has fifteen members.

#### **Officers**

Officers for the 2008/2009 fiscal year are Andy Mayer, Stockyards Bank & Trust Company, president; Scott Davis, Republic Bank & Trust Company, vice-president; Becky Hughes, CPA, DMLO, treasurer; and Eric Marcum, RN, Ten Broeck Hospital, secretary.

#### **Service recognition**

Recognized for their dedicated service at KHF's recent annual meeting were Mike Schultz, Judy Berzof, and Dan Day, who rotated off the board. Mike served as vice president this past year and Judy as secretary during the past two years.

### About Allie's Ride...In her own words.

Preceding my bike ride, I wasn't nervous but very excited. I struggled to find more bikers, originally having two others but, within a week of my trip, losing both of them to the nervous tendencies of parents. This left me at a shaken up state, and I lay awake the night before my trip until five AM wondering if it was safe for me to ride alone.

The next day, after a quick breakfast, I was on my bike and ready to go, and all my fear had transformed into excitement. My first destination was Hodgenville, Ky, which rests about seventy miles down 31 E, the only road I biked on. My road crew, two of my close school friends – Glenn McCool and Julia Nazarenko – and I stayed at the Cruise Inn Motel. It is the

biggest motel in Hodgenville, consisting of ten rarely occupied rooms and limited luxury. I encountered no problems on the way to Hodgenville and conquered some of the biggest hills I have seen (one was two miles high and incredibly steep). We ate dinner at the Hodgenville Grill, a local restaurant, and spent our spare time playing the board game Apples to Apples.

The second day was about 40 miles to Mammoth Cave, where we stayed the night hiking, hanging out in our hotel room, and eating at the hotel's restaurant. The biking was easier than day one, but still incredibly challenging, not to mention full of hills.



By day three, I was in really good shape and used to hills, so my thirty mile trek to Scottsville, Ky. was easy for me although it consisted of my first encounter with semi trucks passing me. We stayed at an Executive Inn complete with cable TV and a swimming pool. It stormed quite badly this night, so we just hung out in

our hotel room, but according to the woman at the front desk there was "nothing to do in this town." We ate at a Chinese restaurant and continued to play Apples to Apples.

Day four was the easiest to me by far. It was 60 miles to Nashville but felt like I only biked ten. Most of the route was flat and there were even some hills to ride down, which was a nice change. This was the only day I had a slight problem, which was a flat tire five miles

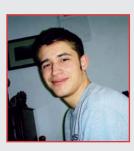
away from my ending spot. This, however, was easily fixed with the help of a nice woman who saw me on the side of the road. My friends and I spent the next two nights in Nashville swimming, shopping, and going out to eat.

The ride itself was very fun and had beautiful scenery. It was a very rewarding experience and I'm happy and proud to have done it. I thoroughly enjoyed the opportunity to raise money to help kids with bleeding disorders like myself and hope this act helps the research process.

### <u>Scholarships</u>

KHF recently awarded two \$500 post-secondary education scholarships. The Herb Schlaughenhoupt, Jr. Memorial Scholarship was awarded to Brittany Gunther of Louisville. Brittany attends Georgetown College, where she majors in Political Science. She starts her junior year this fall.





The Terry D.Turner Memorial Scholarship, which is new this year, was awarded to Michael Travis Johnson of Lexington, Kentucky. Travis attends the University of Kentucky, where he also majors in Political Science. He starts his junior year this fall as well.



### **Programs & Services**

July 2007 – June 2008

- Disseminated 7,354 pieces of educational literature via bulk mailings
- Answered 1,100 phone calls on our toll-free information and referral phone line
- Exchanged 1,000 e-mail messages for information, referral, and support
- Sent 520 birthday and greeting cards, including small gifts for 142 children
- Gave out hundreds of brochures at health fairs and during community talks
- Celebrated our annual Holiday Program for families affected by bleeding disorders with 134 adults and children
- Hosted our annual education meeting for 125 adults and children followed by a social outing to Slugger Field
- Held our annual Fall Family Fun and Information Fest for 42 adults and children
- Held our annual Family Day at the Louisville Zoo for 163 adults and children
- Held our Spring Fling Information and Fun Event for 63 adults and children
- Furnished financial support in 29 instances for rent, utilities, transportation, lodging, and similar crisis needs
- Issued dozens of educational information packets on request, including 12 "First Step" packets to families with newly diagnosed children and individuals/families new to the area
- Provided 47 individuals with MedicAlert emblems, bicycle helmets, and knee pads
- Welcomed 23 men, women, and children with bleeding disorders and their families to KHF
- Held our 5-day, overnight recreational and educational summer camp for 16 Kentucky children and youths with bleeding disorders, ages 7-16
- Awarded 3 C.A.R.E.S. scholarships for cultural and recreational enrichment activities for children with bleeding disorders
- Reached out to the rural areas of Kentucky with 3 semi-annual education meetings in eastern and western Kentucky
- Held 8 educational seminars and support meetings in Louisville, Lexington, Madisonville, and Barbourville attended by 259 men, women, and children
- Provided 2 educational sponsorships
- Made clinic, hospital, and other support visits
- Maintained an informative web site
- Participated in educational health fairs
- Spoke to numerous community groups
- Engaged in public relations and community outreach activities aimed at increasing community awareness about bleeding disorders and the services provided by KHF
- Held our second annual fund drive with a \$25,000 leadership gift from Terry and Marion Forcht of Corbin, Kentucky
- A Raised the monies needed to fund all service activities

All of these programs and services were provided free of charge to the recipients/ participants, and your support made it possible.



### A Sister's Hero

The most difficult things to put into words are describing a hero. There's no better way than to simply describe a hero in just two words: Terry Turner.

Terry Turner left a lasting impression on so many prior to his departure from his short stay on earth. His life ended at only 38 years, well before his time.

Being born with hemophilia, Terry was faced with many challenges. He grew up as a child that was always self-sufficient. He wanted to do everything and try everything, despite his limitations. Many nights during his childhood were spent away from home at numerous hospitals, especially Kosair Children's Hospital. Doctors would often say that due to the extreme blood loss, he wouldn't make it through the night, but Terry's strength always prevailed. Proving people wrong was something he loved to do.

Terry was most proud when he was appointed Chair of the Hemophilia Advisory Committee. This was his opportunity to give back to others. This was his opportunity to share his life experiences.

Terry was a gentle soul. He was so soft spoken, but everything he said was loud and strong. Terry touched more lives than we could have ever imagined. He left this world as a hero. After his death, a friend said it best, "God must have needed a good buddy in Heaven."

#### by Nancy Cutrell, Evansville, IN

Editor's Note: The Terry D. Turner Memorial Scholarship for post-secondary education was established this year by Nancy in memory of her brother Terry. Additional funding will be derived from a kick-a-thon this fall that involves an enthusiastic group of students at her dojo in Evansville.

### IN MEMORY

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

Mrs. Archbell Mr. & Mrs. Henry W. Boyd, III

Josh & Zach Baird English Driveway Derby 2008 family & friends of the English & Meadors families John & Debra Ray Gunning

0. Jean Centers Billie & Jeanne Hurt

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

Spalding Grayson 23rd anniversary of his passing Joyce Lewis at Easter Joyce Lewis at Christmas Joyce Lewis 39th birthday Joyce Lewis Alan Taylor Hall Mr. & Mrs. William W. Hall, Sr.

Timothy LeVay Ruth Ann LeVay Thurston LeVay

Denny Meadors English Driveway Derby 2008 family & friends of the English & Meadors families John & Debra Ray Gunning

William "Bill" Morrison Code 809 Party Fund

Tom Palmer 3rd Annual Topper Open Golf Tournament family & friends of the Palmer, French and Mallory families Edwin J. Huettig Kentucky Corporate Federal Credit Union KYCUL Services Brian L. Mallory Park Community Federal Credit Union TSI Trucking LLC

Aubrey Petty Anna Cooksey Elizabeth Flowers Billie Hurt James Hurt Christine Powell

Julia M. Rhea Mr. & Mrs. Henry W. Boyd, III Berks Brown Jim & Linda Foster Randy & Allison Fuqua Phil & Sally Hasselwander David & Sandra Kinser Jess & Donna Riley Charlotte Shaw Don Shaw Louise Shaw Betsy Shaw Kramer Steve Kramer

Suzanne Robinson Mr. & Mrs. Henry W. Boyd, III

M. L. Rowland Mr. & Mrs. Henry W. Boyd, III

Herb Schlaughenhoupt, Jr. at Christmas 2007 for the Herb Schlaughenhoupt, Jr. Memorial Scholarship Program Ron, Joan, Cody & Quinton Wuetcher

Michael Thomas Mr. & Mrs. Henry W. Boyd, III

Terry D. Turner Jeanette Griffin

Dennis Wheatley Donald & Barbara Grayson



### **Camp** Discovery

#### Best time of the Elijah, 7 yrs. old

**Summer comp** was a fun-filled and activity packed five-day educational and recreational adventure. Twenty-one youngsters and teens participated, including one sibling who did not have a bleeding disorder. KHF has expanded its camp program to accept "unaffected" siblings as well. "Unaffected" is a misnomer. When a family member struggles with the lifelong obstacle course of living with a chronic condition the entire family is affected and involved in helping solve their loved one's daily challenges. We want to help so called unaffected siblings understand their brother's or



sister's bleeding disorder better and provide them with an opportunity to solidify their sibling bond in a fun setting.



Camp started with an outing to LazerBlaze that appealed to boys and girls alike and ended with an awards ceremony that included the coveted big stick and braveheart awards. Big stick awards are given to those campers who stick themselves for the first time at camp. The braveheart award usually goes to a seven year-old, first-time camper who overcomes apprehensions and uncertainty about being at camp and triumphantly completes the program against considerable odds.

Camp had many peaks and very few valleys. The sing-along with real musicians who visited camp was a big hit, followed by the ever popular smores roast in front of the teepee



on the next night. Assembling and painting the pine box race cars and the big race on Thursday stirred excitement, especially when the race was won by a girl, seven year-old Samantha Johnson from New Haven, Kentucky.



German night, complete with sauerkraut, bratwurst, oompah music, and the chicken dance riled up camper spirits as well after learning a few vocabulary terms and cultural tidbits about all things German.

I had a blast here and made a lot of friends — Lizzie, 16 yrs. old

#### 2007–2008 Kentucky Hemophilia Foundation membership

Individual/Family Memberships, 10+ Pamela Kay Blevins Jimmy & Sherry Daugherty Arthur Hackman Barry Hatfield James P. Huff Billie & Jeanne Hurt April Johnson Frances J. Lewis Mike Marlier James Meade Delores Morgan Keith & Becky Rhodes Cody Saylor John Carlos Shackelford Joy Taylor Nita Wayne

Supporting Memberships, \$25+ Gerald E. & Tammy L. Auton, Sr. Wanda Bandy Philip Barron Scott, Jackie & Joe Berry Judy Berzof Pamela Brandt James & Michele Charas Ronald L. DeVary Janet & Lee Goff Keith & Sharen Harmon Judy Hayes Leroy & Barbara Hendrix Dinah Hopper Michael L. Johnson Michael Koziak Justin Lindhorst Terry & Caroline Loeser Betty Meadors Darlean Morrison John & Carol Nord

#### > whole summer

### **Camp** Discovery



Everyone's favorite activities this year were the capture the flag game, a tried and true camp game that apparently has not lost its luster and, as always, daily swimming and frolicking in the pool.

Thanks to our infirmary and counseling staff, camp was once again a safe and enjoyable experience for youngsters and adults alike. KHF thanks the many volunteers who ensured each camper's successful participation, in

particular, Paula Bias, camp director, and Susan Peterson, ARNP, infirmary director. The Todd M. Hurt outstanding

camp volunteer award was presented to Justin Lindhorst this year for his exemplary enthusiasm and dedication to the KHF camp program.



Funding for camp was provided by grants from the WHAS Crusade for Children, Kosair Charities, Louisville Metro Department of Public Health & Wellness, Baxter BioScience, Novo Nordisk, Wyeth, BioRx, CSL Behring, Hemophilia Health Services, and Grifols.



Infirmary staff was on loan from the Lexington Hemophilia Treatment Center and Hemophilia Health Services. Camp staff, including counselors, were also provided by Baxter Bioscience, Critical Care Systems, Hemophilia Health Services, the Louisville Hemophilia Treatment Center, and Matrix Health Group. Other camp volunteers were Lisa Blair, Daniel Cieslak, Scott Davis, Eric Marcum, Jessica Mayse, Doug Means, Annette Pearson, Robbie Pelly, Erick Shannon, Becky Sharp, John Tharp, and members of the Jaywalkers band.

#### I can't wait till next year because I am going to stick myself — Nathan, 7 yrs. old

#### 2007–2008 Kentucky Hemophilia Foundation membership cont.

James A. Ray Carolyn H. Schroering Clara J. Wheatley Gail Yates

Patron Memberships, \$50+ Larry G. Bandy, Sr. Scott & Jennifer Davis William A. Griffis Louise Hardaway David & Leslie Houvenagle Becky Hughes Bill Laughlin Frances Mitchell David & Terry Moore Bill & Susan Peterson Betty H. Shaak William & Christine Shontee Madeline Stempkovski Leeta R. Williams

Sustaining Memberships, \$100+ Diane, Bob & Allie Deitel Barbara & Donald Grayson Charles & Ruth Hall Karen Horton Al & Regina Loeser Robin Mattingly John & Pat Tharp Glenn & Laura Webb

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

Corporate Membership, \$500+ Marion, Terry & Ted Forcht

### Health News



In a recent Hemaware article with the above title, Glenn Pierce, MD PhD sheds some light on the question of whether there will ever be a cure for hemophilia. The short answer is yes; the long answer is yes provided research continues to make progress and is able to overcome expected and unexpected hurdles. Hence, a date for

having a cure cannot be determined yet with any kind of certainty. There will be a cure because hemophilia is a simple disease. It is caused by a single defective gene. A cure will be achieved when that gene can be fixed or when a properly functioning gene can be given to an individual with hemophilia. In the realm of finding cures for genetic disorders, hemophilia is described as a low hurdle disorder.

Dr. Pierce continues to expound on the various paths of research of which one will most likely lead to a cure, but he ponders first about what benchmark of achievement one might consider a cure. The example he presents is that if an individual whose clotting level is 0% can be raised to a level of 5%-10% — i.e. go from having severe hemophilia to moderate or even mild hemophilia — that person can be considered cured. He states that this kind of increase in clotting activity would be life changing and eliminate the risk of spontaneous hemorrhages and alleviate bleeding from minor and moderate traumatic injuries.

Indicative of the low hurdle concept is also the fact that the normal coagulation protein only needs to circulate in the blood to be effective and stop bleeding contrary to other genetic disorders that involve cell specific treatment. You might ask if it looks like it should be fairly simple to find a cure for hemophilia, why don't we have a cure right now?

Dr. Pierce proceeds by elaborating that although for nearly twenty years, a vast amount of research has been conducted and a lot of money has been spent on developing a cure for hemophilia, the crux has been underestimating the complexities of curing diseases in humans using DNA.

However, progress is being made and progress has been made from deciphering the DNA code to recombinant technology to curing dogs and mice with hemophilia.

...the next decade will bring longer lasting clotting factors that will move us closer to a cure.



At this stage, the single biggest obstacle to gene therapy as a cure appears to be finding a vector, a delivery system, that is effective and does not elicit an immune response that destroys the factor gene, which has been the case with the most promising viral vector used in humans so far. Although Dr. Pierce expresses frustration about the

> success of DNA therapies in animals versus the failed attempts in humans and our inability to anticipate these problems in finding a cure, he provides reassurance that hemophilia should be curable through the addition of a normal gene once this obstacle can be overcome.

As some researchers grapple with this issue, others have focused on finding alternative methods by using a nonviral

gene delivery system, by involving bone marrow stem cells to make coagulation proteins, and by developing mutated, improved clotting factors.

As a matter of fact, the combination of gene therapy and mutated clotting factors holds a lot of promise as an effective therapy provided the altered DNA can be delivered to cells, which again brings us back to the issue of an effective delivery system.

While longer-acting clotting factors with longer treatment intervals might essentially "cure" hemophilia in the developed world, they do not negate the need for a more permanent form of treatment or a truer cure, to effectively manage bleeding disorders world-wide, particularly in the developing world.

Dr. Pierce concludes by stating that the next decade will bring longer lasting clotting factors that will move us closer to a cure.

Reviewer's comment: So, the question that remains right now is how soon thereafter will there be a cure? Perhaps the next decade will formulate an answer.

Article reviewed: Where is the Cure? Glenn Pierce, MD, PhD, Hemaware, July/August 2008, Vol. 13, Issue 4

### Health News

### Bleeding disorders may cause heavy periods

It is common knowledge that many women of childbearing age suffer from heavy menstrual bleeding, also called menorrhagia. Although 10-20% of all women are affected by menorrhagia for a significant part of their lives, heavy menstrual bleeding should not be misconstrued as a normal occurrence for women. An underlying bleeding disorder like von Willebrand disease (VWD) may be the cause and, if left

untreated, could result in even more serious problems, including complications from surgery, dental procedures, and childbirth.

Research shows that 26% of women with a diagnosis of VWD had hysterectomies versus 9% who do not have a diagnosis of VWD. Moreover, 7% of women underwent a hysterectomy prior to their diagnosis of VWD. It is important to note that hysterectomies do not aid the diagnosis or the treatment of VWD.

Menorrhagia also affects women's quality of life ranging from missed days at school or work, and sitting out during sports and exercise activities, as well as social functions. The economic implications are obvious as well because of loss of income and the cost of medical treatments that might not be indicated if the diagnosis of VWD had been made. It is not surprising then but highly alarming that the average age of women at the time of their VWD diagnosis is 35.

Earlier diagnosis is crucial for proper treatment, management of symptoms, and the prevention of complications. For instance, seeking relief from cramps via ibuprofen or other nonsteroidal anti-inflammatory drugs is not advisable for women with VWD.

The new federal Genetic Information Nondiscrimination Act was signed into law by President Bush in May. The Act will protect workers from discrimination based on their genetic information. It also keeps group health insurance plans and health insurance carriers from making coverage and premium decisions based on an individual's genetic information or that of a family member. The law also prohibits disclosure of an individual's genetic information. The non-discrimination provisions relating to health insurance took effect in May, while those regarding employment will take effect in November.

Genetic tests are already being used in diagnosing, treating, and preventing inherited health conditions, a trend that will become a routine procedure in health care in the years ahead. determined to have a deficiency in their von Willebrand factor level and 7% showed a deficiency in their platelet function. One expert states that up to 50% of all women with excessive menstrual bleeding will have a bleeding disorder. Compounding this staggering percentage is the difficulty

ages 11-19, who had a history of menorrhagia, were

A recent study also showed that 36% of adolescent women

pounding this staggering percentage is the difficulty in identifying these women due to varying perceptions, for instance, of what is "normal" and intergenerational or sibling bleeding patterns in undiagnosed families.

> Women need to be cognizant of the possible warning signs of an existing bleeding disorder during their menstrual periods, such as changing pads every one to two hours, passing clots the size of a quarter or larger, missing work or school, or being told to be anemic or low on iron.

If any of these signs are experienced, women should discuss them with their gynecologist. When gynecological causes are

ruled out or the problems persist despite having addressed any identified gynecological issues, the likelihood of an underlying bleeding disorder increases and consultation with a hematologist is advisable.

> Summary of article by Kurt Ullman, Hemaware, July/August 2008, Vol. 13, Issue 4

### Genetic Information Nondiscrimination Act

The new law will erase fears of discrimination 1) associated with genetic testing that could benefit a person's health and 2) that DNA information gained through participation in research studies might be used against a person for health insurance purposes or in the workplace.

Although most states, including the state of Kentucky, have some type of genetic nondiscrimination law, the federal law sets a minimum standard that must be met by all states.

As a word of caution, the new federal law does not apply to life insurance, disability insurance, and long-term care insurance; nor does it cover members of the military.

Earlier diagnosis is crucial for proper treatment, management of symptoms, and the prevention of complications.

### **Event** News





# FOR A CURE

xmoor Country Club was this year's venue for KHF's 19th annual golf scramble fundraiser. Nineteen teams enjoyed eighteen holes of golf, lunch, dinner, great prizes, and an ample number of giveaways. Special features were the putting contest with a \$500 guaranteed win, the ever so exciting "Ball Drop" that resulted in a \$815 win, and the Hole-in-One contest for an elegant watch donated by JStaples Jewelry.

Team winners were Wyeth, 1st place; "Fore Kids," 2nd place; and Baxter BioScience, 3rd place. The putting contest was won by Dustin Golladay and Andy Mayer, and the Ball Drop was won by Vince Poma. Andy and Vince graciously donated a portion of their wins back to KHF.

Primary sponsors of the event were Baxter BioScience, Bayer HealthCare, Novo Nordisk, Wyeth, ASD Healthcare, BioRx, Caremark, Critical Care Systems, CSL Behring, Curascript Infusion Pharmacy, Duplicator Sales & Service, "Fore Kids," Hemophilia Health Services, Publishers Printing, Republic Bank & Trust Company, Ten Broeck Hospital, University of Louisville HealthCare, ZLB Plasma, Grifols, and Medford Property Company.

Team sponsors received a hand blown, red glass ornament in appreciation of their support. KHF's event raised nearly \$20,000. We extend many thanks to all sponsors, donors, and volunteers who ensured the success of this fundraiser.



# **\$51,000 POKER CHIP**

unch at KHF's recent annual meeting took on a mantle of celebrity and awe as we hosted the 2003 WSOP Champion, Chris Moneymaker and his family, along with his friend, Donald Hobbs. Donald, a young man from eastern Kentucky, who has struggled all his life with hemophilia and related health complications, is passionate about all things poker. Mr. Moneymaker befriended Donald about a year ago while Donald was recovering from a severe automobile accident. They were drawn together by a common love for poker, a game that dramatically changed both of their lives. While Mr. Moneymaker became almost a household name after his Cinderella 2003 win, Donald's life was literally saved by the game.

Donald's story of incredible recovery and personal triumph that led him to compete in Las Vegas in the 2008 World Series of Poker (WSOP) has garnered national news with USA Today, the Associated Press, and ESPN. In August, the story came back home to Kentucky where it all began because the money will go directly to programs that help people living with hemophilia in Kentucky.

Chris Moneymaker presented Andy Mayer, president of KHF's board of directors, with a giant \$51,000 poker chip, representing the generous donation made by his sponsor, PokerStars. The donation resulted from a charity effort Chris Moneymaker ran during the 2008 (WSOP).



### 2008 Annual Meeting Photos









Give a Hug, Get a Smile





### complications of bleeding disorders

- Get an annual comprehensive checkup at a hemophilia treatment center.
- Get vaccinated Hepatitis A and B are preventable.
- 3. Treat bleeds early and adequately.
  - 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 and services 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.









KENTUCKY HEMOPHILIA FOUNDATION

1850 Taylor Avenue #2 Louisville, 40213-1594

