

KHF Hemosphere

Gettin' in the GameSM

Two youngsters from Kentucky had the exciting opportunity to participate in CSL Behring's Gettin' in the Game Junior National Championship this year in Phoenix, Arizona. Isaac Webb from Louisville and Andy Slate from Mt. Vernon, who are KHF Summer Camp buddies, had the time of their lives learning about, practicing, and competing in their favorite sports of baseball and golf when they joined many other children and teens for this three-day sports clinic and competition, which was specifically developed for the bleeding disorder community thirteen years ago.



Walk 2 Cure

Our 2014 Walk was such a great time! Look for more photos and winner information inside on pages 4 and 5.



Consumers can once again shop for coverage through the Health Insurance Marketplace



Consumers can sign up for health plans for the first time, renew, or change their plans for 2015 on HealthCare.gov. More plans are available this year.

Consumers can sign up for 2015 health insurance plans through HealthCare.gov, the call center, or in-person assistance. With more issuers offering coverage through the Health Insurance Marketplace this year, the consumers will find more options for themselves and their families.

"When Open Enrollment begins tomorrow, consumers who are renewing their coverage or signing up for the first time will have an opportunity to obtain quality health coverage at a price they can afford," said Health and Human Services Secretary Sylvia M. Burwell. "Whether consumers visit the simpler, faster and more intuitive HealthCare.gov or contact the call center, they're going to find more choices and competitive prices."

The Health Insurance Marketplace is a simpler way to purchase health insurance for Americans and their families. Consumers can go online to find and compare options, see if they qualify for lower costs, and select coverage that best meets their needs and budget. About 85 percent of those who signed up last year through the Marketplace received financial assistance. Coverage begins as early as January 1, 2015 for people enrolling by December 15, 2014. Tomorrow, the Centers for Medicare & Medicaid Services (CMS) is launching an education and outreach campaign in communities nationwide to drive both the uninsured and current enrollees to enroll in coverage or renew their coverage. Enrollment events will take place in local communities including in public libraries, churches, festivals, sports events, and community meetings.

"Tomorrow marks the beginning of an intense open enrollment and public education campaign for the Marketplace," said CMS Administrator Marilyn Tavenner. "We want consumers to visit the Marketplace, compare their options, see if they qualify for lower costs, and reenroll or get new coverage that best meets their needs and budget."

CMS has worked to improve the consumer experience by making the application process easier. A window shopping tool allows consumers to answer a few simple questions, such as location and family size, in order to compare plans and get an estimate on how much financial assistance they may qualify for, without needing a log-in or submitting an application.

For most consumers who are renewing coverage, up to 90 percent of their application will be pre-filled based on last year's application. And a new streamlined application reduces the number of screens to 16 with fewer clicks to navigate through the questions for most consumers signing up for the first time. Last year, consumers went through 76 screens to sign up for coverage. This year, along with a simpler, faster application, consumers can shop and enroll on a smartphone, tablet, computer, or by calling the call center or with in-person assistance.

Tomorrow, Secretary Burwell will participate in an enrollment event at the Evergreen Health Center in Manassas, Virginia with local consumers and Certified Application Counselors who are helping consumers enroll.

Open Enrollment for the Health Insurance Marketplace begins tomorrow, Nov. 15, 2014, and runs through Feb. 15, 2015. Consumers should visit HealthCare.gov to review and compare health plan options and find out if they are eligible for financial assistance, which can help pay monthly premiums and reduce out-of-pocket costs when receiving services. All consumers shopping for health insurance coverage for 2015— even those who currently have coverage through the Marketplace — should enroll or re-enroll between November 15 and December 15 in order to have coverage effective on Jan. 1, 2015.

Continued on the next page



A number of different resources are available to help consumers find Marketplace coverage. They can get more information through HealthCare.gov or CuidadoDeSalud.gov. Consumers can find local help at: Localhelp.healthcare.gov or call the Federally-facilitated Marketplace Call Center at **1-800-318-2596**. TTY users should call **1-855-889-4325**. Assistance is available in 150 languages. The call is free.

The Marketplace includes a Small Business Health Option Program (SHOP), designed to give small businesses new health insurance options and a simpler way to cover their employees. The SHOP is available to small employers with 50 or fewer full-time equivalent employees. Starting tomorrow, November 15, 2014, the SHOP Marketplace will allow qualifying employers to find, compare, purchase, and enroll in 2015 SHOP health and dental coverage entirely online through HealthCare.gov. Employees will be able to view offers of insurance from their employer and enroll online through HealthCare.gov. Small businesses and their employees can get help from the toll-free SHOP Marketplace call center at **1-800-706-7893** or for TTY, call 711. The hours are Monday through Friday, 9 a.m. to 7 p.m. EST.

To sign up for individual and family coverage, visit: <https://www.healthcare.gov/apply-and-enroll/>; to sign up for small business coverage, visit: <https://www.healthcare.gov/small-businesses/>; for more information about Health Insurance Marketplaces, visit: www.healthcare.gov/marketplace

Source: Reuters, November 19, 2014

FDA Approves Oral HCV Combination Therapy Free of Ribavirin and Interferon

On November 5, 2014, the US Food and Drug Administration (FDA) approved the combination use of two previously approved separate oral therapies, Simeprevir (Olysio™) and sofosbuvir (Sovaldi™), for the treatment of chronic hepatitis C viral (HCV) infection. It is a ribavirin- and interferon-free regimen, both of which were notorious for causing debilitating side effects.

Simeprevir, manufactured by Janssen Therapeutics, is a protease inhibitor that halts the progression of HCV, thus preventing it from reproducing. Sofosbuvir, manufactured by Gilead Sciences, is a daily oral nucleotide analogue inhibitor composed of a small molecule compound that blocks HCV's ability to replicate. The FDA approval encompasses the combination use of simeprevir/sofosbuvir for both treatment-naïve and treatment-experienced patients. Trial regimens included a 24-week duration for patients with cirrhosis (scarring of the liver) and 12 weeks for those without cirrhosis, both of which excluded the use of either ribavirin or interferon.

The new FDA approval is based on results of the COSMOS study, a phase II trial that included patients with HCV genotype 1. Rates of sustained virologic response (SVR, meaning they no longer had detectable virus in their blood) measured 12 weeks after treatment ended were 93% among those treated with the combination for 12 weeks, and 97% among those treated for 24 weeks. The most common adverse reactions reported by more than 10% of treated patients during 12 weeks of combination treatment were fatigue in 25%, headache (21%), nausea (21%), insomnia (14%), itching (11%), rash (11%), and sensitivity to light (7%). Dizziness (16%) and diarrhea (16%) were the most commonly reported among those patients treated for 24 weeks.

Source: Family Practice News, November 6, 2014

Event News

7th Annual Kickathon



On August 9, ChunJiDo Academy of Evansville held its 7th Annual Kickathon fundraiser. This event is organized by Nancy Cutrell and her husband Bob. Nancy grew up with two brothers who lived with the daily challenges of having hemophilia. Sadly, her brother Terry left us all too soon. This event honors Terry's legacy. All of their ChunJiDo students participate in this fundraiser, and their entire Evansville ChunJiDo family supports it. Monies raised benefit the Kentucky Hemophilia Foundation in support of the Terry D. Turner Memorial Scholarship, Summer Camp for Kids and

Teens, and the annual Holiday Program for our bleeding disorders community. KHF is immensely appreciative for their support of \$3,024.



Kentucky Hemophilia Walk!

The first KHF Walk fundraiser as part of the National Hemophilia Foundation's Walk Program was a resounding success. Two hundred and seventy individuals, most of them connected with Kentucky's bleeding disorders community, had signed up to participate; and more came to walk in support of hemophilia on the day of the event. Forty-three teams of walkers from all corners of the state walked 1-5 K for hemophilia on a crisp October morning at lovely Wetherby Park in historic Middletown.

Musical entertainment, children's activities, and refreshments hit the spot with old and young. The children especially enjoyed the Bouncy House, the clown couple who made balloon animals and did face painting, and Connie's pumpkin painting. The stunning balloon arch served as dramatic start and finish of the Walk and as backdrop for many snapshots. Spirits were high during the invigorating Walk in support of hemophilia.

Some teams wore colorful t-shirts dedicated to a family member or friend. Parents were pushing strollers with sleepy little ones, and there were even a couple of canines in the crowd. Team members and individual walkers had solicited pledges from family members, friends, and co-workers, among others, to raise money for KHF.

All walkers received a complimentary t-shirt and tote bag for their participation. Door prizes, medals, and additional awards could be won by all participants who solicited pledges. The anticipation grew noticeably during the morning as to who the winners would be.



Event News



More Walk!

The winning teams were in **1st place, Team Brody with \$1,318.02, 2nd place, Team Wipperman with \$1,285, and 3rd place, Team Carter's Crew with \$1,040. Team Captains Brody Vanderpool, Renee**

Wipperman, and Amy Tierney proudly accepted their medals and prizes.



For individual fundraising, we recognized **Jamie Beard in 1st place with \$1,165, Brody Vanderpool in 2nd place with \$1,056, and Amy Tierney in 3rd place with \$840.**

We also thank all of our sponsors who contributed generously to the overall gross amount raised of \$35,460. They are Novo Nordisk \$5,000, CSL Behring \$3,500, CVS Caremark \$1,000, BioScrip \$1,000, Kosair Charities \$1,000, Cottrill's Pharmacy, Inc. \$500, Matrix Health \$500, Walgreens Infusion Services \$500, BioRx \$500, Paragon Hemophilia

Solutions \$500, Accredo \$250, Louisville Web Group \$250, Fiducial \$250, and Republic Bank \$250.

The Kentucky Hemophilia Walk will become an annual event and is slated to grow from year to year. All monies raised will support the programs and services that we provide for Kentucky's Bleeding Disorders Community. In addition, shortly after our Walk, Baxter BioScience, the national presenting sponsor, donated \$5,000 in our name to the National Hemophilia Foundation for research.

We thank all contributors, walkers, and volunteers, and our Walk Planning Committee chaired by Venus Marcum, for ensuring the success of our first Walk.



Kentucky Hemophilia Foundation

Membership

July 1, 2014 – November 30, 2014

We thank these members of the Kentucky Hemophilia Foundation for their support!

Individual/Family Memberships, 20+

Frances Joyce Lewis

Supporting Memberships, \$35+

Judy Hayes

in memory of Michael Jason Hayes

Barbara Hendrix

Don Mattingly

John & Carol Nord

Patron Memberships, \$50+

Larry G. Bandy, Sr.

Mark Chavez

Arthur & Terri Hackman

David & Leslie Houvenagle

Laura & Glen Webb

Sustaining Memberships, \$100+

Leah Graham

Barbara Grayson

Fred & Darline Hartman

Thomas & Alice Hendrix

Kim Wearsch

Champion/Corporate Memberships, \$500+

Terry & Marion Forcht

Ted & Jennifer Forcht



IN MEMORY

September 1, 2014 – November 30, 2014

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

Estil Coots

Mrs. Audrey C. Mauk

William L. Farmer, Sr.

Mrs. William L. Farmer, Sr.

Spalding Grayson

46th birthday

Frances Joyce Lewis

Alan Taylor Hall

Mr. & Mrs. W. Walter Hall

Martha & William K. Nord

for Herb Schlaughenhaupt Jr. Memorial Scholarship Fund
John & Carol Nord

Herb & Henrietta Schlaughenhaupt

for Herb Schlaughenhaupt Jr. Memorial Scholarship Fund
John & Carol Nord

Shirley Wilder

Mr. & Mrs. W. Walter Hall





Kentucky Hemophilia Foundation Upcoming Events

At KHF, We're Betting on a Cure.

**So, on February 28th, we're bringing
a bit of Vegas to the 'Ville!**

Vegasville



Betting on a Cure

It's a night of *friends, fortune, and fun* with Casino-style gaming for real money and Vegas-style entertainment. Test your skill and luck with Black Jack, Three-Card Poker, Let It Ride and 21+3 – plus Roulette and Texas Hold'Em. Also enjoy: Auction Items ♦ Open Bar Ben Pine, Certified Broadcast Meteorologist, WHAS Weather ♦ An exciting Grand Prize Drawing Musical entertainment provided later in the evening to dance the night away with [Indigo](#).

Look for your invitation arriving in the mail soon!

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.



February 28th is Vegasville!

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.



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