

# KENTUCKY HEMOPHILIA FOUNDATION

## 2018 – 2019 ANNUAL REPORT

We are proud to be able to acknowledge our 59th service anniversary this year. Since 1960, the mission of the Kentucky Hemophilia Foundation (KHF) has been what drives all of KHF's activities throughout the year. KHF's mission is to assist persons with hemophilia and similar bleeding disorders in our state by providing **education, advocacy, support services**, and to **promote research** for a cure.

**KHF is the Kentucky Chapter of the National Hemophilia Foundation (NHF).** As an affiliate Chapter, we operate independently and with our own governance but are required to meet NHF's Chapter standards that NHF sets forth for optimal organizational, programming, and fundraising capacities and best practices. We are the only organization in Kentucky that exists for the sole purpose of serving Kentucky's bleeding disorders community. We are a state-wide, non-profit health agency with a small staff of two employees. KHF relies on many volunteers to help carry out its mission and raise needed funds to pay for programs and services. More than **120 volunteers** from all parts of the state are involved in this year-round undertaking.

KHF is a 501 (c) (3) charitable organization, federal tax ID: 61-0656750. We do not receive any government funding; nor is there ever a fee to the recipient for services provided. KHF is a Better Business Bureau Accredited Charity. View KHF's full charity report at <https://www.bbb.org/charity-reviews/louisville/health/kentucky-hemophilia-foundation-in-louisville-ky-16388>. Being a BBB Accredited Charity means that KHF has met the Better Business Bureau's 20 Standards for Charity Accountability.

**Historically, most of our funds are raised through yearly special events.** Our Vegasville Gala, Golf Scramble, and two flower sales have been our primary fundraisers for the past twenty-one to thirty-seven years. In addition, we request grants and contributions from corporate, individual, and other charitable giving entities. Since there is a limited life cycle attached to special events, we set out to seek new funding sources and new ways to raise money. Five years ago, we embarked on a new fundraiser that promised to be a win-win activity going forward for all involved. We joined the National Hemophilia Foundation's Walk Program, which has spelled success on many fronts and has resulted in a new revenue stream for participating Chapters, including ours.

**Your participation in the Walk is CRITICAL to its peer-fundraising success! We are very appreciative and proud that our Kentucky Bleeding Disorders Community has accepted and met this challenge! Based on the success of the previous five Walks, we are confident that our Walk will continue to grow.**



We are also continuing with our fund development plan, which was adopted by our Board of Directors thirteen years ago, to grow our annual giving campaign and consistently broaden our base of individual donors to **ensure long-term existence and operational viability of KHF**. Our thirteenth annual fund drive began again with a very generous leadership gift of **\$25,000** that we received from Mr. & Mrs. Forcht of Corbin, Kentucky. This annual challenge gift sets the bar high each year for us to meet their challenge with gifts from other donors, gifts from our Board of Directors, gifts from members of the Kentucky bleeding disorders community, and individual and corporate gifts from the community at large. *With your help we can achieve this goal every year. No gift is too small!*

**The growth of the annual giving campaign combined with the growth of our Walk and new fundraising pursuits will determine the long-term future of KHF.**

This past year as every year, we concentrated our efforts to make ends meet and to achieve a balanced budget without eliminating or decreasing any of our program activities and services. Maintaining a "tightened belt" approach throughout the year in an effort to keep operational expenses in check helped but is not a long-term remedy, whereas increasing our revenue stream is! We are excited and pleased that for year ending June 30, 2019, the Walk revenue, the ongoing support from Mr. and Mrs. Forcht as well as Kosair Charities' increased support allowed us to achieve just that.

**We clearly NEEDED and will continue to NEED your support and that of the larger community to help secure KHF's long-term future for the benefit of Kentucky's bleeding disorders community.**

Today however, we want to acknowledge and thank those individuals, companies, and philanthropic organizations, who supported us this past year — many of them on an ongoing basis. In addition to receiving a total of **\$36,500** from Terry & Marion Forcht of Forcht Bancorp and Forcht Bank, our subsequent top eight financial supporters at the **\$10,000+** level were: **\$31,000** Kosair Charities, **\$27,150** Shire now Takeda, **\$21,150** CSL Behring, **\$19,250** Pfizer, **\$18,600** Genentech, **\$17,400** Novo Nordisk, **\$13,400** Octapharma, **\$10,400** Bayer HealthCare.

Primary supporters at the **\$5,000+** level were: **\$8,700** CVS Caremark, **\$8,150** Genentech, **\$8,000** Hemophilia Alliance Foundation, **\$7,665** IPG for Genentech, **\$6,000** Snow Companies for Shire now Takeda, **\$6,000** WHAS Crusade for Children.

Significant supporters at the **\$2,500** and up level were: **\$4,410** First Choice Home Infusion, **\$4,000** Republic Bank & Trust Company, **\$3,700** Matrix Health now Biomatrix, **\$3,650** BMR Partners-St. Matthews Specialty Pharmacy, **\$3,300** Global Prairie for Bayer HealthCare, **\$2,700** Grifols, **\$2,500** BioRx, **\$2,500** PhRMA, **\$2,500** Laurie & Rodney Shockley, **\$2,500** Patricia P. Thomas Estate.



The next important levels of support were: **\$1,500** and up: Accredo, Aptevo, Bioverativ, Dr. Joseph H. Cieslak of Louisville Oral Surgery and Dental Implants, Community Foundation of Louisville for the Zoeller Company, Cottrills Pharmacy, Alane, Harold, & Mac Foley, Mike Francis, In Touch Pharmacy, Donald L. Mattingly, Network for Good, LTC (R) John & Mrs. Patricia Tharp; **\$1,000** and up: Mr. & Mrs., Henry W. Boyd, III, Chevron Matching Employee Funds, Genentech Louisville Distribution Center, David L. Hasch, Glen E. & Deborah L. Hitt, Sr., Kentucky Bankers Association, Karen Lucky, Cory & Whitney Meadows, Sanofi, Woodmen of the World Chapter 14; **\$500** and up: Bank of Columbia, Barb Bitter, Kelly Blake, Cumberland Valley Insurance Management, Rosemary Johnson-Dean, First Southern National Bank, Greg & Kristi Fiscus, Ted & Jennifer Forcht, Healthcare Alliance Group for CSL Behring, Jennifer Hitt, Thomas L. Jensen, Milton & Ursula Kamala, Kroger Community Rewards, L & M Healthcare Communications for Bayer Healthcare, Eddie & Angie Medley, Ned's Bike Nite, Jerry Schiller, Mason Stout, Keith & Kristin Urbahn; **\$250** and up: William & Karen Black, Community Health Charities, Bob Crawford, Custom Ink, Laura Downs, Debra Duff, Brandy Fox, Charles & Ruth Hall, Amanda Houchens, Craig & Laura Incorvia, Robert E. Mackey, Venus & Eric Marcum, Jimmy Maricle, Lindsay Martin, Milena Pargova, Charlene N. Powell, Monica, Josh & Tag Poynter, Clark & Sally Rhea, John C. Rhea, Pete & Bev Slapikas, William Stopher, Robert Verran; **\$100+** Chris Aaron, Guy Adams, John A. Arceri, Sherry Allen, Susan R. Arnold, Rakesh Asthana, Wanda Bandy, Eric Blankenship, Blue Collar Auto Repair, Burnside Masonic Lodge #634, Asenath Buttram, Camping World RV Sales, Mary Lynne Capilouto, Sara Ceresa, Steve Chaput, Jessica Cherry, Adam Choate, Clark County REMC, R. H. Clarkson Insurance Group, Pat Copas, Janet Coulter, Sean Cuzzart, Danny Daniel, Jewel & Cathy Daugherty, Janie Daugherty, David L. Eager, Ken Eaton, Karie English, Exelon Foundation, Mrs. William L. Farmer, Sr., Hailey Fauver, Gavin Ferrell, Jim Fulkerson, Frank Shoop Chevrolet Buick Chrysler Jeep Dodge, Georgetown Auto Sales, John & Lea Graham, Barbara W. Grayson, D. Spalding Grayson, Eric & Janet Haas, Brenda Hamblin, Dianne Hardman, Chris Harlow, Sandra Harrison, Thomas R. Hendrix, Brett Herald, Heritage Biologics, Hometown Bank, Barry G. Houchens, Pamela Howard, Patricia F. Huff, Humana Foundation, Aisha Irvin, Ricky James, Jim Beam Brands, Co., Johnny Wheels, Kellye Joiner, Gloria S. Keck, Kenny's Department Store, Kentucky Association of Health Care Facilities, Kentucky Bankers Association, Brenda Kilburn, Linda & Dan Larson, Alice Leshner, Andrea Leshner, Justin Lindhorst, Mona Lucky, Marco Island Center for the Arts, Vivian Marcum, Michael McCollum, Scott Meadows, Nancy Mitchell, MLS Powersports, Kevin Moore, Kimberly Tipton Morton, Rebecca Myers, Sally K. Newcomb, Kathleen T. Nichols, Carolyn M. Palmer, Brenda Patrick, Patriot Automotive, Keith Peterson, James Phipps, Vickie R. Phipps, Mr. & Mrs. Dale R. Pike, Vince Poma, Ronnie D. Poynter, Travis Price, Joseph A. Pusateri, Jr., Michael Pusateri, Suzanne Razmus, Mr. & Mrs. James Ray, Republican Party of Kentucky, Stacey Retic, Robert Rhea, Judy Richie, Phyllis Ridge, Ann M. Ritchie, Enoch G. Roberts, Amelia Ruth, Rania Salem, Shamrock Auto Sales, Edwin L. Smith, Ian Stone, Mrs. Steve Surmont, Ronnie Taylor, Thomas Consulting, Top Gun Auto Sales, Briana Vieke, Elizabeth Watts, Glenn & Laura Webb, Tina Weihe, Michael G. Weiler, Jean M. Wells, Mark Wiener, Bradley & Leah Woods, Charles & Kathy Woods, Steven Wylie, Gail F. Yates, Nita Wayne-Zehnder.

*Although we are grateful for and appreciate all donations, only those donors who donated a total of \$100 and more are listed above.*

In-kind contributors included Deibel Greenhouses, Mr. & Mrs. Glen E. Hitt, Sr., JStaples Jewelry, Papa John's, Welch Printing, and Kathy Woods.

We thank all those individuals, companies, and philanthropic organizations who supported us throughout the year financially, in-kind, or through volunteer service for their commitment to our cause and our ability to carry out our mission!

## **LOOKING AHEAD**

One month into the new fiscal year, we again look forward to a productive, proactive, and hopefully prosperous year at KHF. Prosperity to us means being able to raise enough money to be able to pay for the programs and services we provide and end the year with a balanced budget. Our experience during the last few years showed us that we needed to find new and more effective ways of raising funds. **We know now that our Walk is the tool for achieving this goal.**

We thank our Board of Directors for their leadership and wisdom this past year and for charting the course toward a more sustainable future for KHF. We also thank all of our faithful and enthusiastic volunteers for contributing their time, talents, and support. Their combined efforts along with support from our contributors will move our agency forward for the worthwhile cause that unites, motivates, and guides us, namely to provide **education, advocacy, support services** to individuals with hemophilia and similar bleeding disorders in Kentucky and to **promote research** for a cure.

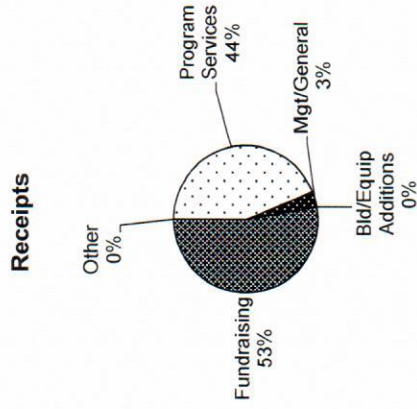
# Thank You!



# Kentucky Hemophilia Foundation

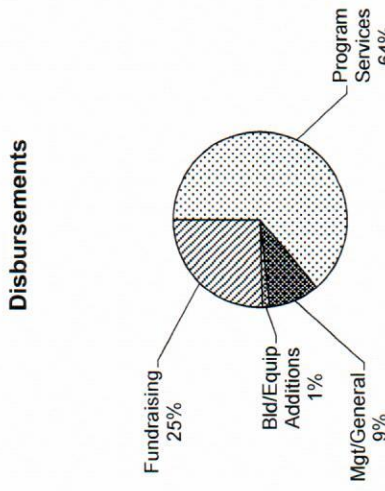
## CASH REPORT JULY 1, 2018 - JUNE 30, 2019

BEGINNING BALANCE JULY 1, 2018	331,365
RECEIPTS	396,213
DISBURSEMENTS	360,600
BALANCE JUNE 30, 2019	366,978



## JULY 1, 2018 - JUNE 30, 2019

SERVICE	RECEIPTS	DISBURSEMENTS
Program Services -10	172,997	229,906
Management/General -00	13,693	34,035
Fundraising -50	209,523	91,690
Building/Equipment Additions	-	4,970
Total Service Receipts and Expenditures	396,213	360,600



Total Net Asset \$437,732.04



**Kentucky Hemophilia Foundation  
Board of Directors  
2019 - 2020**

<b>Officers:</b>	<b>Directors:</b>
Cory Meadows, JD President Louisville, KY	Barbara Bitter Louisville, KY
Laura Webb, Vice President Louisville, KY	Patrick Dunegan Louisville, KY
Brad Comer Treasurer Louisville, KY	Andrew Hartmans, Fisherville, KY
Bradley Woods Secretary Louisville, KY	Christi Hille Louisville, KY
	Eric Marcum, RN Prospect, KY
	Travis Price Louisville, KY
	Brittany Radice, JD (Honorary) San Francisco, CA
	Kristin Taylor, Louisville, KY



# KHF Activities

Highlights 2018 – 2019



## Summer Camp

Twenty-five children and teens participated in this year's KHF summer camp program. The five-day program was jam-packed with outdoor fun and adventure as well as educational and empowerment activities. The goals for every camper are to have fun, make friends, and learn to self-infuse at camp. A special treat this year for our campers and young adults was the "Leading Edge" empowerment program facilitated by Patrick Torrey from acclaimed GutMonkey and sponsored by Pfizer. The canteen program operated by teen campers offered many goodies. Here campers could redeem their virtual dollars which they earned for exemplary behavior, attitude and achievements. All campers proudly donated a portion of their "dollars" to help sponsor a child in India through the Save One Life Program. Our thanks and appreciation go to all of our dedicated volunteers and our sponsors who were Bayer HealthCare, Bioverativ, CSL Behring, CVS Caremark, Grifols, HEMA Biologics, Kosair Charities, Novo Nordisk, Pfizer, Shire, WHAS Crusade for Children.



## 2018 Family Event – Annual Meeting

The Summer Family Event's winning combination of activities were valuable education and information, Walk Kick-Off, and a fun cruise on the Ohio River. Speaker topics were "The Science of Hemophilia: A Changing Landscape," "Resilience: Growing through Life's Changes," "504 Plans and IEPs," and "Parenting with a Chronic Condition." The Walk Kick-Off Luncheon stirred up much enthusiasm for the 2018 Unite for Bleeding

Disorders Walk, and the steamboat cruise on the Ohio River provided a chance to relax. Exhibitors were Accredo, Aptevo, Bayer HealthCare, Bioverativ, Cottrills Pharmacy, CSL Behring, CVS Caremark, First Choice Home Infusion, Genentech, HEMA Biologics, Pfizer, and Shire.

## New KHF Officers and Directors for 2018-2019

Officers elected by the membership during the business portion of the Summer Family Event-Annual Meeting are Venus Marcum, Louisville, President; Cory Meadows, Louisville, Vice President; Kristin Taylor, Louisville, Treasurer; and Laura Webb, Louisville, Secretary. Newly elected Board members were Patricia Ashby, ARNP, MSN, BS, Patrick Dunegan, NORD Ambassador, and GSSI Executive Director; Christi Hille, Homemaker & Caregiver for two young boys; and Travis Price, Supervisor at Amerisource Bergen.

## Fall Scholarships

KHF awarded two \$500 post-secondary education scholarships for the 2018 fall semester. John Rhea received the Herb Schlaughenhaupt, Jr. Memorial Scholarship. John is a graduate student at the University of Kentucky pursuing a Master's degree in Health Administration. Samantha Johnson received the Terry D. Turner Memorial Scholarship. Sam is starting her Freshman Year at Bellarmine University this fall semester. Her major is nursing, and her desired goal is to become a nurse practitioner.



## Kentucky Unite Walk

The theme for this year's Kentucky Unite for Bleeding Disorders Walk was Superheroes under a more inclusive and embracing new name. This was our 5th Walk at Wetherby Park in Middletown. Twenty teams were registered and several individual walkers for a total of one hundred and forty-nine walkers. The newly added pinwheel ceremony put into words the impact and inspiration that this special event holds for its participants. The Walk's atmosphere is so uplifting and moving, giving bleeding disorders a hopeful and united voice, face, and humanity. The Walk raised \$41,334, 83% of our goal. We congratulate all teams and walkers who participated and supported the Walk. Each of



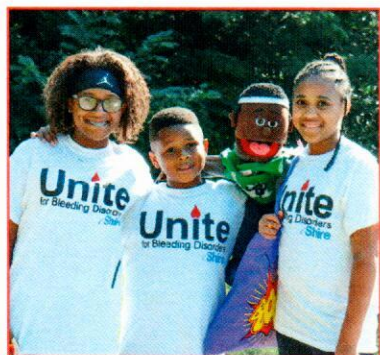


# KHF Activities

Highlights 2018 – 2019



the top six teams raised over \$1,000. They were "Team LEVI," "Team Mac's Pack," "Team Tag's Turtles," "Team GG Babies," "Team Andy's Avengers," and "Team Jackson's Globecloppers." The winning Team was "Team LEVI" from Cynthiana, KY who raised an amazing \$4,724. In second place



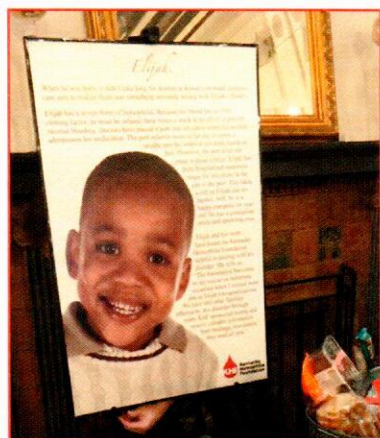
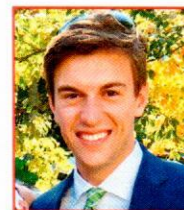
was "Team Mac's Pack" from Lawrenceburg who raised \$3,838, and in third place with \$3,000 was "Team Tag's Turtles," who participated as a virtual team this year, since the date of our Walk coincided with little Tag's birthday. Top individual fundraisers were team captains of their respective teams: Karen Lucky/Levi Hill with \$4,399, Maclan Foley with \$2,380, and Tag Poynter with \$2,595. We're in awe of their achievements, enthusiasm, and commitment to our shared cause, and we thank them from the bottom of our hearts. We thank all our volunteers and Board members who planned for and helped at the event and our donors and sponsors. Sponsors were Novo Nordisk, Gold Sponsor; Bioverativ, CVS Caremark, Genentech, Silver Sponsors; Octapharma, Bronze Sponsor; and First Choice Infusion and Republic Bank & Trust Company, Kilometer Sponsors.

## Year-End Community Event

More than one hundred and seventy community members registered to attend this annual event on a beautiful Sunday afternoon in December. The event offered an uplifting and carefree get-together to catch up with old friends and meet new ones. We had guests from the Bluegrass area, northern Kentucky, Frankfort and surrounding area, and as far south as Glasgow. Exhibitors provided valuable information about their products and services in a relaxed and casual setting. The Bake Contest generated fierce but friendly competition. Of several delectable entries, Karen Lucky's famous Pecan Pie won first place; Tira Miller's Peanut Butter Cake came in second, followed by Roger Harrell's Jam Cake in third place. We thank all volunteers who helped us get ready for this event. Exhibitor support was provided by CSL Behring, CVS Caremark, Genentech, Grifols, Matrix Health, Novo Nordisk, Octapharma, Pfizer, Shire, and BMR Partners-St. Matthews Specialty Pharmacy.

## Spring Scholarship Award

The \$500 Betty Meadors Mattingly Memorial Scholarship was awarded to John Rhea who is pursuing a graduate degree in Health Administration at the University of Kentucky with an impending graduation date of May 2019. John plans to work in the healthcare field and has a strong desire to focus on bleeding disorders in particular.



## Vegasville Event

The 22nd Annual Vegasville Gala was attended by nearly two hundred guests who enjoyed this year's festivities at the Olmsted in Louisville. The event featured dinner during which we honored Elijah Eke and his mother Aisha Irvin. Elijah was one of twenty-five talented young people from across the US who were invited to participate in the production of "Hemophilia: The Musical" on Broadway in New York City. Elijah spoke about the empowering experience of being a cast member and the powerful and inspiring message that the musical exudes. He also talked about growing up with hemophilia and the confidence he has derived from participating in KHF's summer camp. Elijah's mother spoke of the trials and trepidations of parenting a young child with a chronic condition and the joy and pride she has felt watching her son grow up to the accomplished and talented young man he is now.



# KHF Activities

Highlights 2018 – 2019

After dinner, some of our guests proceeded to the casino games that were offered by John Silletto and friends in the West wing and dance music provided by the band Indigo, while others perused the large selection of alluring silent auction items in the lobby. Sean Cuzzart of Louisville won the 50/50 drawing, and Carolyn Creech of Louisville won the mystic topaz necklace set in 14 kt. gold, which was donated by Mr. & Mrs. Glen Hitt, Sr. and JStaples Jewelry. We thank all donors and volunteers and especially this year's table sponsors: High Roller Sponsor - Forcht Bank; Blackjack Sponsors - Bayer HealthCare, CSL Behring, Novo Nordisk, Pfizer, Republic Bank, and Takeda.



## Kentucky Advocacy Day



Thirty-five advocates met with legislators on February 27, 2019 for our 6th Annual Bleeding Disorders Advocacy Day. Training and orientation facilitators were James Romano from Patient Services, Inc. (PSI) and Roy Pura from CSL Behring. Kollet Koulianos from the National Hemophilia Foundation (NHF) shed more light on the Co-Pay Accumulator issue, which was included this year's talking points. Advocates sought legislators' support for 1) Senate Bill 54 - a prior authorization reform bill, which has been signed into law by Governor Bevin; 2) House Bill 374 - which would keep insurers from prohibiting third-party financial assistance for prescription drugs from being applied toward any cost sharing unless the prohibition is required to comply with federal law; and 3) Senate Bill 16 - which asked for the establishment of a rare disease advisory council was also passed. Senator Julie Raque Adams presented proclamations in recognition of the month of March as Bleeding Disorders Awareness Month and February 28th as Rare Disease Day to KHF and NORD respectively. Speakers invited by NORD included Laura and Isaac Webb. We thank our sponsors who were CSL Behring, Pfizer, Takeda, Genentech, and Novo Nordisk.

## Washington Days

Washington Days represent the National Hemophilia Foundation's annual advocacy activity on the Hill in Washington, DC. Teams from many states, including Kentucky, met with their respective legislators to educate them about living with a bleeding disorder and related challenges and to seek their support for ensuring that the healthcare protections that are in place right now for individuals with chronic conditions would continue under any future forthcoming legislative changes regarding healthcare. Our two younger advocates, Mason Stout and Isaac Webb, deserve special recognition for their efforts. Laura Webb of Louisville recalls: "It was such a great experience to take part in a national effort to make a positive impact on the lives of those living with bleeding disorders. Sitting side by side with legislators and their staff, discussing the insurance and healthcare concerns of the bleeding disorders community and sharing Isaac's story, gave us both a greater appreciation for how fortunate we are to live in a country where our voices are allowed to be heard."



## Easter Lily and Spring Flowers Sale

KHF continued with its long-standing Easter Lily and Spring Flowers Fundraiser this year. We received orders from Lexington, Frankfort, Cynthiana, Lebanon Junction, Campbellsville, Columbia, Owensboro, the Louisville Metro area, and southern Indiana. Most orders are delivered to various churches and businesses in these communities. Our dedicated volunteers are the ones who facilitate and place many of the orders. We want to thank Sharon McMahan, Sadalia Sturgill, Tina Pelly, Jenifer Schultz, Nita Wayne-Zehnder for helping us sell 700 plants with this important fundraising effort.





# KHF Activities

Highlights 2018 – 2019

## Family Day at the Louisville Zoo

One hundred and seventy adults and children from all across the state enjoyed a warm and sunny Saturday with us on May 18th. Our guests gathered at the Hillside Gazebo to enjoy a satisfying picnic lunch and chat with exhibitors and friends. We entertained the little ones with a variety of popular carnival games. The small animal presentation by the zoo handlers also attracted a crowd of smiling and adoring children. We thank our volunteers and our exhibitors who were Bayer HealthCare, CSL Behring, CVS Caremark, First Choice Home Infusion, Genentech, Grifols, InTouch Pharmacy, Matrix Health, Novo Nordisk, Octapharma, Pfizer, Specialty Care Rx, and Takeda.



## 2019 Kentucky Unite Walk Call to Action

The 6th Annual Kentucky Unite for Bleeding Disorders Walk will be held on Saturday, October 26 at E.P. "Tom" Sawyer State Park here in Louisville. We will have a Halloween theme with prizes for best costumes, trick or treat candies, "ghoulish" music, "scary" games, pumpkin painting, door prizes, and more.

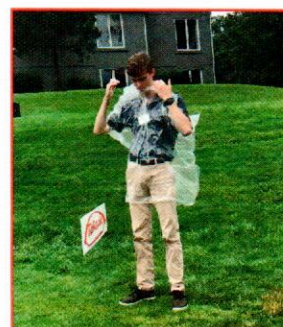
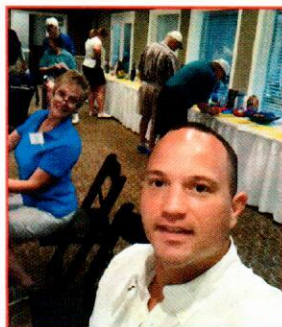
We issued a "Call to Action" during the Family Day at the Louisville Zoo and invited our attendees to participate in this year's Walk as Team Captains or individual Walkers. Awards will go to the top 3 Teams and top 3 Fundraisers and prizes and medals to these winning teams. Incentive prizes will be awarded for amounts of \$250 and more raised. Moneys raised help support scholarships, summer camp, advocacy, and child safety items. The Walk gives visibility to individuals affected by bleeding disorders and increases awareness in the larger community of what life with a bleeding disorder entails.



## Play a Round for a Cure Golf Scramble

The 30th KHF Golf Scramble fundraiser was held on Monday, June 24th at Glen Oaks Country Club in Prospect. Fifteen teams enjoyed eighteen holes of golf followed by dinner, silent auction, and awarding of prizes. Players also received a box lunch and snacks for the course, and a goodie bag and commemorative gift. The afternoon rain shower did not dampen the spirits of our players and dedicated volunteers.

The BMR Partners/St. Matthews Specialty Pharmacy team won 1st place. The Bayer HealthCare team achieved 2nd place, and the HEMA Biologics team came in 3rd. Sam Browning of Louisville won the Putting Contest, and Steve Chaput, also of Louisville, the \$430 "Ball Drop." We thank our sponsors who were CSL Behring, Gold Level; Bayer HealthCare, Novo Nordisk, and Takeda, Silver Level; BMR Partners-St. Matthews Specialty Pharmacy, Diplomat Specialty Infusion Group, Genentech, Octapharma, and LTC (R) John & Patricia Tharp (in memory of Gary Bandy), and Glen E Hitt, Sr. and Friends.





# WHAT DOES KHF STAND FOR?

**The Kentucky Hemophilia Foundation (KHF)** stands for more than a thousand families across Kentucky whose lives revolve around incurable bleeding disorders and related health complications. What we do is provide a safety net of education, advocacy, and support services. Our programs and services help guide those families through the daily challenges of living with a chronic illness.

## **Outreach & Support**

Outreach efforts focus on affected families offering many support activities and a source for information and encouragement.

### **Other support services we offer:**

- Bicycle Helmets and other Child Safety Items
- Clinic, Home, and Hospital Visits
- Emergency Financial, Transportation, and Lodging Assistance
- "On the Road" Outreach and Peer Outreach
- School Presentations, Seminars, Health Fairs and other Educational Meetings
- Medic Alert Emblems
- Recreational Activities
- Toll-free "800 Answers" Line
- Fun Fund-raisers and more

## **Advocacy**

- Legislative Advocacy Activities including annual Advocacy Day at the Capitol in Frankfort

## **Education**

- Educational Literature and Video Resource Library
- Educational seminars
- Mentoring program for teens as they transition into adulthood
- Annual education meeting with nationally known speakers
- Scholarships for post-secondary educational pursuits
- Hemosphere newsletter
- C.A.R.E.S — cultural and recreational enrichment scholarship program
- Updates on advocacy, education, and KHF events and activities and other educational mailings

## **Health & Independence**

- Summer camp for children and youths with bleeding disorders and their siblings combines life skills education and leadership development with outdoor adventure
- Men's Retreat allows men to frankly discuss the effects of living with a bleeding disorder
- Women's Retreat offers an opportunity for women and teens with von Willebrand disease (vWD) to discuss women-specific issues

## **Hope**

Many advances have been made in the treatment of hemophilia. The development of laboratory-made recombinant DNA clotting factor has led to the elimination of a number of infusion-related viral infections. Thanks to changes like these, men, women, and children with a bleeding disorder can now participate in a healthier, more active life.