

KHF Hemosphere



The Power of Flowers

For more than a quarter of a century, KHF has sold poinsettias during the annual November/December Holiday season. At one time, because of its widespread appeal, this was the only fundraiser that KHF had. The volunteer-driven activity relies on dedicated volunteers to solicit orders from friends, family, community businesses, and churches. Small orders are picked up at designated locations and times, and larger orders are delivered by our grower.

It sounds like a winning fundraiser. At one time it was. Now, we struggle to compete with other non-profits, schools, and a multitude of retail outlets that have poinsettias readily and conveniently available. Distinguishing characteristics are that our poinsettias are fresh because they are locally grown, and they are of florist quality. A true bargain for the price that, more importantly, serves a very good cause. We were so fortunate in being able to sell 3,870 plants recently and raise close to \$14,000.

This accomplishment was due to the valiant efforts put forth by our dedicated volunteers. The largest orders were generated by Janet Goff and Sharon Carter, Owensboro; Pat Cooper, Kentucky Blood Center in Lexington; Marion Forcht, Corbin; and Betty Meadors, Louisville. We extend our utmost gratitude and appreciation to all our volunteers for their commitment to this fundraiser.

If you would like to help with our flower sales, please give us a call. We have two flower sales per year. Easter lilies and other spring flowers are sold right before Easter, and poinsettias are sold starting in November until Christmas.



Top Ten

Top 10 Primary Supporters for the Fiscal Year Ending in 2008

Terry & Marion Forcht

Baxter BioScience

Kosair Charities

Wyeth

CSL Behring

Hemophilia Health Services

Novo Nordisk

Bayer HealthCare

WHAS Crusade for Children

BioRx

Thank you all for your generous support and commitment to our cause.



CHRONIC PAIN DRAINS BRAIN

Obviously, there is a linkage between the perception of pain and the central nervous system, but who would have thought that chronic pain affects brain function in unexpected areas of the brain with telling consequences. Research conducted at Northwestern University in Chicago showed that the brain functions of individuals with chronic pain stayed active even when they should have been at rest. This may account for increased levels of anxiety, depression, sleep disorders, and inability to make decisions in chronic pain sufferers.

Research further showed that the brain functions of individuals with chronic pain varies markedly from that of pain-free individuals even when performing small tasks unrelated to their pain. In the healthy person, the brain's default-mode network (DMN) takes over when there is no external task to be performed and the brain is at rest, and the DMN ceases upon engaging in an external activity. However, the DMN never stops in people with chronic pain.

The study examined a group of people with chronic back pain and a group of healthy individuals to carry

out a simple task that required visual focus. Results showed that even though both groups performed the task equally, brain function of the chronic pain sufferers showed increased activity in a number of primary DMN zones.

The researchers were astonished to find that the area of the brain needed by the people with chronic pain to perform this small task was fifty times larger than that needed by the healthy group. Chronic pain apparently has a vast impact on brain function and taps areas of the brain not ordinarily associated with pain.

Moreover, chronic pain appears to alter the healthy brain much like other neurological conditions that are accompanied by cognitive impairments. The inference is that cognitive therapy may be able to help individuals suffering from chronic pain.

Article reviewed: Chronic Pain Drains Brain, Sarah Aldridge, Hemaware, September/October 2008, Vol. 13, Issue 5

Contraceptive helps decrease bleeding in women

An intrauterine device (IUD) that has been on the market since 2000 for the purpose of birth control has also been found to have a positive effect on hemostatic disorders of the uterus. The IUD releases a synthetic version of the hormone that is responsible for the growth and breakdown of the lining of the uterus. A recent study by the Carolina Women's Research and Wellness Center in Durham, NC shows promise in that seven women of child-bearing age who suffered from abnormal menstrual bleeding (menorrhagia) experienced positive results from the use of the IUD.

Four of the women had von Willebrand disease (vWD), one had vWD and factor V Leiden, and four were undergoing anticoagulation treatment. Five of the seven women reported a decrease in the duration of their menorrhagia with a median drop from nine to three days. Although two women did not experience a reduction in symptoms, an improvement in quality of life was denoted by most.

The levonorgestrel-releasing IUD device appears to offer a dual benefit to women with bleeding disorders as an option for birth control and as a means for reducing excessive menstrual bleeding. The IUD is manufactured by Bayer HealthCare under the name Mirena®. Women who suffer from menorrhagia and suspect an underlying bleeding disorder should consult their hemophilia treatment center (HTC) for testing and diagnosis before seeking appropriate treatment for their menorrhagia.

Summary of article by Patrick Hayes, Hemaware, March/April 2009, Vol.14, Issue 2

Easier access

The Pros and Cons of Infusion Devices

A central venous access device (CVAD) provides easier venous access for frequent infusions. CVADs are implanted under the skin and offer a reliable alternative to accessing hard-to-find veins in young children. In addition, they offer convenience and longer-term service, allow for more frequent infusions, and facilitate home infusion. Although there are different types of CVADs, the Port-A-Cath (port) has become the most popular CVAD among the bleeding disorders community.

However, there are disadvantages associated with CVADs, primarily the risk of infection and the development of blood clots, or even worse, thrombosis. To reduce the likelihood of these complications, it is imperative to keep the port site sterile. Parents must learn how to cleanse and flush the port and then consistently carry out this procedure. Reportedly, the rate for developing at least one bloodstream infection is 30% in children with ports and as high as 50% in children with ports who develop an inhibitor. Before deciding on a CVAD implant for easier venous access, the advantages and disadvantages must be carefully considered.



Children with ports need to be closely monitored. Since ports are foreign bodies implanted under the skin that are regularly accessed from the outside, bacteria can easily get into the blood stream. Any sign of a possible port infection, such as a fever, must be evaluated. A child with a confirmed port infection must receive proper and immediate treatment. Children under two years and those with frequent port access are most vulnerable for developing an infection. Bloodstream infections are also caused by failure of keeping the port site sterile before and after the infusion and by poor oral health. Moreover, if a bruise (hematoma) develops on the surface of the port because of blood leakage when the needle is removed, the port should not be used in an effort to prevent an infection. Children with frequent port access and those with inhibitors are more likely to develop a hematoma. Applying ten minutes of direct pressure to the stick site can prevent bruising.

Nearly 50% of patients suffer the formation of blood clots in the port or in the vein accessed by the port's main line. Blood thinners for flushing the port can be used to prevent the formation of blood clots and possible infection and to treat blood clots. Sometimes the removal of the port is the only recourse. Other problems experienced with ports are factor leakage, twisted line, or displacement of the port.

Ports are typically used as venous access devices for children with severe hemophilia and those – including some adults – who have an inhibitor and require frequent infusions, or if healthcare facilities are not within a reasonable travel distance. It is recommended that a CVAD is removed within a period of four years or sooner.

Summary of article by Bridget Murray Law, Hemaware, March/April 2009, Vol. 14, Issue 2



Celebrate his life

It was my husband who set in motion an event that would honor someone whom I loved dearly and will always miss. Following the death of my brother, as expected; I was very emotionally distraught and even the mention of his name or seeing something that reminded me of him would send me into a shower of tears. After several weeks of continued grieving, it was a short phrase from my husband that helped me cope with my grief over losing my brother and bring peace and relief from my pain. My husband reminded me that the greatest remembrance you could give to someone who has passed is to move beyond the grief and celebrate the person's life.



Strange as it seemed at first, I knew this was exactly what I needed to do in memory of someone who with his gentle persona and enduring strength through a life of continuous pain had been a hero and role model to me. As we discussed how to celebrate the life of my brother, it occurred to me that one of his regrets was that he never had the chance to attend college. What better way to preserve the memory of Terry than to give the opportunity to others with this illness to attend college with a scholarship in Terry's name?

My husband and I initially donated \$500 to establish the Terry D. Turner Memorial Scholarship. To make sure the celebration of Terry's life and his memory would endure, we decided to establish an annual fundraising event in his honor. My husband and I operate martial arts schools in Evansville, Indiana, so he recommended we do a Kick-a-thon to raise money for the scholarship. We set an initial goal of \$1000 not really expecting to reach it since this was our first time but hoping for the best.



When we announced our intentions to our martial arts students and their parents, the support and involvement was amazing! We had parents who immediately began calling to lineup sponsors and donations. To our surprise, even though the economy was in a very tough time, we received numerous donations and over 30 students participated in the Kick-a-thon.

The event was a tremendous success and the room was full of parents and students who, through the kindness of their hearts, dedicated themselves to someone they only knew through the memories we shared and the pictures we displayed during the event. At the end of the Kick-a-thon, I remember shedding tears; but this time they were tears of appreciation as the grand total collected was announced. The event raised \$5,325, far exceeding all of our expectations!

Now, for a very long time, we can remember Terry and help others to attend college in his name. Even though recipients of the scholarship will never know Terry, he will be smiling from Heaven happy that we not only shed tears for his passing, but that we also loved him enough to celebrate his life.



by Nancy Cutrell, Evansville, Indiana

Securing the future of KHF

Kentucky Hemophilia Foundation's Second Annual Fund Drive, Concluded in 2008 — We thank the following individuals and companies for their generous support

Challenge Gift, \$25,000
Mr. & Mrs. Terry Forcht
Corbin, Kentucky

Forcht Challenge Donors, \$1,000+
Baxter BioScience
The Community Foundation
of Louisville made possible by
Zoeller Company
Novo Nordisk

\$500 - \$999
Nancy Cutrell

for the Terry D. Turner
Memorial Scholarship
Ruth F. Goldstein
in memory of Terry Turner
David L. Hasch
The Prudential Foundation
Mike & Jenifer Schultz

\$250 - \$499
Aebersold Charitable
Lead Trust
GE Foundation
John & Lisa Harrison
Bill & Jane Stopher

\$100 - \$249
Baxter International Foundation
Eva A. Brenner
Neda Buckman
in memory of all my family
that is no longer with us
Chevron
Scott Davis & Family
Curt E. Flock
Mike Gatton
in memory of Margaret E.
Gatton and in honor of
Greg Gatton
John & Leah Graham

William A. Griffis
Ken Hays, Jr.
LABSCO
Eric D. Marcum
Bart Must
John & Carol Nord
in memory of Nord &
Schlaughenhaupt Family
Rev. & Mrs. William J. Schultz
Betty Jo Shaak
William & Christine Shontee
Andrew & Patricia Stone
Visual Scientists, Inc.
Polly & Keith Williams

Ann T. Young
\$50 - \$99
Gerald & Tammy Auton, Sr.
Mickey & Sandy Clark
Preston & Lori Ellis
Barbara B. Garrison
Billie & Jeanne Hurt
Raymond Jeffers
Raymond S. & Nancy T. Kramer
Mary E. Marasa
Betty L. Meadors
in honor of Francene
Frances Mitchell

The Marketing Research Bureau
Frances Shultz Mitchell
Melynda Riley
Dave Smith
Sherry Mattingly Thompson
Wilma C. Wallace
Woman of Immanuel,
Immanuel United Church
of Christ
Up to \$49
Anonymous
Ken & Judy Berzof
Lisa Blair

Jewel & Cathy Daugherty
Frances G. Gentry
William P. Hartlage
Emily J. Hext
The Johnson Family
Barbara R. Kinnard
Luise K. Montgomery
Sanford Parker
Ready Cab Company
Mary Ellen Ritchie

Saint Gobain
Corporation Foundation
David Sanders CPA, LLC
Romaine W. Scholl
John L. Silletto
Cheryl A. Thomas
Levi & Betty Weaver
Marylou Westling
Ida S. Whitledge
Edwin Wilson

Note: Third Annual Fund Drive contributions will be acknowledged at the conclusion of the fund drive in 2009

Helping Hats Indeed

What's that, you may wonder! At different times throughout the year, you will see many businesses in your community sell \$1 paper cut-outs for a good cause. The KHF Helping Hat cut-outs are sold and displayed during October because of the natural affinity of a good witch's type hat with Halloween. This is a winning fundraiser in all respects. It appeals to the general public at a very low cost. Each cutout requires only a \$1 donation. It does not cost sponsoring businesses anything to participate and support our worthwhile cause. The fundraiser is easy to sell and to monitor for our volunteers. Most importantly, the fundraiser increases public awareness about bleeding disorders while raising needed funds for KHF's programs and services.

Thanks to the contacts made by our volunteers, these businesses participated in 2008: Forcht Bank, Le Bliss Salon, Louisville Oral Surgery & Dental Implants, Republic Bank, Moreno Express, Stock Yards Bank, all in Louisville; River Ridge Marathon in Brandenburg; and Mathis Automotive Center in Greenville. A total of 900 hats were sold and \$900 were raised.

If you own or work in a service oriented business or if you are willing to contact a business in your community, please give us a call this summer. This fundraiser is easily implemented no matter where you live.



Fall Fun

The largest crowd to date of 120 ghosts and goblins and their parents participated in this annual family event on the Saturday before Halloween. In addition to skating, bowling, shooting hoops, and playing air hockey in the game room, the Mad Scientist Laboratory, Pinning the Nose on the Pumpkin, and best Costume Awards also proved to be big hits.

Halloween decorations, ghoulish music, and an ample amount of trick or treat candy added to the Halloween ambience of this event. The evening was rounded out by a drawing for a super selection of door prizes provided by our sponsors.

We appreciated the support of Baxter BioScience, Critical Care Systems, CSL Behring, Factor4Life, Grifols, and Matrix Health for this event and thank our volunteers from UPS who helped with the activities, set-up, and clean-up.



Holiday Cheer

The annual Holiday Party was a cheery event. More than 150 guests joined us for an afternoon of friendship, entertainment, and pure joy.

Activities included the traditional bake contest, silent auction, arts and crafts for children, and drawing for door prizes. Entertainment was provided by the Clark Brothers. The bake contest featured thirteen entries and was won by Leslie Houvenagle with her Orange Juice Cake. Renee Wipperman provided the children with beaded bracelet kits for easy assembly with very pretty and colorful results. The silent auction that consisted of a selection of sought-after items provided by our guests added another layer of merriment.

As the excitement in the room noticeably rose, the afternoon culminated in the arrival of Santa Claus who had a gift for every child at the party.

KHF volunteers were recognized and thanked for their investment of time, talent, and resources throughout the year. Each received a practical but attractive "hot and cold bag" as a small token of our abounding appreciation.

In the end, the "KHF elves" were content with glee that the afternoon's goal had been achieved: No one left empty handed and fun was had by all.

We thank our sponsors, who were Bayer HealthCare, Novo Nordisk, Baxter BioScience, Wyeth, BioRx, Caremark, CSL Behring, Critical Care Systems, Grifols, Hemophilia Health Services, and Factor4Life. We also thank all of our volunteers who helped ensure the success of the event.



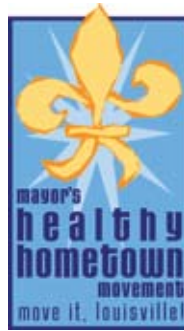
IN MEMORY

July 1, 2008 – December 31, 2008

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

All my family that is no longer with us Neda Buckman	Nord & Schlaughenhaupt Families John & Carol Nord
William L. Farmer, Sr. Mrs. William L. Farmer, Sr. Mrs. William L. Farmer, Sr.	Julia Minor Rhea Virginia S. Akins Mr. & Mrs. Henry W. Boyd, III John & Mary Jane Collins Martin & Marianne Nitzken Mrs. Jane D. Norton
Margaret Gatton Michael A. Gatton	Don Robinson Patricia P. Thomas
Spalding Grayson on his 40th birthday Joyce Lewis at Christmas Joyce Lewis	Herb Schlaughenhaupt, Jr. Joan & Ron Wuetcher
Alan Taylor Hall William & Norma Hall	Carolyn Hall Schroering Mr. & Mrs. Kenneth Arnold Robert & Thelma Ebert Julie Gutermuth Mr. & Mrs. Clarence Parsons Mr. & Mrs. Roy "Pete" Ruckriegel Mary E. Schroering
Nan Hawley Hawkins, Harrington, & Meyer Families Betty Jo Shaak	Paul Wathen Donald Grayson
Tim Levay Ruth Ann & Thurston Le Vay	Dennis Wheatley at Christmas Barbara & Donald Grayson
Carolyn Lockwood Sandra K. Arnold Walter Kleinstauber	Bob Wrege Mrs. David Allen Thomas
Erika Meissner Judy Berzof Star Tyree	

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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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**.

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