

# FACTOR-NET

Hemophilia Foundation of Illinois

July / August, 2005

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## Welcome!

*The Board of Directors of the Hemophilia Foundation of Illinois is pleased to announce the appointment of Bob Robinson as Executive Director as of June 1, 2005. Many of you may already know Bob, as he has been involved in our community for the past twelve years as a volunteer. His roles have included committee member, Board member and more than five years as President of the Board of Directors.*

*In addition to this commitment to people with hemophilia and other related bleeding disorders, Bob brings nearly twenty years of professional experience to our organization. He has in-depth knowledge of mission-centered program development, not-for-profit management, marketing expertise and fundraising.*

*We are very pleased that Bob has agreed to support our efforts in this position. Join us in welcoming Bob to this new leadership role. He can be reached by telephone at 312-427-1495 or e-mail at [brobenson.hfi@mindspring.com](mailto:brobenson.hfi@mindspring.com).*



## HEMOPHILIA HOT BUTTON

First off, I want to thank everyone who was able to join us for the Education & Fun Day at the Brookfield Zoo. It was terrific to see more than 250 people in attendance. This strong participation supports the importance of this type of activity and we are definitely planning to repeat this event next year and possibly schedule others like it.

By the time you are reading this issue of the FactorNet, the 33<sup>rd</sup> session of Camp Warren Jyrch will be in full swing. We are expecting nearly 70 campers and 30 volunteer staff to be participating. We are holding it at a new camp this year – Camp White Eagle in Leaf River, Illinois. We'll include pictures from camp in the next issue.

As you all know, the Hemophilia Foundation of Illinois, has gone through many changes over the past several years. The Board of Directors and staff are working to get on the right track. We are doing this by developing a strategic plan that is true to our mission and the needs of the Illinois bleeding disorder community. Critical to the effectiveness of this effort is input from you. In the next few weeks, we will be sending you a short survey to ask for your insights. When you receive this please take some time to complete it and return it to the Foundation. Thank you in advance for doing this, and we will share the results of these planning efforts with you in the near future.

For the golfers in our community please mark your calendars for the 2005 Benefit Golf Outing, Driving Fore Hemophilia. The golf outing is scheduled for Wednesday, September 21, 2005 at Cantigny Golf & Tennis, 27W270 Mack Rd., Wheaton, Illinois from 10:30 a.m. to 8:00 p.m. This event raises significant funds to help us support our advocacy, education, counseling and consumer services program. There is complete information on the web site on how you can participate, but do not hesitate to contact us if you have questions.

That's what's hot at HFI for now. Enjoy the rest of your summer.

Bob Robinson  
Executive Director

## Becky Ryan Retires

The patient voice on the other end of the telephone for the Hemophilia Program for the State of Illinois has retired. Personal health reasons have



forced

Becky to step down earlier than anticipated. She started her involvement with hemophilia in 1974! HFI would like to acknowledge Becky and thank her for many years assisting the bleeding disorders community of Illinois. If you would like to send Becky a card, her address is:

Becky Ryan  
150 W. Brown St.  
Waverly, IL 62692

## In Memorium

HFI lost a long-time supporter and volunteer in April with the passing of Mil Radvansky. We would like to thank the following individuals who memorialized his life with contributions to the Foundation.

Gary & Linda Berger	Jason & Sarah Bethke
Mirian Cioe	Ann Dobia
Joseph & Beverly Gimpert	Tom Hedrick
Jeremiah & Susan Kenney	Louianne & Philip Lofgren
Howard & Lorraine Walther	

If you would like information on how to direct memorial and honorary gifts to HFI, please contact Lily Schwartz at (312) 427-1495.

## State Hemophilia Program

The State Hemophilia Program begins its fiscal year on July 1<sup>st</sup>. At this time each year, all individuals and families that wish to participate must re-enroll. The State of Illinois' Hemophilia Program is designed to assist families, that are not otherwise eligible for Medicaid, with the costs of factor and up to two comprehensive visits at a Hemophilia Treatment Center (HTC) that are not covered by health insurance. The State calculates the individual's/family's Participation Fee (an annual deductible amount). Insurance co-pays and deductibles for Factor and Comprehensive Care Visits are eligible expenses. For persons using the State's High Risk Insurance Pool (ICHIP) coverage, if you also apply for the State Hemophilia Program, the factor bills can be billed to the Hemophilia Program and thus helps to preserve your ICHIP coverage limit (cap). Enrollment in an HTC is a requirement, as is an annual check up. Speak with your HTC about enrollment in the State Hemophilia Program. Cindy Cox is the current State Hemophilia Program Contact and can be reached at 217-524-7018.

**“Bleeding Disorders have been part of our family for decades...you can trust that we really do understand.”**

**“Until there is a cure...there is AHF.”™**

Our families may look a bit different from each other, but we all have one thing in common. We live every day with a bleeding disorder and we deserve the highest quality care and home infusion services! For the past 15 years AHF® Inc. has set a standard of care that is unsurpassed, we have remained family owned, family operated, and we have deepened our commitment and our promise to provide the very best programs, services, and resources to families from coast-to-coast.

- Full range of clotting medications and ancillaries
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- Safety equipment and biohazard disposal
- Ongoing client education program and permanent usage log
- Medic Alert Program and medication wallet cards
- Ongoing corporate support for research including over \$1,000,000 to *It's Time for a Cure*

### Here is what some of our families have to say:

- “More like family...We feel a closeness that comes from your sense of sharing and dedication to help in so many aspects, i.e., insurance, medications, factor information, just caring and trying to make things better.”
- “Our supply needs are always met, orders are shipped correctly, and the professionalism of the staff is refreshing. We pinch ourselves with joy that we finally found a company that meets the needs of our child so beautifully.”
- “We want also to thank Don personally for being such a devoted person to people that your company provides their services to. When my husband saw your company he called immediately and that was the beginning of our homecare. And the end of the worry about being one hour away from the closest hospital. THANK YOU ALL”



**Donald Colburn**  
CEO and President



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for the Bleeding Disorders Community**



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For more information about products, services, and programs we offer to the hemophilia community, visit our Web site at [www.hemophiliavillage.com](http://www.hemophiliavillage.com) or call 1.888.999.2349.



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## Women with Bleeding Disorders

NHF has announced that there will be a three part session for women with von Willebrand Disease on October 27 at the Annual Meeting in San Diego. Also of note, Barbara (Evans) Forss, formerly of the Chicago Area and HFI, has formed a support group for women with bleeding disorders under the title 'Lady Bugs'. (Evidently Lady Bugs are known to bleed into their joints!) The Lady Bugs have been mentioned in *Hemaware*, *Dateline Federation*, and the *IEBD Times*. They can be reached via Email: barbfors@yaho.com

## Dealing with HCV

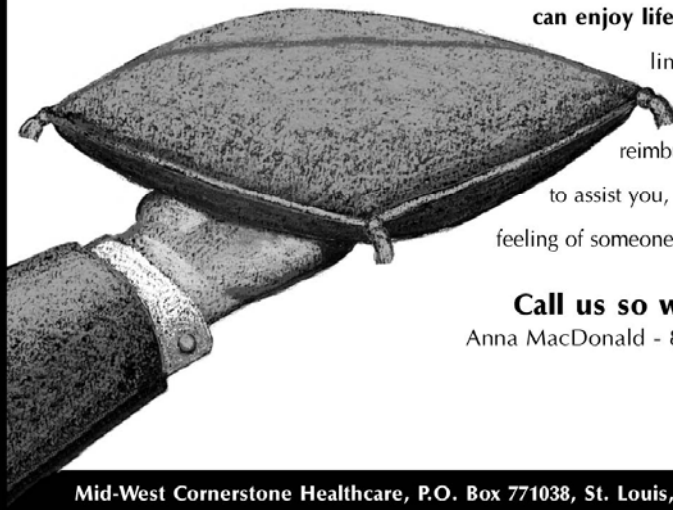
For those in our community dealing with HCV and HIV the website [www.hivandhepatitis.com](http://www.hivandhepatitis.com) is a good resource for current news on treatments and tests. Some recent articles of interest are:  
**Are Current Serum Markers an Adequate Alternative to Liver Biopsy?**  
[[www.hivandhepatitis.com/2005icr/easl/docs/050205\\_hcv\\_e.html](http://www.hivandhepatitis.com/2005icr/easl/docs/050205_hcv_e.html)] 06-05-21  
**Coffee Consumption Reduces the Risk of Liver Cancer** [[www.hivandhepatitis.com/hep\\_c/news/2005/040405a.html](http://www.hivandhepatitis.com/hep_c/news/2005/040405a.html)] 06-05-22  
**Triple Anti-HCV Drug Therapy for Nonresponders**  
[[http://www.hivandhepatitis.com/2005icr/ddw2005/docs/hcv\\_052705\\_a.html](http://www.hivandhepatitis.com/2005icr/ddw2005/docs/hcv_052705_a.html)] 06-05-23  
**Statins Protect Against Hepatocellular Cancer in Patients with Hepatitis C**  
[[www.hivandhepatitis.com/2005icr/ddw2005/docs/hcv\\_060105\\_c.html](http://www.hivandhepatitis.com/2005icr/ddw2005/docs/hcv_060105_c.html)] 06-05-24

## Articles and Publications Received

Project Red Flag: Focus on Women with von Willebrand Disease, NHF Meeting 10/27/05	06-05-01
AIDS Legal Council of Chicago, Spring 2005 [ <a href="http://www.aidslegal.com">www.aidslegal.com</a> ]	06-05-02
Dying in Vein: Blood, Deception . . . Justice by MacKay and Milbouer, Hollis Publishing Co [ <a href="http://www.hollispublishing.com">www.hollispublishing.com</a> ]	06-05-03
Von Willebrand Disease: A Guide for Patients and Families, Hemophilia Health Services [ <a href="http://www.hemophiliahealth.com">www.hemophiliahealth.com</a> ]	06-05-04
PSI Post Script Informer, Spring 2005, [ <a href="http://www.uneedpsi.org">www.uneedpsi.org</a> ]	06-05-05
Big Red Factor, Summer 2005, Nebraska Chapter of NHF [ <a href="http://www.nebraskaNHF.org">www.nebraskaNHF.org</a> ]	06-05-06
Annual Report 2004, Project Share [ <a href="http://www.kelleycom.com">www.kelleycom.com</a> ]	06-05-07
Dateline Federation: Spring 2005 vol. 9, No. 5 Hemophilia Federation of America, [ <a href="http://www.hemophiliated.org">www.hemophiliated.org</a> ]	06-05-08
SevenSecure Scholarships and Edu-Grants, <a href="http://www.us.novoseven.com/content/us_vers/us_seven_secure.asp">www.us.novoseven.com/content/us_vers/us_seven_secure.asp</a>	06-05-09
Foundation Report, Spring 2005, Factor Foundation [ <a href="http://www.factorfoundation.org">www.factorfoundation.org</a> ]	06-05-10
The Hemophilia Bulletin, Feb. 1 <sup>st</sup> Issue, 2005, Carol K. Kasper, M.D. [Email: <a href="mailto:ckasper@lach.ucla.edu">ckasper@lach.ucla.edu</a> ]	06-05-11
Clotting Factor Concentrates in the USA, 2005, Carol K. Kasper, M.D. [Email: <a href="mailto:ckasper@lach.ucla.edu">ckasper@lach.ucla.edu</a> ]	06-05-12
Hemophilia World, January 2005, Vol 12, No 1 [ <a href="http://www.wfh.org">www.wfh.org</a> ]	06-05-13
Bleeding Times, Volume 2 May 2005 Comprehensive Bleeding Disorders Center [ <a href="http://www.hemophilia-ctr-peoria.com">www.hemophilia-ctr-peoria.com</a> ]	06-05-14
The Source, Summer 2005, Plasma Protein Therapeutics Association [ <a href="http://www.pptaglobal.org">www.pptaglobal.org</a> ]	06-05-15
Center Update, Spring 2005, Mary M. Gooley Hemophilia Center [ <a href="http://www.hemocenter.org">www.hemocenter.org</a> ]	06-05-16
IEBD Times, Vol. 2, Issue 2, Inland Empire Bleeding Disorders [Email: <a href="mailto:iebd4u@verizon.net">iebd4u@verizon.net</a> ]	06-05-17
Hemaware, July /August 2005 Vol. 10, Issue 4 [ <a href="http://www.hemophilia.org">www.hemophilia.org</a> ]	06-05-28



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## Looking for a Job, Knee Replacement, Dental Care, and Liver Biopsy

These are three issues of interest that are found in the current issue of Hemaware. One article explores issues involved for a person with a bleeding disorder in looking for employment and while on the job. The article on Knee replacement follows a man with hemophilia from North Carolina step by step through his knee replacement surgery in Boston. The article on Dental Care draws on the experience of a Dental Hygienist who has been working almost 25 years in an HTC. Also you can find an article on the safety of Transjugular Liver Biopsy in hemophilia patients. There is something for everyone in this issue.

Hemaware, July /August 2005 Vol. 10, Issue 4, NHF  
[www.hemophilia.org] 06-05-18

## Adult Bleeding Disorders Camp

Jenny Massey, together with Carl Weixler of HFA, and Pam Doelle, are bringing to reality a camp for adults. This is their project and Jenny says "this year we will hold the very first every Hemophilia Adult Weekend Camp. We would love any man or woman with a bleeding disorder age 18 and older to attend." It will be September 3rd-5th in Potosi, Missouri. For more info contact: Jenny Massey – Chair, Camp HAWC, 527 Wren Hill Rd, Troy, IL 62294, 1-618-667-1864.

## vWD Information Resources / Recursos en Español

Thanks to Cook Children's Hospital in Texas and to Hemophilia Region 9 there are several useful brochures available about von Willebrand Disease. There are versions for Parents and Caregivers, Middle School age and up, and for School Personnel. There are versions in Spanish as well. These are downloadable from the Internet or by contacting HFI.

*Gracias al Cook's Children's Hospital en Texas y al Region 9 de Hemofilia hay varios folletos utiles sobre la enfermedad de von Willebrand. Hay versiones en español para los padres de familia, los muchachos de secundaria y mayores, y para los adultos. Hay los mismos en el inglés mas otro para el personal en las escuelas.*

Von Willebrand Disease Informational Brochures  
By Susan Zappa, RN, Cook's Children's Hospital  
[www.hemophiliaregion6.org] 06-05-19

## Promising Gene Therapy for Arthritic Inflammation

In studying gene therapy for other diseases, scientists have come across an unexpected "decrease in the production of inflammatory chemicals linked to arthritis in the knuckles . . . ."

Pitt Gene Therapy trial offers hope for crippling arthritis, June 7, 2005 Pittsburgh Tribune-Review [PittsburghLive.com] 06-05-22

## Dying in Vein

Kathy MacKay and Stacy Milbouer have published a pictorial account of the effects of the blood crisis in the USA. Their touching photographs and descriptions are a testament of the legacy of our community.

Dying in Vein: Blood, Deception . . . Justice by MacKay and Milbouer, Hollis Publishing Co [www.hollispublishing.com] 06-05-03

## PLACE YOUR AD HERE!

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Half Page (7¾" W X 5" H) **\$175**  
Quarter Page (3 5/8" W X 4 7/8" H) **\$100**  
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Contact Bob Robinson or Dennis for details: [dpenning.hfi@mindspring.com](mailto:dpenning.hfi@mindspring.com)  
Ads must be submitted one month in advance of publication. Jpeg format please.

◆ Discounts for multiple issues ◆  
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You and your family are cordially invited to attend the:  
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## Junior National Championship in Golf and Baseball



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Event activities for competitors and their siblings will include:

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- Question and answer session
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- Art programs, Baseball activities, Bingo and much more . . . .

To register please call 1-888-508-6978.

Always consult with your Hemophilia Treatment Center to determine if a particular sport or exercise is right for you.



**SAVE THE DATE**

**July 24-30**

**July 30**

September 3-5

September 21

October

October 14

October 27-29

**Camp Warren Jyrch**

**NHF—ZLB Jr. Nat'l Championship**

Hemophilia Adult Weekend Camp (HAWC)

Annual Golf Outing

Southern IL Family Symposium

Wine Tasting Dinner and Auction

NHF 57th Annual Meeting

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**St. Louis, Missouri**

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