

FACTOR-NET

Hemophilia Foundation of Illinois

December, 2004

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Camp Warren Jyrch

Close collaboration with staff from the hemophilia treatment centers, volunteers from the community, manufacturers, and homecare companies provided Camp Warren another successful summer. 54 campers, including 11 junior counselors, and 41 volunteer counselors and health professionals participated. Photos from Camp are on our website www.hemophiliainillinois.org. You can also look for your HFI Holiday Card which has many scenes from Camp. If, you do not receive your card and would like one, please call the office at (312) 427-1495.

The 33rd session of Camp Warren Jyrch is scheduled for the last week in July—Sunday July 24, 2005 through Saturday, July 30th 2005 at a new location. This year camp is going to be held at Camp White Eagle near Rockford, Illinois. For the first time camp will also be open to girls with bleeding disorders. Make sure that we have your current email address and profile so that you receive information and applications as the details are made available. HFI is exploring ways to keep Camp friendships alive throughout the year. Mini camp reunions? Email or IM connections? Any ideas? Let us know.



Transformation at HFI

In the Spring, HFI welcomed **Kathleen Drayton** as the new Executive Director. Kathleen had been Director of Development and had experience as an Executive Director for the "Y". Kathleen has stepped up to the plate combining her skills as E.D. and fundraiser. **Terry Toohey**, completing and complimenting her role on the HFI transition team, took on the part time role of HFI's Financial Director. In the Fall, Erin Kimball, left the office to resume academic life, working on her PhD. This led to the introduction of **Lisa de Paris** as Special Events Coordinator and Administrative Assistant, the friendly telephone presence of HFI. In October, shifting responsibilities brought **Faith Romano** back to her familiar role as Case Manager, attending to the needs of community members impacted by HIV. November found **Dennis Penning** back on the HFI team as Clinical Services Coordinator on a part time basis. Dennis is available Monday through Friday from 8 A.M. until 1 P.M. at (312) 224-8966. There is also a toll free line (866) 492-1143 for families throughout the State.

After a long hiatus, with this issue of FactorNet, we bring back a regular appearance of information of importance to the Illinois Bleeding Disorders Community. Since email is changing the way many communicate, we would like to be able reach as many members of the community as rapidly as possible. This would be especially useful if there are any urgent product alerts. We ask those of you who have email to please send Dennis an email [dpenning.hfi@mindspring.com] so that we can capture your current email address. Because it is not always obvious to whom the email address belongs, please include your name and postal address as well.

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Articles and Publications

In the FactorNet you will find brief summaries of articles and publications received by HFI during the past several months. If you would like to receive a copy of any of the cited articles, please contact Dennis at HFI. Have the number found at the end of the summary available. If we do not have copies, we will inform you how they may be obtained. This material is provided for general information only. **HFI does not give medical advice, engage in the practice of medicine, or endorse any product or treatment. Please contact your Hemophilia Treatment Center or your physician before pursuing or changing the course of treatment.**

Community Heads Up

The current issue of the Parent Empowerment Newsletter (PEN), Laurie Kelly's publication, is full of valuable information regarding the changing way insurance companies, the State and Federal Governments are dealing with families and individuals with hemophilia and von Willebrand Disease. Laurie lays out some of the seemingly immovable obstacles that even she, a nationally known and knowledgeable bleeding disorders advocate encountered. Also in PEN is an article by Dana Kuhn of Patient Services Inc. (PSI), a nonprofit organization that helps people with expensive chronic illnesses look for solutions for health insurance problems and assist with insurance premiums and co-pays according to the resources available. Understanding all of these issues is very important. HFI has ordered a supply of this issue of *PEN*. If you would like a copy, please call or send us an email.

Parent Empowerment Newsletter: November 2004[www.kelleycom.com] 11-04-09

Treatment Center News

Hemophilia Treatment Centers adhere to the Standards and Criteria as approved by the Medical and Scientific Advisory Committee of the National Hemophilia Foundation.

HFI Social Worker, Greg McClure, who provides social work assistance at **Michael Reese HTC**, will now be collaborating more formally with the **Northwestern Center for Bleeding Disorders**. In June, Elizabeth Fung, PhD, Social Worker with the **Children's Memorial Hospital HTC**, received the Life Time Achievement Award from the Chicago District Chapter of the National Association of Social Workers. Congratulations Elizabeth! The **Comprehensive Bleeding Disorders Center** in Peoria welcomes four new staff members: Mary Brooks, Nurse Coordinator; Dana Stephens, Nurse Practitioner; and Bob Vericker, Nurse

Coordinator. CBDC has outreach clinics scheduled in **Rockford** in January, **Decatur** in February, and **Danville** in April. **Rush Hemophilia and Thrombophilia Center** also has regular outreach clinics in **Aurora** and **Hoffman Estates** and also sees patients in Kankakee.

Daughters, Mothers,

and Sometimes Sisters, Aunts and Cousins . . . At times we forget that the daughters of men with hemophilia inherit the hemophilia gene and are carriers. This is important health information that the child's physician needs to know. Many carriers have normal factor levels and never experience any bleeding episodes but some carriers have lower than "normal" factor levels which could be very important, even life threatening in some circumstances such as a car accident, surgery, childbirth and others. Every carrier should know their circulating factor level. Stress can increase the amount of circulating factor, so drawing blood for factor levels on a child under stress (crying) might not give an accurate picture. Carriers and their families will want to read the article *Symptomatic Carriers* in NHF's May/June 2004 HemAware. Also the May issue of PEN had three very good articles of interest to Carriers and Women with Bleeding Disorders such as von Willebrand disease. One of the values of maintaining ongoing contact with a MCHB/CDC recognized Hemophilia Treatment Center (HTC). You might have to travel farther but you will find a team of health professionals that are knowledgeable about bleeding disorders. HTC professionals deal with the situations that arise from the hemophilias and von Willebrand Disease on a daily basis, not just once in a great while.

HemAware: May/June 04 vol 9, No 3: 08-04-33
Parent Empowerment Newsletter: May 2004 [www.kelleycom.com] 08-04-07

Substances that May Cause Bleeding

A recent study in the *Archives of Internal Medicine* concluded that "in a large population of new antidepressant users we found a significant association between degree of serotonin reuptake inhibition by antidepressants and risk of hospital admission for abnormal bleeding . . ." Earlier there have been reports of bleeding caused by nutritional supplements such as omega-3 fish oil and Saw Palmetto. We all know that aspirin interferes with clotting but if you are taking antidepressants or any over-the-counter supplements they may impact your bleeding. You need to make

sure that your hemophilia treatment center physician is aware of all of the medications and supplements you take. **Association of Risk of Abnormal Bleeding, Archives of Internal Medicine 2004;164: 2303 11-04-08 Hemophilia Outlook: Summer 2004 Hemophilia Association of New York 8-04-16A**

Community Health Charities and HFI

HFI is an active participant in Community Health Charities of



Illinois (CHC), the largest workplace giving program dedicated solely to health causes. HFI joins 35 other health agencies that receive funds for medical research, health education and patient services from CHC. CHC donations to HFI over the past five years have assisted in our efforts to serve the Illinois bleeding disorders community.

CHC give employees the opportunity to support HFI and 35 other health agencies through their paychecks. Workplace giving is the most effective and efficient method of fundraising and usually results in donations that are 4-6 times higher than one-time gifts. CHC promotes the mission of HFI in corporations, as well as state and local governmental entities across Illinois.

HFI benefits every time a new employer decides to run a CHC workplace giving campaign. Each campaign brings needed funds to the mission of HFI. If you work for an employer that offers a CHC campaign, you can designate your gift to HFI by using the **code number 5543**. If your employer offers a United Way only campaign, speak to your Human Resources representative about the option of expanding the campaign to include CHC.

If your employer does not offer you any way to support charity at work, we encourage you to consider approaching your employer about implementing a workplace giving campaign. CHC is available to assist you with making this approach. For more information or to start a campaign, please contact Gael Mennecke at Community Health Charities, at 312-939-6275 or gael@healthcharitiesillinois.org or Lisa de Paris at HFI at (312) 427-1495 or ldeparis.hfi@mindspring.com.

Von Willebrand Disease 2004

Carol Kasper MD has published a 58-page booklet **Von Willebrand Disease 2004: An introductory discussion for**

Hepatitis C

The liver is a vital organ for everyone but it has a greater than usual role in the well-being of so many in the bleeding disorders community because of the historical prevalence of hepatitis (B, C, and A) infections through plasma based products in years gone by. Fortunately new infections from factor infusions have been practically speaking relegated to the past here in the U.S. Nevertheless many in the Community have to deal with the realities of Hepatitis C and in many cases together with HIV. The November/December 04 issue of NHF's *Hemaware* has a special section on Hepatitis C including an article by a Hep C/HIV impacted liver transplant survivor and others regarding compensation efforts and advocacy on the Hill. *HemAware*, November/December 2004 Vol 9, Issue 6: NHF 11-04-01

Serving in Iraq



Eivira Brown, hemophilia mom and former HFI

Board Member, is far from home and family serving with the Army Reserves during this holiday season. Please keep the Browns in your thoughts and prayers along with all of those caught up in the dangers of these struggles.

HFA & NHF

HFI is a Chapter of the National Hemophilia Foundation and now is also a member of the Hemophilia Federation of America. The HFA Annual Symposium is going to be held in Nashville April 1-3. The NHF On the Road for this part of the country is to be held in Indianapolis, April 29-30, 2005. Dateline Federation. HFA: Fall 2004 [www.hemophiliafed.org] 11-04-05

NHF Annual Meeting

At the Annual meeting there are always so many different sessions to attend and so much information for families and professionals to absorb. Frequently it is difficult to find ways to share the

experience with all of the people back at home that were not able to attend. This time there were two excellent videos introduced. These are available to you, upon request, through NHF's HANDI. Both feature real members of the bleeding disorders community.

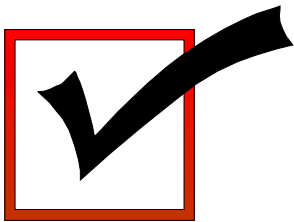
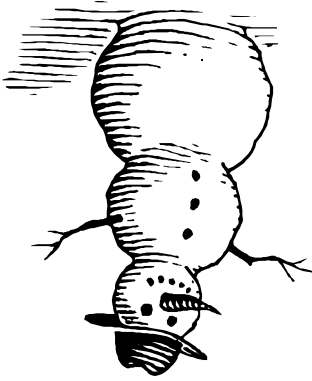
An Unexpected Life, looks at the lives and experiences of members of the Community. It has been made with the idea that it could be presented on television at some point. You might even recognize some familiar faces.

A Long and Happy Life is a classy video that comes from our neighbors in Wisconsin. It looks at families and preparing youth for the transition to adult responsibilities. Ask for copies. These videos can be used by families at home and in a variety of settings.

An Unexpected Life: Living with Hemophilia (video) distributed by HANDI 11-04-03
A Long and Happy Life (Transition video) Great Lakes Hemophilia Foundation: distributed by HANDI 11-04-04

Articles and Publications Received

HemAware: July/August, 2004. [www.hemophilia.org]	08-04-01
Quest: Volume 1, Issue 1, 2004. Email: quest@coram.com	08-04-02
Hemophilia Leader: September 2004 www.kelleycom.com	08-04-03
Baxter: Important Correction of Drug Information, August 2004	08-04-05
GMHC Treatment Issues: May June 2004. [www.gmhc.org]	08-04-06
Parent Empowerment Newsletter: May 2004 [www.kelleycom.com]	08-04-07
Hemophilia Literature Review: June 2003 Patients Educational Resources	08-04-08
Positively Aware: May-June 2004. [www.tpan.org]	08-04-09
Von Willebrand Disease 2004: By Carol Kasper MD. [Email: ckasper@laoh.ucla.edu]	08-04-10
Blood Therapies in Medicine: Vol 4 No. 2 [www.blood.remmedica.com]	08-04-11
Positives for Positives: Community Treatment Update 2004 [www.pos4pos.org]	08-04-13
Hemophilia Foundation News and Views (Nevada):Spring 2004, Volume 13, Number 1 [www.hemophilianeveda.org]	08-04-14
HIV Notebook: Summer 2004. Hemophilia Association of New York	08-04-16
Hemophilia Outlook: Summer 2004 Hemophilia Association of New York	8-04-16A
GMHC Treatment Issues: May/June 2004 Volume 18, Number 5/6 [www.gmhc.org]	08-04-18
World Federation of Hemophilia Annual Report [www.whf.org]	08-04-19
Posi-Views, May 2004 Volume 3, Issue 1 Positudes., [www.positudes.org]	08-04-20
Foundation Report: Factor Foundation: Spring 2004 Volume 4, [www.factorfoundation.org]	08-04-21
Together We Prepare, American Red Cross of Greater Chicago, [www.chicagoredcross.org]	08-04-22
The HemoLink: Summer Issue 2004, Northern Ohio Hemophilia Foundation, [www.nohf.org]	08-04-23
Center Update Mary M. Gooley Hemophilia Center: Summer 2004. [www.hemocenter.org]	08-04-24
WFH: April 2004, Treatment of Hemophilia No 33 Chronic Hemophilic Synovitis: The Role of Radiosynovectomy	08-04-25
The Winning Spirit: Summer 2004 Vol 11 Num 3. NHF Delaware Valley Chapter [www.hemophiliasupport.org]	08-04-26
Hemalog: Vol 15, Num 2, May 2004	08-04-27
NHF Enotes: April 2004	08-04-28
NHF Enotes: May 2004	08-04-29
Hemalog Report: January 2004	08-04-30
Hemophilia World: June 2004 Volume 11 No. 2,	08-04-31
Dateline Federation:Spring 2004 vol 9, #1 Hemophilia Federation of America), [www.hemophiliafed.org]	08-04-32
HemAware:May/June 04 vol 9, issue 3: NHF	08-04-33
NEHA News: New England Hemophilia Association [www.newenglandhemophilia.org]	08-04-34
Family Life Education Series: Jewish Family & Community Services [www.jfcschicago.org]	08-04-37
HemAware, November/December 2004 Vol 9, Issue 6: NHF	11-04-01
GLHF Headline News, Fall 2004 [www.glhf.org]	11-04-02
An Unexpected Life: Living with Hemophilia (video) distributed by HANDI	11-04-03
A Long and Happy Life (Transition video) Great Lakes Hemophilia Foundation: distributed by HANDI	11-04-04
Dateline Federation. HFA: Fall 2004 [www.hemophiliafed.org]	11-04-05
NEHA News: Fall 2004, New England Hemophilia Association www.newenglandhemophilia.org	11-04-06
Bleeding Times, December 2004, Comprehensive Bleeding Disorders Center [www.hemophilia-ctr-peoria.com]	11-04-07
Association of Risk of Abnormal Bleeding, Archives of Internal Medicine 2004;164: 2303	11-04-08



<u>SAVE THE DATE</u>		
March 9-12	NHF Washington Days	Washington DC
March 19	HFI Annual Auction Announced	Location to be
April 1-2	HFA Symposium	Nashville
April 15-16	NHF On the Road	Santa Fe
April 29-30	NHF On the Road	Indianapolis
May 27	Wine Tasting Dinner & Auction Country Club	Eagle Brook
June 18	HFI Annual Meeting & Symposium	Brookfield Zoo
July 21-23	Camp Training	Camp White Eagle
July 24-30	Camp Warren Jyrch	Camp White Eagle
September 21	Annual Golf Outing	Cantigny Golf Course

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Full Page (7 ³ / ₄ " W X 10 ¹ / ₄ " H)	\$350
Half Page (7 ³ / ₄ " W X 5" H)	\$175
Quarter Page (3 5/8" W X 4 7/8" H)	\$100
Business Card Size	\$ 75

Contact Lisa de Paris for details ldeparis.hfi@mindspring.com
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