

FACTOR-NET

Hemophilia Foundation of Illinois

May / June 2005

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Hemophilia
Foundation of
Illinois

332 S. Michigan Ave.
Suite 1135
Chicago, IL 60604

Phone: (312) 427-1495
FAX: (312) 427-1602

hemophilia@earthlink.net
www.hemophiliainillinois.org

Toll Free (866) 492-1143

Introducing the HFI Hot Button

What's Hot At the Foundation this Month?



The Hemophilia Foundation of Illinois exists to help our community live stronger with hemophilia and other inherited bleeding disorders. We are constantly planning and supporting activities that assist our community to achieve this goal.

It always pains us to hear someone say that they wish they would have known about an event. "I would have really liked to be a part of that." So – we are going to work to strengthen our communications so that this happens less and less.

Each month we will highlight what is upcoming through the HFI Hot Button. We'll provide background and details in the FactorNet, while also making it easy to have this information at your fingertips through a link on the front page of our web site, www.hemophiliainillinois.org. So let's get to this month...

2nd Annual Education & Fun Day

Saturday June 18 is the date for our second annual Education and Fun Day at the Brookfield Zoo. You should have received the invitation in the mail (if not, please call the office at 312-427-1495) and we have included all of the details once again in this FactorNet. We have filled the morning with up-to-date presentations and roundtables for adults. In addition to child care services, we also are offering children under 12 the opportunity to participate in the unique "Karing for Kids" workshop (this program requires one or both parents to attend).

We follow all of this with a picnic lunch and the **Annual Meeting** for the Foundation. The Annual Meeting is our opportunity to report to you – our community – about the financial health of your organization, what we have done over the past year and some glimpse into our plans for the future. Best of all, we are doing this all at the world famous Brookfield Zoo. You will have all afternoon to check out what is up with your favorite animals and meet some of the newest babies that have been welcomed this spring.

Please make your reservations today.

Camp Warren Jyrch

For all of you campers – start packing. Plans are well underway for Camp Warren Jyrch's 33rd year. Camp is being held from July 24 to July 30 at a brand new facility – Camp White Eagle located near Rockford. This new camp has a beautiful setting. We are convinced this is going to be the best year ever.

Camp applications have been mailed. Space is limited so make sure you get these materials returned quickly. If you have not received the materials to date, please call the Foundation today so that we can correct this.

Camp Superfly

Not to be confused with Camp Warren Jyrch, this is a unique activity to promote positive health awareness and get everybody – young and old – excited about Camp. In addition, this is a potential Camp funding opportunity. HFI will get points for you taking the time to complete the outlined activities. These points will be tallied and the Chapter that has the most points will get \$30,000 for their Camp!

Out Among The Dragons

We have a star among us. Our own Dan Noonan, long-time HFI Board member and past President, has written a play that is having its world premiere in Evanston at the Northminster Playhouse from June 23 – July 10. The play is a comedy that explores how the mode of transmission can affect the way we view people with HIV and the way positive people view their world, their dreams and themselves. Please see Dan's Bio, play summary and performance dates in this issue.

So there you have it for this month. As always, please do not hesitate to contact us if you have any questions – 312-427-1495. We look forward to seeing you at one or all of these events.

Medical News

Pregnancy and Bleeding Disorders

The Current issue of Hemaware has a feature article that is of interest to women with vWD and carriers of hemophilia.

Bleeding Disorders and Pregnancy, NHF Hemaware, May/June 2005 Vol 10, Issue 3 04-05-03

New Gene Therapy Approach

Researchers at Washington University Medical School in St Louis announced that they used a different hemophilia gene therapy approach with newborn mice and dogs. ““We are really pleased with the results, because the animals produced about 20 times more factor than has been achieved in prior attempts using gene therapy for hemophilia A in dogs” . . . The animals in this study have not formed inhibitors against factor viii after more than a year of follow-up.””

Gene therapy completely corrects hemophilia in laboratory animals, 4/19/05, Washington University in St. Louis 04-05-01

Springfield to Host Hemophilia Outreach Clinics

The Comprehensive Bleeding Disorders Center in Peoria announced that they will hold Outreach Clinics in Springfield in June and November. **Bleeding Times, Vol. 2 May 2005, CBDC** 04-05-10

Weight, Bleeds, and Joint Health

At the NHF On the Road meetings held last month, Sally Crudder of the CDC gave a dramatic presentation showing how obesity has been spreading throughout the general population in the USA. Then she introduced information gleaned from the UDC to which bleeding disorder patients contribute information at their recognized hemophilia treatment center check ups. The extra weight influences the number of bleeds and joint health. The physical therapist at your HTC can provide valuable suggestions about ways to increase your activity which, when coupled with information from the dietitian can help. Importantly, even just a little weight reduction can help with the bleeds and joint health.

New Directions

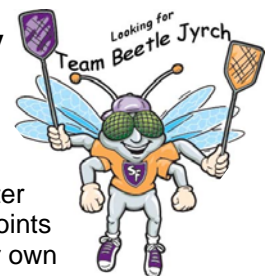
In April, the HFI Board of Directors reopened the Executive Director search. Bob Robinson, long time HFI volunteer and Board member has been tapped to lead HFI. Bob will start June 1.

Camp Warren Jyrch July 24-30

Applications are being accepted now for both boys and girls with bleeding disorders ages 7-16. The applications are available online at the HFI website: **www. Hemophilia-illinois.org** The basic application should be submitted to HFI by **June 13.**



Look for your **Camp Superfly** mailing. This is an opportunity to turn your regular annual Treatment Center check up into points to help fund our own Camp Warren Jyrch!



Help Camp!

Send in your Forms

INSURANCE ALERTS

Even though the information below comes out of New York, the caution is valuable for everyone. There has already been a situation in Illinois of a policy that would not cover the cost of factor, even in the E.R. With all of these changes in the wind, it is advisable for all families to be enrolled in the State Hemophilia Program. It costs nothing to enroll each year.

Review Your Health Insurance Decisions

Recently the NY association (HANY) has heard of employers making sudden and drastic changes in health coverage. You may be faced with large co-insurance costs or caps on factor, or even an end to factor coverage. There is no law requiring private health plans to cover factor. In many families, both wife and husband have health insurance available from their employers. Sometimes, because they have to pay larger premiums for family plans, only one of the couple opts for the family policy, choosing the policy with better benefits. This decision, which worked well in the past, may need to be reconsidered.

If the employer of the spouse who holds the family plan withdraws essential benefits, the other spouse probably will not be able to enroll in a family plan until the employer's annual open enrollment. To protect against being left without coverage in the interim, it may be prudent for both spouses to have family plans. In such a case, the primary policy is the one held by the spouse whose birthday month is earlier in the year.

Save Your Child's Insurance Coverage

If your child is reaching the age limit of coverage by your employer's family health insurance, you are likely to be able to continue his/her coverage by your plan, at your own expense, under a program called COBRA. If you plan to do so, it is essential that you sign up for the COBRA coverage as soon as it is available, so you will not lose the opportunity. Should COBRA **not** be available, your child must find and be enrolled in another health insurance plan within 63 days, or probably have to wait a year before a new policy takes affect. Emphasize to your child that when choosing a job, it is important to consider whether the employer offers health insurance which includes factor coverage. (With permission from HANY's *Hemophilia Outlook*)

When Only The Best Will Do!

For the past 15 years, the AHF home care pharmacy has set a standard of care that is unsurpassed, we have remained family owned and operated, and we have deepened our commitment and our promise to provide the very best programs, services, and resources to families coast-to-coast.

- Full range of clotting medications and ancillaries
- Overnight delivery and 24 hour a day client services support
- Benefit coordination services and negotiated reimbursement
- Visiting nurse services where required
- Safety equipment and biohazard disposal
- Ongoing corporate support for research including over \$1,000,000 to *It's Time for a Cure*

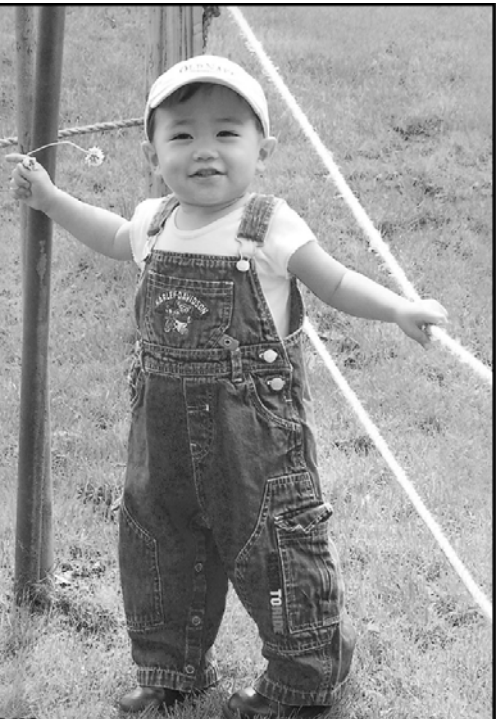


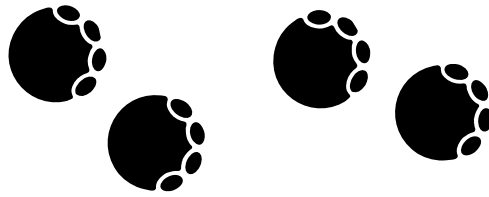
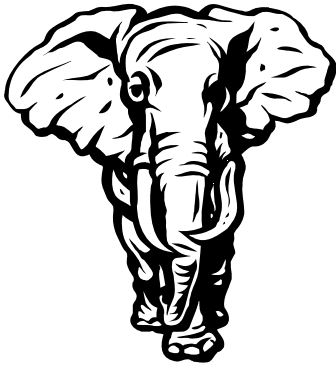
The Hemophilia Disease Management Company

**Setting the Standard of Care
for the Bleeding Disorders Community**

31 Moody Road,
P.O. Box 985, Enfield, CT 06083

800-243-4621 www.AHFinfo.com



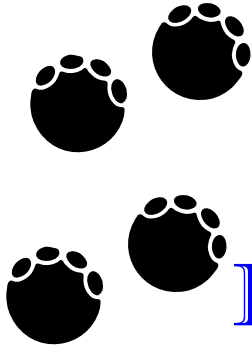


*The Hemophilia Foundation of Illinois
Invites you to the 2nd Annual
Family Education & Fun Day*

Saturday June 18, 2005

8:30a.m.—2:00 p.m.

Brookfield Zoo



Please join us for a fun and fact filled day at Brookfield Zoo. For our opening session this year we have assembled some of the top national policy advocates in our community to bring you up-to-date on the latest issues facing the clotting disorders community. Then stick around to learn more at our break out sessions, followed by lunch and HFI's annual meeting to hear how we have worked over the past year to support our community. Our program ends at 2:00 pm, then you and your family are free to explore the zoo, see the dolphin show, and take the motor safari ride.



Break Out Sessions
(Subject to change, based on demand)

- ◆ ABC's of Hemophilia for New Parents
- ◆ Alternative Health Strategies
- ◆ Bleeding Disorders and your School
- ◆ Blood Safety
- ◆ Exercise and Hemophilia
- ◆ Hemophilia Wives
- ◆ Hep-C Current Treatment
- ◆ HIV Infection Issues
- ◆ Medicare—What's Charged?
- ◆ Ports & Prophylaxis
- ◆ Sibling Issues
- ◆ Women with Bleeding Disorders & Manifesting Carriers

Karing for Kids Workshop
(Offered during the Break Out sessions)

An opportunity for the whole family to learn about how blood clots, the infusion process and other hemophilia related topics. Your kids will love the Coagulation Slime and Genetics demonstrations. Note: At least one parent must attend this workshop with their children.

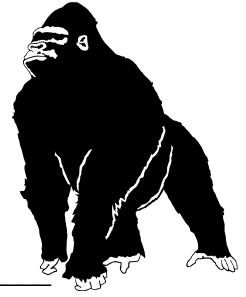
- ◆ Cost is \$10 per adult, \$5 per child. No one will be turned away due to finances
 - ◆ Childcare available for children over 1 year old during the opening session and Break Out Sessions



Please see enclosed registration form



**2nd Annual Family Education & Fun Day
at the Brookfield Zoo
REGISTRATION FORM
(Pre-Registration is Required)**



Name: _____
Nombre

Address: _____
Direccion

Daytime Phone: _____ E-Mail Address: _____
(Teléfono diurno)

List All Attending: _____
(Indique los nombres de todos que asistirán:)

Please check one of the following payment options (Favor de señalar una de la opciones siguientes):

Check*/Cash is included for registration for _____ number of adults _____ number of children.

**Please Make Checks Payable to the Hemophilia Foundation of Illinois*

Charge \$ _____ to Credit Card. (Visa or Master Card)

Account Number _____

Expiration Date _____

Registration Assistance Needed (Requiere ayuda financiera para la entrada)

Names, Ages & T-Shirt Sizes for Children (Nombres, Edades y las Tallas de camiseta para niños) :

The following children are interested in participating in the "Karing for Kids" Workshop

Note: One parent or guardian must be present with their child at this workshop

(Los niños siguientes de 12 años y menores quieren participar en El Taller "Cuidando los Niños")

Help Us Best Manage Our Discussion Breakouts.

Please check the top three (3) sessions you are interested in attending:

(Favor de indicar las tres sesiones que más les interesa.)

- | | |
|--|---|
| <input type="checkbox"/> ABC's of Hemophilia for New Parents | <input type="checkbox"/> Hep-C - current treatment |
| <input type="checkbox"/> Alternative Health Strategies | <input type="checkbox"/> HIV infection issues |
| <input type="checkbox"/> Bleeding Disorders and Your School | <input type="checkbox"/> Medicare - What's changed? |
| <input type="checkbox"/> Blood Safety | <input type="checkbox"/> Ports & Prophylaxis |
| <input type="checkbox"/> Exercise and Hemophilia | <input type="checkbox"/> Sibling Issues |
| <input type="checkbox"/> Hemophilia Wives | <input type="checkbox"/> Women with Bleeding Disorders and Manifesting Carriers |
| | <input type="checkbox"/> Pláticas en español. |



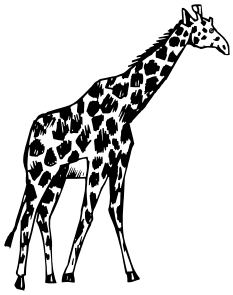
Registration Deadline: Mail or Fax by June 7, 2005

Hemophilia Foundation of Illinois

332 S. Michigan, Suite 1135

Chicago, IL 60604

Phone: 312-427-1495, Fax: 312-427-1602



La Fundación de Hemofilia de Illinois

Les invita al

Segundo Día Anual de Educación y Diversión Familiar

Sábado el 18 de junio de 2005 en el Parque Zoológico de Brookfield

8:30 A.M.

El Costo de es \$10 por el adulto y \$5 por niño.

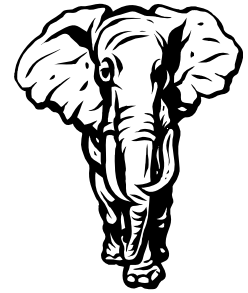
¡SIN EMBARGO NADIE SERÁ NEGADA ENTRADA DEBIDO A FINANZAS!

Tenemos algo de apoyo financiero

Por favor, llámenos para información sobre ayuda en (312) 224-8966 o llamada gratis: 866-492-1143.

¡No Se Olvide!

Hay que reservar los cupos antes del 7 de junio!



Todo está incluido: La Admisión al Zoológico, Estacionando del Auto, el Desayuno y el Almuerzo.

El almuerzo será del estilo de la merienda campestre y habrá la reunión anual donde aprenda cómo HFI ha trabajado durante el año pasado sostener la comunidad.

El Permiso para el Estacionamiento se incluye con este envío y cuando usted estaciona en el Zoológico se debe demostrarlo en el parabrisas de su automóvil.

El Taller "Cuidando los Niños" está disponible para familias con niños de 12 años y menores.

Una subvención limitada del transporte está disponible. Llame por favor HFI para detalles.

La ubicación del: **Zoológico de Brookfield esta situada en 3300 Golf Road en Brookfield, IL 60513**

Teléfono del parque zoológico: 708-785-0263 www.brookfieldzoo.org

¡LA ENTRADA SERA EN LA PUERTA DEL NORTE (NORTH GATE)!

Hagan sus reservaciones hoy!

Envíe el formulario a la vuelta de esta hoja por correo o por telefax antes de la fecha tope de junio 7.

Habrà la oportunidad de platicar en español con otras familias con hemofilia y la enfermedad de von Willebrand.



Hemophilia Foundation of Illinois
332 S. Michigan Avenue • Suite 1135
Chicago, Illinois 60604 - 4419
HFI General Office Numbers:
(312) 427-1495 Fax: (312) 4271602

Para preguntas en español

Dennis Penning - Clinical Services Coordinator

Direct Line: (312) 224-8966

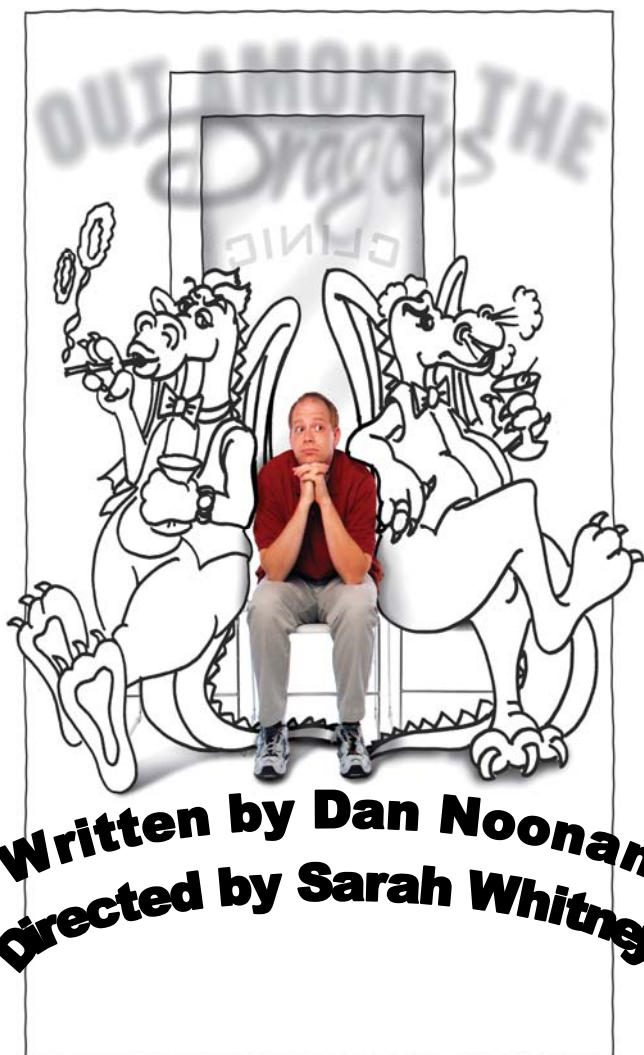
Direct Fax: (312) 224-4646

Illinois Toll Free: (866) 492-1143

dpenning.hfi@mindspring.com

OUT AMONG THE DRAGONS

DAN NOONAN'S NEW DRAMATIC COMEDY ABOUT A YOUNG MAN WITH HEMOPHILIA, HIV, AND A HANKERING FOR LOVE, PROMISES TO BE A CHICAGO SUMMER THEATER STAND-OUT



Out Among the Dragons will receive its first professional production in true Chicago-style, in a church basement on Chicago's North Shore, at Northminster Presbyterian Church's Logan Hall, 2515 Central Park Avenue, in Evanston. Performances are June 23-July 10, 2005: Thursdays at 7:30 pm, Fridays at 8 pm, Saturdays at 2:30 pm and 8 pm, and Sundays at 2:30 pm. **Press opening is Saturday, June 25, 8:00 pm curtain.**

Tickets are \$15, and go on sale online on Monday, May 23, 2005 at Ticketweb.com and via phone by calling **(866) 468-3401**. Advance tickets will be sold at all League of Chicago Theatres Hot Tix locations, including the nearby North Shore Center for the Performing Arts, 9501 Skokie Blvd. in Skokie, starting Monday, May 23, 2005.

Walk-up sales will also be available at Northminster Church one hour prior to performance (cash and check only.) For groups of 8 or more, call the *Out Among the Dragons* group sales hotline, **(847) 622-4467**. For more info. check out outamongthedragons.com. Please note: two-thirds of all *Out Among the Dragons* ticket sales will be donated to the Hemophilia Foundation of Illinois.

Dan Noonan (Playwright) is a native of Skokie and attended high school at Loyola Academy in Wilmette, studied playwriting and acting at the Abbey Theater in Dublin, earned his BA in Theater and Political Science from Boston College, and his MA in Theater from Northwestern University. In 1998, Noonan was accepted to the Carnegie Mellon MFA in Dramatic Writing. Today, Noonan is a Public Health Administrator at the Chicago Department of Public Health, STD/HIV/AIDS Public Policy and Programs. He specializes in Title 1 Care Services, a program funded by the Ryan White Care Act, which provides services to people who have contracted HIV. His other plays include *Set Up* (staged readings at the Chicago Cultural Center by The Playwright's Collective, and Chicago Dramatists), *Bountiful Gifts* (readings at Circle Theater, Victory Gardens, and SART Repertory Theatre in Asheville, NC), and *Being in Touch* (readings at Victory Gardens and the Goodman.) His awards include Winner, Agnes Nixon Playwriting Competition, Northwestern University; Finalist, SART Repertory Theatre Playwriting Festival; and Semifinalist, Ukiah Comedy Playwriting Competition. His screenplay *Poetry and Showtunes*, a semifinalist in Chesterfield's Screenwriter's Competition in Los Angeles, was optioned by Hyperion Entertainment. He currently lives in Chicago's Rogers Park neighborhood, is married, and the proud father of an 18-month-old son.

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R2 KIT: CUSTOMIZED CARE FEATURES^{1,2}

- Prefilled diluent syringe

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- Simplifies preparation
- Needle-less reconstitution



- Fewer components

- All vials of ReFacto®, including the **2000 IU vial**, now come with the R2 Kit
- If you would like more information about hemophilia, log on to www.hemophiliavillage.com

ReFacto® is indicated for the control and prevention of hemorrhagic episodes and for surgical and short-term routine prophylaxis in patients with hemophilia A. The effect of regular routine prophylaxis on long-term morbidity and mortality is unknown.

As with the intravenous administration of any protein product, adverse reactions may include headache, fever, chills, flushing, nausea, vomiting, tiredness, or symptoms of allergic reactions. The remote possibility exists for hypersensitivity to non-human mammalian proteins.

Please see brief summary of Prescribing Information on the following page.

References: 1. ReFacto® Prescribing Information. Wyeth Pharmaceuticals Inc., Philadelphia, Pa.
2. Data on file, Wyeth Pharmaceuticals Inc.

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 **ReFacto®**
Antihemophilic Factor
(Recombinant)

HIS LIFE. HIS THERAPY.



Matrix Health is proud to sponsor and support Out Among The Dragons, a play written by Dan Noonan.

Please join us to an evening out, including the play and dinner at no cost to you. Matrix Health is inviting those that have been touched by hemophilia to experience this funny and touching play and have a great dinner afterward. Dan Noonan will join us for dinner, giving everyone an opportunity to talk with him about the play.

If you would like to join us at the Sunday, June 26 show at 2:30p.m. with dinner following, please contact the Hemophilia Foundation of Illinois office (312) 427-1495, and let them know. There are a limited number of tickets being offered on a first come, first served basis, so please call right away.

We look forward to having you join us.

Articles and Publications Received

Gene therapy completely corrects hemophilia in laboratory animals, 4/19/05, Washington University in St. Louis [www.wustl.edu]	04-05-01
Student Looks For Cell Damage in Use of Hydrogels To Repair Injured Cartilage, 4/19/05, Johns Hopkins U. [www..sciencedaily.com]	04-05-02
Bleeding Disorders and Pregnancy, NHF Hemaware, May/June 2005 Vol 10, Issue 3 [www.hemophilia.org]	04-05-03
Hemophilia Outlook, Spring 2005, Hemophilia Association of NY	04-05-04
HIV Notebook, Spring 2005, Hemophilia Association of NY	04-05-05
The Ninth Annual HIV Drug Guide, Positively Aware, January/February 2005 [www.tpan.com]	04-05-06
COTT Washington Update, April 2005 [www.cott1.org]	04-05-07
Bloodstone Magazine Spring 2005	04-05-08
The Artery, Spring 2005, Hemophilia Foundation of Michigan [www.hfmich.org]	04-05-09
Bleeding Times, Vol. 2 May 2005, CBDC [www.hemophilia-ctr-peoria.com]	04-05-10

Save The Date

June 7	Family Education Day at the Zoo Registrations Due	
June 13	Camp Applications and Medical Forms Due	
June 18	HFI Annual Meeting, Family Education Day	Brookfield Zoo
July 21-23	Camp Training for Junior Counselors /Staff	Camp White Eagle
July 24-30	Camp Warren Jyrch	Camp White Eagle
August 19	HFI Wine Dinner /Auction	Oak Brook Tennis Club
August	Southern Illinois Family Symposium	TBD
September 21	Annual Golf Outing	Cantigny Golf Course

Hemophilia Foundation of Illinois
332 S. Michigan Ave., Suite 1135
Chicago, IL 60604-4419

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