



# FACTOR-NET

Spring



2009

## Hemophilia Foundation of Illinois

### On the Inside:

- A Spring Gala Recap  
Gala Pictures
- A Message from our Board  
President
- A Brief History of Hemophilia  
Treatment (Part1)
- The Importance of  
Comprehensive Care
- Recession Proofing Your  
Healthcare
- News You Can Use
- Advocacy 101
- Thriving with HVC
- Caring for the Caregiver
- Transitions: Your First Job
- Scholarships Available
- Why Bob Goes to Camp and  
Camp Info



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### HFI HOT BUTTON

2009 kicks off the 60<sup>th</sup> year that the Hemophilia Foundation of Illinois has been in existence for the Illinois bleeding disorder community. I didn't really grasp the depth of this milestone until I began looking at the history of our disorder. While hemophilia has been recognized and somewhat understood for centuries, effective treatments were virtually non-existence

before very long ago.

I have had the pleasure recently to speak to some of our founding families. It is amazing the foresight these people had into the needs of the bleeding disorder community. While treatment has changed exponentially during this time – many of these people remember whole blood transfusions being the only option available – the cornerstones for our founding remain solid today. We were founded to provide education, advocacy and support and remain strong and dedicated to this as we move into the next chapter in our history.

Before we move forward I ask you to join me in an effort to protect a linchpin in our services – the state Hemophilia Program. Governor Quinn, faced with significant state deficits, presented a budget that recommends cutting the state program by \$700,000. Working with our administrators we had taken the policy position to not ask for an increase this year, but a cut of this size can cause drastic effects. In addition to the people who already depend on this resource we anticipate that there will be more people in our community who need to access it because of the downturned economy.

A group of nearly 50 representatives from the community went to Springfield on March 17. We met with nearly 60 legislators and talked about the importance of this program. This was before the draft FY 2010 budget was released so we did not know what funding was being proposed. Since these visits we have re-contacted those elected officials, asking them to re-instate this \$700,000 during the budget deliberation. We need you to help also. There is a draft letter on the HFI web site. Take a few minutes and personalize it – include why this program is important to you – and then send it to your Senator and Representative. The more letters they receive from us the better. If you need any help with this please contact the office and we will be glad to help.



While we are on advocacy, there is a piece of federal legislation being considered again this year that will greatly aid our community. S. 442/H.R. 1035 will increase lifetime caps on health insurance. The current million dollars cap has not been changed since the 1970s and as many of you can attest is not adequate. There are sample letters on the National Hemophilia Foundation's web site ([www.hemophilia.org](http://www.hemophilia.org)) for you to send to your national Senator and Representative. It is especially important if you have capped out of insurance and/or getting close to a cap that you write to these decision-makers sharing with them how this has affected you and your family.

*continued on Page 2*





## A Message from the Board President

Hi Everyone!!

Advocacy for ourselves and for our community is always one of our most important duties. I want to take a few moments to encourage each and every one of you to find your voice and get involved in HFI's efforts. Our economy, healthcare worries, new government priorities and challenging personal issues have made advocacy even more important.

We are working on a two very important issues right now. Earlier this year, federal legislation was re-introduced into the House of Representatives to increase lifetime caps on insurance. This is our second year to have this considered and there is great hope that it will go further. A strong contingency from Illinois participated in NHF's Washington Days to promote this important legislation to our Senators and Representatives. I had the opportunity to take part in this event and it was amazing to share our stories with our elected officials.

In Illinois, we are working to make sure that funding remains strong for the state Hemophilia program. Nearly 50 of your compatriots took part in our own Legislative Day on March 17. The message that was shared with more than 60 legislators was to support funding of the program at the FY 2009 level in the new budget. We learned the next day when Governor Quinn released his budget that he was recommending cutting the program by \$700,000 – not good.

So my request of everyone is to make advocacy part of your everyday life. Both of these issues are very important to the Illinois bleeding disorder community. Please make it a priority to contact your elected officials – federal to support the increased cap legislation and state to fund the Illinois state hemophilia program at the current level. There are letters on the HFI web site to support you doing this. If you need help in identifying your legislators one of the best resources is the following web site: <http://capwiz.com/hemophilia/home/>. If you do not have access to the internet call the HFI office and our staff will be glad to help.

You and I have the power to influence everyone from your dog catcher to the President. Please use this privilege. I look forward to celebrating our successes with you in the near future.

We are strong if we work together for the benefit of all.

Salvatore LiVolsi—President HFI Board of Directors



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Do you randomly search for information, hunt for a recipe, Google friends for fun? If you, or your kids, or your mother does: Here's an easy way to raise money for your favorite cause:

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NET FACTOR READERSHIP:	1300
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	= \$39.00 a day
	\$39.00 per day x 30 days in a month is <u>\$1170.00</u>
	and <b>THAT SENDS A KID TO CAMP</b>

Here's the web site — <http://www.goodsearch.com>.

You can also read about this in the New York Times, Wall Street Journal, CNN and Oprah.

# Spring Gala twenty

On March 7th, friends of the Foundation gathered for our 20th Annual Spring Gala, held in the elegant ballroom of the Chicago Marriott O'Hare. Over 300 stylishly dressed guests were in attendance. The atmosphere was enchanting with the silent auction items creatively displayed and highly coveted by the guests. Glenn Fladeboe, from Fladeboe Auctions in Minneapolis was once again our live auctioneer. He entertained and enticed the crowd to bid on the premier live auction items and to solicit campership donations for Camp Warren Jyrch. HFI Board President, Sal LiVolsi and Gisele Mills, a mother whose son has hemophilia, shared their moving stories of how HFI has impacted their lives before guests again showed their generosity by pledging \$65,00 in camperships for Camp Warren Jyrch. The entire evening raised nearly \$120,000 to help us continue to provide services to our community for hopefully another 60 years. We would like to again thank all of our guests, sponsors and contributing businesses for their continued support of our organization and the people we serve.

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# 20th Annual Spring Gala



twenty

Spring Gala

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### In Memory of Dolalene Hesse

Maurice A. Hesse

### In Memory of John Speedwell

Sharon Speedwell

*This is the 60th Anniversary of the Hemophilia Foundation of Illinois. We will be celebrating throughout the year recognizing how far we have come while also envisioning where our future will take us. We take this opportunity to review just how far identification and treatment have come:*

## The Face of Bleeding Disorder Treatment Before the 21st Century

The history of hemophilia (and additional bleeding disorders that have been identified as medical research and funding have improved) have a clouded and secretive history. Reference to a condition which caused death from bleeding after circumcision in male infants was noted in both Jewish and Islamic religious and 'medical' texts as early as the 2<sup>nd</sup> century, additional vague mention is made in similar texts through the 18<sup>th</sup> century (1700's). Actual identification and treatment attempts were not made until the early 19<sup>th</sup> century. The term hemophilia (haemophilia) was first coined by German physician Schoenlein in the early 1800's. Schoenlein also suggested using some form of transfusion as a treatment. Sporadic forays into studying blood clotting times and treatment options were made throughout this century.



"The Dismal Era" as this time frame is often referred to, continued into the 20<sup>th</sup> century. However, a more open and focused attempt at diagnoses and treatment began when hemophilia was identified in the British royal family and was passed on as the royal family married into the Russian, Prussian and Spanish monarchies. The 20<sup>th</sup> century dawned dim, but with a light at the end of the tunnel. The first major historical/medical research was done and released, tracking hemophilia through history and setting a clearly defined standard of diagnosis based on "a triad of symptoms, sex incidence and inheritance" (Blood Saga, Resnik, pg. 14). Research was making major advances in understand blood functions and a myriad of treatments were being attempted. Throughout the 1920's & 1930's, the United States and England published guidelines for doctors to identify and treat hemophilia. Many treatments were as dangerous and painful as the disease itself, but patients and families were willing to sacrifice and endure in attempts to end their isolation, suffering and attempt to lead 'normal' lives.

Several men living through this time period reflected on the varying approaches taken by both their doctors and families in attempting to treat and maintain a positive quality of life for their patient and child. The men remembered missing a great deal of school and spending large amounts of time in the hospital for transfusions. They recounted treatments that included eating vast amounts of peanut butter, forced drinking of cod liver oil and poisonous snake venom either injected into gums or applied through the skin to increase clotting. While all of the remedies proved ineffective it reflects the approaches at the time. Family attitudes varied as widely as well. Some parents severely limited their child from any activity. Frank Schnabel, who founded the Canadian Hemophilia Society and the World Federation of Hemophilia recounts his mother striking a compromise that he could do anything the other children could, just a little less. "I might not have climbed as high in a tree as my friends, but I climbed, I jumped off a fence but not a roof" (Blood Saga, Resnik, pg. 18) His diary through this time reads as a healthy boy but is punctuated with references to bleeding gums from a loose tooth, nosebleeds, soreness from playing sports and transfusions that interrupted his childhood.

World War II changed the entire world, and as in every other aspect of modern life, it changed the research and treatment of hemophilia. The use of plasma and albumin to treat the wounded on the front lines of battle showing increased survival, post war funding and research for blood product and blood related illnesses exploded. Scientific and medical research, were no longer viewed as frivolous and the United States Government began to pour funding into academia. In the past, government monies were mostly dedicated to research of farming and husbandry, those things which affected our agrarian based society. Academic research such as medicine was funded through private individuals and foundations. Research into identification and treatment of hemophilia had been continuing, but with federal funding through the newly formed National Institutes of Health and with the focused advocacy of the newly formed National Hemophilia Foundation in 1948, the information and viable treatment options expanded exponentially.

This brings us to the formation of the Hemophilia Foundation Illinois. In our next issue we will look at the establishment of HFI and how the Foundation and the treatment of bleeding disorders have changed and grown to now.

## Comprehensive Care—Why It is So Important

The HFI strongly encourages all newly diagnosed families to enter comprehensive care at a federally funded treatment center as soon as possible. Bleeding disorders are a relatively rare but complex in terms of diagnosis and management. Managing a bleeding disorder requires more than the treatment and prevention of acute bleeding. At present, even in developed nations, a standardized set of guidelines is not formalized.

Recently in an endeavor to develop a comprehensive standard of care and treatment of bleeding disorders internationally, the World Hemophilia Federation has gathered an international panel of treatment experts and they have developed a publication called 'Guidelines for the Management of Hemophilia'. Following is an excerpt from that publication regarding comprehensive care.

### Guidelines for the Management of Hemophilia

*Keys to improvement of health and quality of life include:*

- Prevention of bleeding;
- Long-term management of joint and muscle damage and other sequelae of bleeding;
- Management of complications from treatment including:
  - Inhibitor development; and
  - Viral infection(s) transmitted through blood products requiring long-term management.

#### *Comprehensive Care*

These management goals are best met by a team of healthcare professionals providing comprehensive care. Hemophilia patients should ideally be managed in a comprehensive care centre staffed by the following core team members:

- Hematologist(s);
- Nurse coordinator;
- Physiotherapist; and
- Social worker.

These staff members should have expertise and experience in treating bleeding disorders. The core team members should have access to the following support resources:

- A coagulation laboratory capable of clotting factor assays and inhibitor detection;
- Appropriate clotting factor concentrates, either plasma derived or recombinant; and
- If clotting factor concentrates are not available, a blood bank with expertise in preparing fresh frozen plasma (FFP) and cryoprecipitate.

Specialists should be available as consultants, as needed, and should include, among others, the following:

- Orthopedic surgeon;
- Physiatrist/rheumatologist;
- Occupational therapist;
- Dentist;
- Geneticist;
- Hepatologist;
- Infectious disease specialist; and
- Immunologist.

In centers where there are many patients with chronic musculoskeletal problems from frequent bleeding, an orthopedic surgeon should be a core team member. Additional specialists could also be members of the core team, depending on the needs of the patient population served.



*Comprehensive Care cont...*

*Functions of comprehensive care program*

- To provide or coordinate care and services to patients and family:
  - Patients should be seen by all team members at least yearly (children every 6 months) and a comprehensive management plan should be communicated to the patient and all treatment personnel.
  - Smaller centers and personal physicians can provide day-to-day care in coordination and consultation with the comprehensive care centre, particularly for patients who live a long distance from the nearest hemophilia treatment centre.

*Communication is important.*

- To provide education to patients and family members (parents, spouse, children, and others), other healthcare workers, schools, and the workplace to ensure that the needs of the person with hemophilia are met.
- To conduct research to further our knowledge and improve the management of this condition. Because the number of patients in each centre may be limited, clinical research could best be conducted in collaboration with other hemophilia centers.
- Documentation of the treatment given and measurement of long-term outcome, particularly with reference to musculoskeletal function, is very important.

*The Family*

Since hemophilia is a lifelong condition, requires expensive treatment, and can be life threatening, it significantly affects many aspects of family life. It is, therefore, important that parents, spouses, and other family members are educated, supportive, and active participants in all aspects of the patient's care. The comprehensive care team should have the resources to support family members of a person with hemophilia. This may include identifying resources and strategies to help cope with:

- Risks and problems of everyday living, particularly with management of bleeding;
- Changes during different stages of the patient's growth and development;
- Issues regarding schooling and employment; and
- Risk of another affected child and the options available.

This is accomplished through education and counseling, as well as identifying and using community resources. All family members are encouraged to become involved with the comprehensive care team in order to best meet the needs of the patient.

Hopefully, this will encourage newly diagnosed families to seek comprehensive care as soon after diagnosis as possible, and to make informed decisions regarding treatment center options. Following is a list of Hemophilia Treatment Centers serving the Illinois Bleeding Disorder Community:

Northwestern University Hematology/Oncology Department 676 North Saint Clair, Suite 850 Chicago, IL 60611 Phone: (312) 695-4041 Fax: (312) 695-4530	Stroger Hospital of Cook County 900 West Polk Street, Administration Bld, Room 1151 Dept. of Pediatric Hematology Chicago, IL 60612 Phone: (312) 864-4167 Fax: (312) 864-9002 Se habla español.
Children's Memorial Hospital 2300 Children's Plaza, Box 30 Chicago, IL 60614 Phone: (773) 880-3393 Fax: (773) 880-6989 Se habla español.	Rush Children's Hospital 1653 W. Congress Pkwy Chicago, IL 60612 Phone: (312) 942-6747 Fax: (312) 942-8975
Comprehensive Bleeding Disorders Center 4727 N Sheridan Road Peoria, IL 61614 Phone: (309) 688-1345 Fax: (309) 688-0917	The John Bouhasin Center for Children with Bleeding Disorders, Saint Louis Univ. Dept of Pediatrics 1465 South Grand Blvd. St. Louis, MO 63104 Phone: (314) 577-5332 Fax: (314) 577-5309

## Recession Proofing Your Healthcare

On February 7, 2009 HFI hosted a workshop on how the current economy is affecting the bleeding disorder community and what we can do to protect ourselves now and in the future. Currently the United States is facing the worst recession since the Great Depression. We are seeing massive layoff from major corporations and smaller businesses closing completely. This means fewer workers producing fewer goods and services and Americans spending less. The U.S. deficit has now hit \$1 trillion dollars and 43 states including Illinois are facing major budget short falls. Housing values are estimated to drop by 14%.

One of the main effects of the unemployment rate being at its highest in 15 years is the loss of healthcare benefits for many families. The cost of COBRA (the portable healthcare provision) is unaffordable for most unemployed individuals. There are waiting lists or time constraints for all or most state and federally funded assistance programs. These two factors combine to leave most newly unemployed individuals with no health or prescription drug coverage.

The healthcare system has often been considered recession proof because people always will become ill and need care but according to the March 2008 issue of Business Week magazine, "Contrary to accepted wisdom, the recession is likely to cause, an estimated 5 to 10 million people to lose their health insurance who will be older and more obese than in past recessions. People with high deductibles will delay payment for care received, doctors and hospitals will be forced to absorb the resulting bad debt and primary and preventive care will be delayed. There will be an increase in bankruptcies due to medical debt.

The economic recovery plan proposed by President Obama has been passed by both the House and Senate and will be signed and in effect by the time this is published. The plan is far reaching and will affect all Americans in one form or another. It provided for saving or creating up to 8 million jobs over the next three(3) years, assists states with their budget shortfalls, increases and extends unemployment benefits, provides tax cuts and incentives for both individuals and businesses, invests in our national infrastructure and assist with higher education funding. In relation to healthcare, the economic recovery plan provides for expanded federal coverage for the unemployed, low income and part-time workers. Additional subsidies will be provided for COBRA, Medicaid and transitional medical assistance.

So, what does this mean for the bleeding disorder community? It is imperative that we maintain access to insurance and prescription coverage, this can be done using COBRA, the public assistance programs such as All Kids, Family Care, ICHIP, the pharmaceutical assistance program or by transferring to a spouses insurance plan. Most of these programs take time to apply and go into affect; it may be prudent to look into them now even if you are not in immediate need.

There are also some suggestions that can reduce the necessity of needing to access care outside of chronic or acute issues and reduce costs. You can:

### Maintain General Health:

- Eat a healthy diet including, fruit, vegetables and whole grains
  - Garden to keep healthy food available and reduce costs, it's also good exercise
  - Exercise regularly
  - Get adequate sleep
  - Reduce stress
- If sick or healing from injury or surgery, STAY HOME so you can rest and heal.

### Track Medications Costs:

- Take your medications as prescribed, to avoid a reoccurrence or becoming sick.
- Buy medications in bulk.
- Some medications are less expensive when a higher dosage is purchased and pills are split.
- Buy generic brands, when feasible.

### Comparison shop

Walmart \$4 List  
Meijers

- Enroll in your pharmacy discount programs.
- Don't be afraid to ask what a medication costs before you present your prescription.

Investigate and enroll in pharmaceutical manufacturer programs, coupons, etc.



Ask us a Question!

Got a Question related to a Bleeding Disorder Issue?

Send it to HFI and we will ask a variety of experts to offer answers, ideas and suggestions.

Check out the Summer Factor Net

- Oversee Medical Costs and Advocate for Reasonable Costs
- Negotiate with Doctors and Hospitals
- They will fare better negotiating discounts with you than they will if they have to write off your entire bill.
- Take advantage of free or reduced-cost services
- Health Department Immunizations
- Flu shots
- School and sports physicals offered by sports leagues, schools, etc.
- Health Fairs
- Ask for itemized bill from providers, including hospitals

Appeal any discrepancies found on provider billings or insurance Explanations of Benefits (EOB)

#### Know Your Insurance Policy:

- What are the co-pays and/or coinsurance for:
- Inpatient stays and Professional Services
- Hospital outpatient/Ambulatory Surgical services
- Doctor's office visits
- Preventative care?
- Diagnostic Lab and x-ray tests
- Preventative lab and x-ray tests
- From whom can I get my care?
- How much "shopping" am I free to do?
- Hospital
- Physician
- Specialists
- Pharmacies
- Are Emergency Room Visits Covered?
- How is "emergency" defined?
- What are the family and individual deductibles?
- Are there separate limits, deductibles, or co-payments/coinsurance for Prescription coverage?
- Do all deductibles, co-payments, and coinsurance amounts apply to the out-of-pocket maximums?
- Are there limits to the number of covered visits for certain services?
- Are there coverage (\$) limits for certain services?
- Are conditions excluded?
- Is the Plan automatically renewable?
- Is there a waiting period before coverage begins?
- How are Replacement Clotting Factor claims paid?
- As a medical benefit or pharmacy benefit?
- Coinsurance/Co-payments?
- Assessing Your Choices
- What types of plans are available?
- Which plans are the most affordable?
- Which plans best meet my needs and the needs of my family?

- Which plans are the most recession proof?
- Traditional Indemnity Plans
- Reimburse enrollees for covered expenses incurred due to sickness or injury.
  - Expenses are reimbursed after **coinsurance** (percentage share of cost for which the enrollee is responsible) and **deductible** (annual amount of out-of-pocket that must be paid by enrollee before benefits begin) amounts are met.
- Preferred Provider Organizations (PPOs)
- Payment mechanism is the same as traditional indemnity.
- Expenses are reimbursed after coinsurance and deductible amounts are met.
  - Coinsurance is higher when out-of-network.
  - No referral process is required.
- Health Maintenance Organizations (HMOs)
- Enrollees must choose a physician as their primary care physician (PCP).
  - Founded on the premise that covering preventive care while controlling costs will result in better health care and lower rates of health care inflation.

PCP is the "Gatekeeper" for all medical services.

#### Other Considerations:

Premium amounts vs. choice.

Will premium savings be neutralized by more costly factor or other services?

Will premium savings be neutralized by out-of-pocket expenses?

Will premium savings be worth giving up providers with whom I am comfortable?

#### Know Your Rights

Appeal any Discrepancies to:

Internal Grievance Procedure – all insurers are required by law to have a procedure.

External Grievance Procedure – If internal procedure does not resolve problem.

Illinois Department of Insurance, [www.idfpr.com/DOI](http://www.idfpr.com/DOI)

Department of Labor – Self-funded ERISA plans,

[www.dol.gov/ebsa](http://www.dol.gov/ebsa).

Recession-Proof Summary

Maintain Your Health

Comparison Shop

Use cost-saving techniques

Negotiate bills when necessary

Know your insurance policy

Appeal any discrepancies

Know your rights

Investigate other coverage options

Stay abreast of federal legislation



## Hemophilia Treatment Program

Illinois Governor Pat Quinn released his budget proposal for 2010. The Hemophilia Treatment Program was allocated money again this year. The money committed was less than we had last year, we are asking members of the bleeding disorder community to send a letter to the Illinois State Senator and Representative in Springfield asking that they support allocating more money so that the money available in 2010 is the same amount of money as was available in 2009. We are aware in these tough economic times that it is highly unlikely that we would get more money than in the past, but we certainly need the same amount. One of the reasons the Hemophilia Treatment Program received less funds was that on paper it looked as if all the 2009 money had not been spent. That is not accurate and the letter will explain that.

If you would like a sample letter to send, please check the HFI web site. We have a sample letter that you can put your Congressman's name and your name on and send right out. You can locate your local representatives by going to the National Hemophilia Web site, click on Advocacy Center>Get Involved and follow the directions under contact your state and local representatives. The representatives' name, address and/or email address will be available. Also, if you hear back from your representative, please let us here at HFI know by sending us a copy of the letter or e-mail you receive. By working together, we can meet the needs of the entire community.



### COBRA Premium Assistance Affects Employees and Employers

The American Recovery and Reinvestment Act (the Act) provides COBRA premium assistance, which offers a temporary 65% reduction in COBRA premiums for eligible beneficiaries. This new provision will affect former employees receiving or eligible to receive COBRA health insurance coverage and their families, as well as employers.

COBRA is a federal law that allows employees, their spouses, and dependent children who lose health insurance benefits due to involuntary termination of employment to elect to continue that coverage for up to 18 months. Qualified beneficiaries are obligated to pay up to the full cost of coverage plus a 2% administrative fee. However, under the COBRA premium assistance provisions, the employee's cost of COBRA insurance premiums is reduced to 35% of the total premium cost, including the 2% administrative fee. However, if the employer pays any portion of the premium, no subsidy is payable on that portion.

The COBRA premium reduction is available to assistance-eligible individuals (AEIs). These include the employee (and members of his or her family) whose employment is involuntarily terminated between (and including) September 1, 2008 and December 31, 2009, and is otherwise eligible for, and elects COBRA continuation coverage. The coverage subsidy is payable for a maximum of 9 months and is not available prior to February 17, 2009. There are additional provisions. Check the HFI website for more details.

### ILLINOIS LEGISLATORS UPDATE INSURANCE ACT

The Illinois State Legislature approved and the Governor signed Public Act 095-0958 on July 1, 2008. It included several positive changes to the Illinois Insurance Act of 1971 that will benefit our community. First, it extends coverage of unmarried dependants on policies to age 26. Coverage on plans cannot be terminated or denied on these dependants. Also, health insurance plan providers will be required to continue coverage for dependant college students for twelve (12) months if they have to take a medical leave or reduce their course load to part time due to a catastrophic illness or injury. The twelve months begins with notification to the provider of the status change. Just so you know, this Act also includes mastectomy aftercare as a requirement under health and injury policies. All of these changes go into effect on June 1, 2009.



Our nation is focused on righting itself from its economic downturn and with new leadership in Washington addressing education and healthcare issues that are also effected by our economy, HFI is striving to prepare the bleeding disorder community to speak for itself and use its expertise in dealing with chronic illnesses to assure the needs of our community are met. Many of our community members have attended Washington Days and the Illinois Legislative Advocacy Day using the following resource to prepare. Keep this handy if you need or want to talk with your governmental leaders, whether national, state or local about the needs of the bleeding disorder community. And, as always, if you need assistance, HFI is only a call or click away.

## Advocacy 101



Grassroots advocacy is the systematic effort to affect public policy by influencing the views of policy-makers whether in a state legislature, city council. Government agency, or anywhere decisions are made that affect citizens and businesses. Grassroots advocacy is nothing more than the organized and intensive exercise of a citizen's constitutional right to petition the government. In fact, grassroots advocacy makes an important contribution to effective and responsive government by making vital information available to public officials who cannot possibly know the full impact of every law and regulation that comes before them.

It is crucial to remember that *all* legislators—on the federal, state, and local levels—are politicians whose continued success depends on their ability to satisfy voting constituents. Re-election, recognition, and status are powerful motivators. Effective grassroots advocacy can wield as much influence on these outcomes as the biggest corporation or trade association.” (LSN.com)

We have spent the last year hearing about the grassroots movement that elected a president. A group of citizens connected around a common goal, individually they did not have a great deal of time, money or influence, but banded together with direction, and combining their resources of time, money, or influence towards a common goal, they changed a nation and potentially the entire world. This same technique can be used to influence our peers and our leaders regarding a common cause. HFI and our constituents will be looking at a number of issues that affect the bleeding disorder community over the next few years and with your guidance regarding priorities we will be putting our time, money and influence into providing direction to the grassroots, the bleeding disorder community, to influence our peers and leaders to support our common needs and goals.

The next two(2) years we will see a move towards providing comprehensive healthcare in some manner for all Americans. As this plan takes shape the special needs of the bleeding disorder community needs to be heard loud and in one voice to ensure the appropriate comprehensive care to meet our long term needs. Our recent seminar on “Recession Proofing Our Healthcare” also provided the basics of community advocacy and is the first in a series of trainings that will be available in a variety of forums so that each individual can join the one voice to meet our goals.

In the past Advocacy was viewed differently than it is today. It was perfected by people often called lobbyists who promoted their cause fulltime, with a large funding source that attempted to influence government officials to pass laws that benefited their employer. These advocates were often, a lawyer or political operative, were forceful and sometimes demanding, and communicated in a clear and compelling manner. They often name dropped names and knew everyone, everywhere they went. This form of advocacy still exists, but it has fallen from favor. Today, groups and individuals have taken the most effective techniques and used them to educate government officials on the specialized needs of specialized groups and to effect great change.



Access                      Choice                      Education

## Advocacy 101 cont...

An Advocate is defined as “One that argues for a cause; a supporter or defender”

There are three main types of Advocacy:

**Individual** – helping people understand their rights under federal and state laws, helping individuals resolve situations with employers, insurers, schools, community programs or other issues

**Grassroots Advocacy**- involving individuals with Hemophilia, family members and interested individuals in advancing the community’s goals

**Legislative/Regulatory Advocacy**- working to change a law or regulation to make it more favorable for people with Hemophilia.

**Legislative/Regulatory Advocacy** involves the law and the impact of a new law or regulation, or to change a current law or regulation in Illinois and/or in Washington, DC.

### Examples of Federal Legislative/Regulatory Advocacy Issues:

Increasing Medicare Reimbursement for Hemophilia Therapies

Removing LIFETIME CAPs on Health Insurance Policies

### Examples of State Legislative/Regulatory Advocacy Issues:

Medicaid Reimbursement Challenges that Impact Open Access to All Hemophilia Therapies

SUPPORTING funding for IL’s Hemophilia Care Program which supports Hemophilia patients.

How do we as individuals go about working as a Legislative/Regulatory Advocate?

- ✦ Develop Relationship with Your Officials and Administrators
- ✦ Share Your Story
- ✦ Who you are
- ✦ Share your experience with Hemophilia
- ✦ How a policy/law will affect you
- ✦ Know where they stand on your issue
- ✦ Set up a meeting to introduce yourself and make them aware of your personal experience with Hemophilia
- ✦ Provide them with accurate and current information
- Follow-Up
- ✦ Know Your Officials and Administrators and Communicate Effectively with Them:
- ✦ Personal Visit
- ✦ Letters
- ✦ Phone calls
- ✦ E-mail
- ✦ Letters to the Editor and/or OP ED pieces
- ✦ Paid Media – newspaper, radio or TV advertising
- ✦ Golden Rules to Effective Advocacy Communication
- ✦ Be Prepared
- ✦ Be Honest
- ✦ Know Your Subject
- ✦ Know Your Opponent/s and Their Position
- ✦ Know Your Proponent/s and Their Position
- ✦ Know Your Time Constraints/Deadlines
- ✦ Know When to Pull Away

In the coming months, HFI will be setting up an official advocacy project that will provide, training, information and opportunities for advocacy outreach to both state and federal leaders. Each individual connected with the bleeding disorder community is needed to join with others to gather support from those around them and communicate for the our needs with our leaders. Join the grassroots movement to be a Legislative/Regulatory Advocate.

### Volunteers Needed

Volunteers are needed for input on new Emergency/Preparedness Tools. RTI Intl. is conducting discussions for the American Thrombosis and Hemostasis Network under a grant funded by the CDCs. It will be a 90 minute discussion over the phone on a toll free number. Those eligible to participate are Adults over 18 years of age with a bleeding disorder and who have received care at an HTC in the last year or who have a child who has been diagnosed with a bleeding disorder for at least two (2) years and have received care at an HTC in the last year. People selected to participate will receive a \$75.00 stipend after completing the discussion. If interested contact Charlotte at RTI International toll free at 1.800.334.8571 x. 21718.

# Hepatitis C and Bleeding Disorders

We are proud to be part of a team that has developed innovative educational materials meant to help those in our community who have been infected with the hepatitis c virus. The intent of this project is to assist these individuals in managing the virus' health impact and improve or extend their quality of life. Additionally, the project wants to educate consumers and their support systems to encourage and affirm positive health behavior changes and choices. We have conducted workshops addressing this issue in the past and will be continuing to provide information at our various gatherings throughout this year. We will also design a little survey to help us determine if our information is making out there into our community.

HFI sees Hepatitis C (HVC) as one of the major potential killers of those living with a bleeding disorder. As discussed in our article "The Face of Bleeding Disorder Treatment in the 21<sup>st</sup> Century", the options for treatment and improved quality of life with a chronic bleeding disorder is improving on almost a daily basis. It is now time to look at the secondary infections or threats to our long term survival. We lost many in the days before we understood and could prevent HIV infection though screening and protection. The more learned about HIV, the longer we can maintain a positive quality of life being dueling infected. We now know much about HVC, and can screen, prevent and better live with dual infection, using many of the same techniques.

## Overview

### What is hepatitis?

"Hepatitis" means inflammation of the liver. Toxins, certain drugs, some diseases, heavy alcohol use, and bacterial and viral infections can all cause hepatitis. Hepatitis is also the name of a family of viral infections that affect the liver; the most common types are hepatitis A, hepatitis B, and hepatitis C.

### What is the difference between hepatitis A, hepatitis B, and hepatitis C?

Hepatitis A, hepatitis B and hepatitis C are diseases caused by three different viruses. Although each can cause similar symptoms, they have different modes of transmission and can affect the liver differently. Hepatitis A appears only as an acute or newly occurring infection and does not become chronic. People with hepatitis A usually improve without treatment. Hepatitis B and hepatitis C can also begin as acute infections, but in some people, the virus remains in the body, resulting in chronic disease and long-term liver problems. There are vaccines to prevent hepatitis A and B; however, there is not one for hepatitis C. If a person has had one type of viral hepatitis in the past, it is still possible to get the other types.

### What is hepatitis C?

Hepatitis C is a contagious liver disease that ranges in severity from a mild illness lasting a few weeks to a serious, lifelong illness that attacks the liver. It results from infection with the hepatitis C virus (HCV), which is spread primarily through contact with the blood of an infected person. Hepatitis C can be either "acute" or "chronic."

**Acute hepatitis C virus infection** is a short-term illness that occurs within the first 6 months after someone is exposed to the hepatitis C virus. For most people, acute infection leads to chronic infection.

**Chronic hepatitis C virus infection** is a long-term illness that occurs when the hepatitis C virus remains in a person's body. Hepatitis C virus infection can last a lifetime and lead to serious liver problems, including cirrhosis (scarring of the liver) or liver cancer.

## Symptoms

### What are the symptoms of acute hepatitis C?

Approximately 70%–80% of people with acute hepatitis C do not have any symptoms. Some people, however, can have mild to severe symptoms soon after being infected, including

- Fever
- Fatigue
- Loss of appetite
- Nausea
- Vomiting
- Abdominal pain
- Dark urine
- Clay-colored bowel movements
- Joint pain
- Jaundice (yellow color in the skin or eyes)



**How soon after exposure to hepatitis C do symptoms appear?**

If symptoms occur, the average time is 6–7 weeks after exposure, but this can range from 2 weeks to 6 months. However, many people infected with the hepatitis C virus do not develop symptoms.

**Can a person spread hepatitis C without having symptoms?**

Yes, even if a person with hepatitis C has no symptoms, he or she can still spread the virus to others.

**Is it possible to have hepatitis C and not know it?**

Yes, many people who are infected with the hepatitis C virus do not know they are infected because they do not look or feel sick.

**What are the symptoms of chronic hepatitis C?**

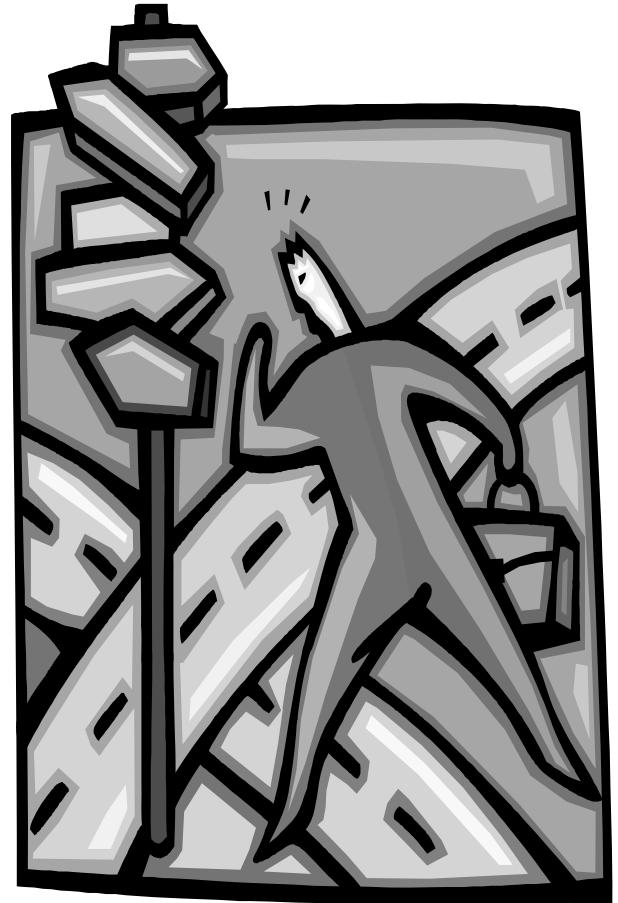
Most people with chronic hepatitis C do not have any symptoms. However, if a person has been infected for many years, his or her liver may be damaged. In many cases, there are no symptoms of the disease until liver problems have developed. In persons without symptoms, hepatitis C is often detected during routine blood tests to measure liver function and liver enzyme (protein produced by the liver) level.

**How serious is chronic hepatitis C?**

Chronic hepatitis C is a serious disease that can result in long-term health problems, including liver damage, liver failure, liver cancer, or even death. It is the leading cause of cirrhosis and liver cancer and the most common reason for liver transplantation in the United States. Approximately 8,000–10,000 people die every year from hepatitis C related liver disease.

**What are the long-term effects of hepatitis C?**

Of every 100 people infected with the hepatitis C virus, about  
75–85 people will develop chronic hepatitis C virus infection;  
of those,  
60–70 people will go on to develop chronic liver disease  
5–20 people will go on to develop cirrhosis over a period of 20–30 years  
1–5 people will die from cirrhosis or liver cancer



**How is chronic hepatitis C treated?**

Each person should discuss treatment options with a doctor who specializes in treating hepatitis. This can include some internists, family practitioners, infectious disease doctors, or hepatologists (liver specialists). People with chronic hepatitis C should be monitored regularly for signs of liver disease and evaluated for treatment. The treatment most often used for hepatitis C is a combination of two medicines, interferon and ribavirin. However, not every person with chronic hepatitis C needs or will benefit from treatment. In addition, the drugs may cause serious side effects in some patients.

We will continue to look at Living with HVC and in our next edition, we will discuss how healthy lifestyle choices, such as daily exercise, eating healthy foods, limiting alcohol and tobacco and abstaining from drugs can improve your physical, mental and spiritual well-being while managing both your bleeding disorder and your HVC infection. Please contact your doctor to discuss HCV and its treatment. If you would like a copy of the HCV educational materials HFI has developed please contact 312.427.1495.

*The greatest compliment in  
Legislative / Regulatory Advocacy  
is when a  
Legislator or Administrator  
CALLS YOU for  
YOUR expertise and comments.*

## Caring for the Caregiver\*

There are 2 sounds that you will hear when this article is read, one is the resounding “DUH” by the primary caregiver around you and hopefully, “A-HA!” as everyone who reads this finds at least one way to care for themselves or the caregiver in their world. There is a great deal of information and studies available regarding caregivers, especially of women providing care for the elderly. There has been much less focus on caregivers of children. There is one generally pervasive understanding through out all of this literature, whether related to caring for adults or children, and that is caregivers are predominately female (that would be the duh sound you just heard). The second general consensus is that care giving is stressful in a variety of ways and effects the care giver physically, mentally, and spiritually. (ditto)

Now for the “A-HA!” moments: Approximately 45 million people in the United States devote a large portion of their lives care giving for someone with a disability. Combine that with the demands of jobs, additional children and marriage, and the product is a tailor-made recipe for stress. All forms of care giving take both physical and emotional tolls on caregivers. According to their study, Shadden and DiBrezza found that caregivers reported lower ratings of overall health, higher levels of stress, and lower overall health satisfaction than non-caregivers. The biological effects of caregiver stress show increased levels of cortisol and IL-6 levels, which have been linked to heart disease and other health problems. The emotional impact of care giving can be just as strong. Shadden and DiBrezza found that many care givers are subject to feelings of increased sadness, irritability, fatigue and guilt. These feelings, if left unaddressed, can lead to chronic depression. "Because our definitions of what constitutes stress are fairly subjective, some people may be under great stress and not really be conscious of it, so they may not report being stressed." DiBrezza noted.

A University of Arkansas study asked care givers what support they need to provide care: Here's what most caregivers said they wanted:

- Access to more information and education
- The availability of professional resources
- The option of family leave time from employers



These point to the need for practical, real-world assistance to help care givers better manage their situations. Sharon O'Brien at ASK.com offers the following advice to all care givers to assist in reducing stress and increasing a care givers' overall health and balancing the needs of those in her life:

- **Accept your own limits.** As a caregiver, you don't have to do it all, and you shouldn't try. Accept that there are limits to what you can do as a caregiver. Admit when you feel overwhelmed, and ask for help.
- **Create a caregiver support team.** Before you can ask for help, you need to know who you can ask. Plan ahead for times when you'll need help by making a list of people who are willing to help you with caregiver support. Family members, friends and professional respite care workers can give you a break or help out when you can't be there. Include their phone numbers on your list, along with the times they are available and the tasks they're willing (or unwilling) to perform. Always keep a copy of the list with you; you never know when you may need to ask someone for help.
- **Get organized.** Being a caregiver can be a full-time job, even if you already have a full-time job. Make a realistic schedule with your family and friends to make sure you get the caregiver support you need; assign chores, and make sure everyone knows what to do and when to do it. This will help everyone stay organized, and it will help you, as primary caregiver, to manage the extra demands on your time.
- **Schedule time for yourself.** Don't forget to schedule time for activities you enjoy. There are more important things than doing the laundry, and caregiver support is one of them. Remember, this is about staying healthy in mind and body, so you need to make time to have fun now and then.
- **Make your own health your first priority.** This may sound selfish, but it's not. Being a caregiver is a big job, and the only way you can provide the care giving your loved one needs is to make sure you stay healthy. The kind of stress you're trying to manage every day can easily lead to depression; staying fit and healthy can help you cope, reduce stress, and make it easier to get through tough days when they come.
- **Eat a balanced diet.** This is vital to good long-term health, and it shouldn't be hard to manage. Chances are the person you're caring for has been ordered to eat well, and you're probably preparing and/or sharing many of those meals.
- **Get plenty of rest.** Try to get the requisite eight hours every night. If you're short on sleep because your caregiver duties require you to be up and down during the night, take naps the following day when your loved one is sleeping.



*Continued in the ad section...*

## Be Honest. Just Not Too Honest.

by Kevin Correa

Your first job interview. You stayed up late last night researching the company on the Internet. This morning you retied your tie three times until it was perfect. You remembered to offer a firm handshake and maintain eye contact. So far so good. The interviewer seems to like you and even says she thinks you'd be a good fit for the position. And then it happens. She asks if you have a medical condition that she should know about. How should you answer? Should you lie? Is it even legal for her to ask? Unfortunately, not knowing how to maneuver through the stressful interview process is costing many young applicants with hemophilia a shot at jobs.

### **Cat Out of the Bag**

Tim Ochoa is a hemophilic young man who applied for a food service position, confident that his hemophilia would not prevent him from performing the responsibilities of the job. During his interview, Tim disclosed that he had hemophilia. Suddenly the tone of the interview changed, and Tim was asked to obtain documentation from his doctor stating that he was fit to work. As requested, Tim obtained the letter. But he did not get the job.

Being a novice and an honest applicant, Tim told a potential employer that he had hemophilia *prior* to being offered the job. Like scores of hemophilic young people, he simply wasn't prepared to address his hemophilia in an interview setting.

Bobbie Kincaid, community advocate with Acreedo's Hemophilia Health Services, said that Tim isn't alone when it comes to spilling the beans about hemophilia during an interview: "We're not doing enough to educate job seekers on the interview process." Bobbie is passionate about increasing efforts on this front because she sees firsthand the positive effect holding a job has on the lives of young people.

"Getting that first job — regardless of what it is — is an important step that starts young people with hemophilia on their way to realizing their dreams," says Bobbie. "And it's a shame when a young man is excited about a job, is a good fit for the job, and then doesn't get it because he innocently discloses that he has hemophilia."

### **Confusion Over Rights**

"There's definitely a lack of education on the subject of employment rights in the hemophilia community," observes Beth Sufian, an attorney who runs the Bleeding Disorders Legal Information Hotline. With respect to employment issues, she notes, many of the people she speaks with either don't know or have serious misconceptions about their legal rights. Of the calls Beth fields, those involving employment discrimination are surpassed only by those relating to insurance.

Many job applicants with hemophilia are at least vaguely aware that they may receive some protection under The Americans with Disabilities Act (ADA). But what they may not realize is that protection under the act is as much about the employer as it is about the applicant.

For instance, in order for a company to be covered by ADA, it must have at least fifteen employees. As for the applicant, ADA defines an individual with a disability as a person who

- has a physical or mental impairment that substantially limits one or more major life activities;
- has a record of such an impairment; or
- is regarded as having such an impairment.<sup>1</sup>

Assuming both the company and applicant are covered by ADA, then certain aspects of the act are particularly important to people with hemophilia: "Employers may not ask job applicants about the existence, nature, or severity of a disability. Applicants *may* be asked about their ability to perform specific job functions."<sup>2</sup>

In other words, an employer covered by ADA can't ask if you have a disability, but can ask if anything prevents you from doing the job for which you're interviewing. If you're asked whether anything would inhibit your ability to perform specific job functions, responding with a simple "no" is appropriate.

But the situation gets muddled if you're asked directly whether you have a medical condition the employer should know about. Legal or not, if you push back on this issue, you're likely to raise red flags. Again, your response can be simple:

"No, I don't have any condition that would prevent me from performing the job."

Once the company offers you a job, you *can* be asked questions that might reveal a disability — as long as the same questions are asked of all applicants. At this point, if you decide to disclose your hemophilia, the company cannot withdraw its offer unless it determines that your condition prevents you from performing essential job functions or that you would pose a risk of injury to yourself or others.

As you can see, the interview process can become a game of semantics. The bottom line? Be prepared. Have a response ready if the subject of hemophilia surfaces. Worst-case scenario? You're not prepared for the question, and you're caught like a deer in headlights.

### **When In Doubt, Seek Help**

The subject of discrimination in the hiring process involves complex legal issues. If you think you're a victim of discrimination, seek legal assistance and consider filing a claim with the Equal Employment Opportunity Commission (EEOC).

Bear in mind that there are time limitations for filing claims, and that legal action far from guarantees a satisfactory outcome. Obtaining representation is difficult, and according to Beth Sufian, only 3% of ADA cases are won by the employee.

If you decide to pursue legal remedies, the Bleeding Disorders Legal Information Hotline is a sound place to start. The toll-free number is (800) 520-6154.

There's no way to predict if the subject of your hemophilia will arise during a job interview. In any case, you should be prepared to address it. Handling the issue with poise could end up landing you the job.

1. For the full text of the The Americans with Disabilities Act of 1990, Titles I and V: [www.ada.gov](http://www.ada.gov)

2. Emphasis added. This excerpt is from the Equal Employment Opportunity Commission's website, a good resource for questions employers are allowed to ask: [www.eeoc.gov](http://www.eeoc.gov)

## Scholarship Information

Now is the time of year when many begin to think about college scholarships. The HFI website has a list of some of the scholarship opportunities that are available to different segments of the bleeding disorders community. Some are only available to the individual with hemophilia, while others are open to siblings, or children of affected individuals. There are some that are open to families with von Willebrand's disease. While many are aimed at persons who will be attending college or university there are some which support technical or vocational studies. Each application and deadline is different. Some require letters of recommendation and essays. Read over the requirements and ask questions if you are not sure about the requirements. The social workers at the Hemophilia Treatment Centers may be able to provide you with some suggestions and orientation.

### Applications Available for the Bradley Krueger Scholarships

We are proud to announce that we are now accepting submissions for this scholarship. Brad's family started this fund to help other people with hemophilia achieve a higher education—to live a full and productive life. Those who knew Brad understand that he lived life to the fullest and never let illness “get him down” for long. He was fun loving and had many friends and family who adored him. This scholarship will live on as a testament to his strengths and determination. It is available for people with a bleeding disorder, parents, siblings and/or carriers. Scholarship(s) can be used for tuition for any type of post-secondary institution – including trade schools, room and board, books, and supplies (including computer equipment). Scholarship(s) will not be paid to the individual – must be paid to an educational institution or in the case of supplies directly to the vendor. Applications will be accepted until June 1st and are available on our web site – [www.hfi-il.org](http://www.hfi-il.org). The Committee has made up to \$2,500 available for scholarships this year which will be awarded at the HFI Annual Meeting in July.

### Additional Education Opportunities

This is a list of some of the scholarship opportunities available to members of the bleeding disorders community.

An entire list of scholarships can be found at: <http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=53&contentid=150>

**Please check all particulars including deadlines with the responsible organizations.**

Scholarship	Source	Deadline	Contact	Web Addresses
Mike Hylton and Ron Niederman Memorial Scholarships (5) - Includes immediate family members	Factor Support Network Pharmacy	April 30	(877) 376-4968	factorsupport.com
Millie Gonzalez Memorial Scholarships for WOMEN with bleeding disorders (2)	Factor Support Network Pharmacy	April 30	(877) 376-4968	factorsupport.com
Academic Scholarship for Women with Bleeding Disorders. Inspired by Josephine Droney and Lindsey Hanson-- two (2) extraordinary young women in the bleeding disorders community. (2) \$2,500.	NHF 2009 Project Red Flag	May 15	Dorothy Noel, NHF Health Education & Prevention Coordinator: <a href="mailto:dnoel@hemophilia.org">dnoel@hemophilia.org</a>	<a href="http://www.projectredflag.org">www.projectredflag.org</a>
Education is Power Scholarship (several)	MedproRX	May 1	(866) 528-4963	medprorx.com
HHS Memorial Scholarships (Multiple) Open to a wide variety of bleeding disorders	Hemophilia Health Services	May 1	(615) 850-5175	accredohealth.net/hhs/
Rachel Warner Scholarship	Committee of Ten Thousand	?	(800) 488-2688	cott1.org
Renee Paper Academic Memorial Scholarship	NHF Project Red Flag	May 15	(800) 424-2634	projectredflag.org
Lawrence Madeiros Scholarship	Lawrence Madeiros Scholarship	June 1	(518) 863-2668	adirondackspintacular.com
Kevin Child Memorial Scholarship	NHF	June 26	(800) 424-2634	hemophilia.org
Eric Delson Memorial Scholarships (1) H.S. (3) College	Caremark	July 1	(800) 323-8083	caremark.com

## Why Bob Goes to Camp!

Many of you might not know how I became involved with the bleeding disorder community. In 1991, I was working in Illinois with a group of people establishing a camp for kids with AIDS. Staff and volunteers from the Hemophilia Foundation of Illinois joined this group. In the end, it turned out that the people from HFI really served as consultants to the rest of us. We were all amazed at how much they knew about camping and the willingness to share everything with us. When this project was finished I asked to become involved as a volunteer with HFI and have been part of the organization ever since.

After nearly twenty years now it doesn't surprise me that my introduction to this important community was through camping. This is a very common route to a lifelong family commitment to bleeding disorders. Young families faced with dealing with a bleeding disorder are often isolated. Slowly during the first years of their children's lives they develop a relationship with healthcare providers, some other impacted families and the local organization. It is recognized that there are others out there that share a commonality with them – but I believe that many do not feel a connection until that child returns from camp for the first time.

Camp has so much to offer but the most important aspect is that for a short period of time – in Illinois this is one week – each year, everyone has a bleeding disorder. Our kids are the included ones – not the ones excluded for a medical condition. Everything is for everyone. The parents don't need to worry that the neighbor may be holding a birthday party at an arcade and not invite their child because they are not comfortable with the risk of a bleed. No child is faced with an adult suggesting they be a "scorekeeper" because this is the safest way for the adult to assure themselves that they are protecting the child's health. I could go on and on with examples but hopefully you get my point – if you don't, contact me and I can tell you bizarre stories of how our children are isolated each day.

Camp starts out each day around a flag pole with a moment of reflection. There is nothing remotely religious about this activity but it is one of the most spiritual times of my life. I don't get through most of these mornings without a tear – but those of you who know me know that I'm a big softy. To hear our young people stand in front of their peers and openly express what it means to be part of the group is truly astounding. Most of us can't get teenagers to grunt once for yes and twice for no, let alone tell us how they feel. We all are, and must continue to be, proud of the great children we are all raising.

This experience, while it may only last one week, permeates the rest of the year and for most of us our entire lives. How many people out there – I'm talking to you – are still friends with their cabin mates from their first year at camp? How many of you are now counselors yourselves at camp? How many of you have decided to pursue a career serving others because of what you learned at camp? It would be great if we could find a way to quantify the positive outcomes from camp but I'm not sure there is a number that goes that high.

When I talk with other colleagues who work in other areas of social service they are always amazed at how many people with bleeding disorders are truly involved with HFI. They want to know what the secret is to getting people to be a part of their own organization. I tell them that there are a variety of reasons but none more important than our camping program. From this one activity each participant has the opportunity over the years to develop thousands of relationships that can aid them in living a strong, independent and healthy life.

In closing, I want to talk directly to new families that are still a little unsure of sending their son or daughter to camp for the first time. We understand this reticence. You have been caring and protecting your child for the past seven to ten years largely all by yourselves. Know that we are here for you to help you (mom and dad) get over your uncertainty. We will help you in anyway we can because this will be a terrific experience for your child.

I'm proud to report that the camping program for children with AIDS that the Hemophilia Foundation of Illinois helped start continues to grow and develop – as does our camp. We will be holding the 37<sup>th</sup> session of Camp Warren Jyrch from July 26 – August 1 at the Timber Pointe Outdoor Center in Hudson, Illinois. I can't wait!!

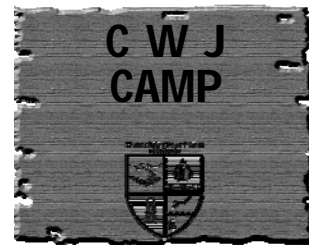
### \* CALLING ALL CAMPERS & POTENTIAL CAMPERS \*

#### Camp Warren Jyrch

July 26—August 1, 2009

Timber Pointe Outdoor Center  
Hudson, Illinois

Camp Applications will be available for the 37th Session of Camp Warren Jyrch as of April 20th. You can access them from the HFI web site or by contacting the office.



### Marcus McClure Family Camping Weekend

May 15—17, 2009

Timber Pointe Outdoor Center  
Hudson, Illinois

Calling all new campers between the ages of 6 and 10 years old. Pack up your family and join us for this fun-filled weekend of camp activities. You, your parents and your siblings will get to "try out" bleeding disorder camp. Reservation forms are available on the HFI web site or by contacting the office.

### \* CALL FOR CAMP STAFF \*

We are looking for dedicated, experienced volunteers who are interested in being counselors for Camp Warren Jyrch. There is complete information and applications available on the HFI web site.



Caring for the Caregiver cont...

- **Exercise regularly.** Aim for 30-60 minutes of exercise four to six times a week; even a walk around the block will help clear your mind and keep you more fit. Regular exercise will give you more energy, reduce your stress, and elevate your mood. If you can work in some strength training twice a week, that will help keep your bones firm and your muscles strong, both essential if you have to help lift and support the person in your care.
- **Relax.** Do relaxation exercises--such as deep breathing or meditating--to reduce caregiver stress. If possible, set aside a few minutes at the beginning and end of your day to practice these techniques. Consciously relaxing in this way will help you enter the day more calmly, and make it easier for you to sleep at night. You can also do deep breathing now and then throughout the day to help keep your stress under control.
- **Take a break.** At least once or twice each week, stop being a caregiver for awhile and take some time for yourself. If you do, you'll be happier and better able to care for your loved one.
- **See your doctor.** Get regular medical check-ups; you need them more than ever now, because you're managing a lot of extra stress and emotional turmoil.

Being a caregiver for someone you love is one of the toughest jobs imaginable. It's frustrating and terrifying, exhausting and overwhelming, but it can be one of the most rewarding things you'll ever do — a supreme act of love. But don't forget caregiver support: in order to provide the best care for your loved one, you have to take care of yourself.

\* This article is a compilation of information found on Ask.com in reference to Care Giving.

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at RUSH Hemophilia and Thrombophilia Center,  
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- May 16-17, 2009:** Marcus McClure Family Camp
- May 23, 2009:** Hispanic/Latino Family Activity-Stress Management, Diet and Exercise
- July 26-Aug. 1, 2009:** Camp Warren Jyrch, Timber Pointe Outdoor Center in Hudson, Illinois

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