

# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SPRING 2007

## Hemophilia of North Carolina - A New Beginning

In the over 25 years of its existence Hemophilia of North Carolina (HNC) has been an organization run by volunteers. These kind hearted individuals were primarily the families of hemophiliacs or in some instances the hemophiliacs themselves. They and a few of their friends took on all of the tasks necessary to organize and support a North Carolina chapter of the National Hemophilia Foundation. Over time, the scope of HNC's mission grew to include not only hemophiliacs but all persons with bleeding disorders. This task, an overwhelming undertaking, with administration, fund raising, news letter publications and client services all remained the responsibility of a small group of volunteers. For the last several years the officers and directors of HNC have struggled with the need to transform our chapter into a professionally run organization in order to truly accomplish our mission of service to the bleeding disorders community. The chapter, however, was simply unable to generate the funds necessary to support a much needed Executive Director.

That was then, this is now! We are extremely excited about our new beginning. Hemophilia of North Carolina has been able to hire a highly qualified Executive Director, Susan Cowell. Sue will take over day to day management of HNC, plan and promote fund raising activities and provide communication with our patients and care providers. This long sought after change in the chapter comes about as a direct result of the generosity of many of our supporters. We are

particularly indebted to the CSL Behring (formerly known as ZLB Behring) Foundation which in 2006 provided a grant for Chapter Development.

Sue Cowell brings to HNC the management and organizational skills obtained from many years of experience as an executive with a major corporation. She has also been involved in fund raising activities for non-profit organizations. We anticipate a number of changes and improvements in HNC going forward. You will note differences in The Concentrate, the HNC news letter. New format and content are being chosen to provide more news-worthy articles and useful information. It is our hope that we will receive for publication more stories about individuals and their families, members of the bleeding disorders community, their lives, problems and accomplishments.

The HNC Board of Directors and the Executive Director are planning a number of events from which they believe members of the community they serve will benefit. Fund raising activities, educational programs and outreach to the community as yet unaware of our services are among the goals of a newly energized Hemophilia of North Carolina. It is our sincere hope that members of our community will take advantage of HNC services, contacting Sue or any Board Member with their questions, suggestions or requests.

### UNDER CONSTRUCTION

The chapter is under construction! We will be moving from Winston-Salem to Cary on March 31, 2007. This move will enable us to better serve the community with quick responses and better lines of communication. Also under way is a new and improved web site that will provide all the up to date information at your fingertips! Please make note of our new address and email:

PO Box 70, Cary, NC 27512-0070 • [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)

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On the Health Front

On the National Front

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June 2, 2007  
Concord, NC

HNC Annual Golf Tournament  
June 22, 2007  
The Preserve at Jordan Lake  
Chapel Hill, NC

Camp Rainbow  
June 10-16

Durham Bulls Concession Dates  
7/7, 7/27, 8/4, 8/17 & 8/31

Camp Carefree  
July 22 – 28

Victory Junction Gang Camp  
July 30 – August 4



HEMOPHILIA OF  
NORTH CAROLINA

PO Box 70, Cary, NC 27512-0070

(800) 990-5557

[info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)

## MISSION STATEMENT

Hemophilia of North Carolina is a non-profit organization whose goal is to assist, involve and educate persons affected by bleeding disorders and to educate the medical community and the public about bleeding disorders.

## Contact Numbers

Hemophilia of North Carolina  
(800) 990-5557

Executive Director, Sue Cowell  
(919) 460-1536

National Hemophilia Foundation Office  
(800) 42-HANDI  
[www.hemophilia.org](http://www.hemophilia.org)

Hemophilia Federation of America  
(800) 230-9797  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

## About This Publication

THE CONCENTRATE is the official newsletter for Hemophilia of North Carolina. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

We maintain a membership mailing list. However, we never release any personal information without your permission. You may occasionally receive information that is mailed from our office. Your response to these mailings will be of your own choosing and if you would like to "opt out" of all third party mailings, please contact us to remove your name from these mailings.

Hemophilia of North Carolina does not endorse any specific products or services and always recommends that you consult your physician or local treatment center before pursuing any course of treatment.

## Hemophilia Treatment Centers & Medical Resources

### East Carolina University

Brody School of Medicine  
PCMH 288 West  
Greenville, NC 27858-4354  
Phone: (252) 744-4676  
Fax: (252) 744-8199

### University of North Carolina at Chapel Hill

School of Medicine  
W1022 Old Clinic Building  
CB # 7016  
Chapel Hill, NC 27599-7016  
Phone: (919) 966-4736  
Fax: (919) 962-8224

### Wake Forest University School of Medicine

Wake Forest University Baptist Medical Center  
The Bowman Gray Campus  
Department of Pediatrics  
Medical Center Boulevard  
Winston-Salem, NC 27157-1081  
Phone: (336) 716-4324  
Fax: (336) 716-3010

### North Carolina Duke University Medical Center

Hemostasis and Thrombosis Center  
Box 3422 Medical Center, 0563 Stead Bld  
Durham NC 27710  
Phone: (919) 684-5350

### University of North Carolina

Thrombophilia Program  
CB 7035 Rm 932, Mary Ellen Jones Building  
Chapel Hill, NC 27599  
Phone: (919) 966-3311



## A New Face On The Scene

Greetings to everyone! It is my honor to introduce myself as the new Executive Director of Hemophilia of North Carolina. My name is Sue Cowell and I currently reside in the Cary area with my husband of 20 years and two teenage daughters.

I am excited about working with a group of individuals on the board who tirelessly continue their mission of providing support to the community. The needs of the bleeding disorder community of North Carolina are as vast as the state itself. Our commitment is strong and we are steadfastly working on seeking out opportunities to improve the quality of life for all. We intend to meet our obligations through ongoing educational seminars, the annual meeting and providing you with the most current, up to date information in The Concentrate. It is our hope that you will take advantage of these opportunities as each of them is designed with you and the mission in mind.

Let us look to the future with a unified purpose and work together on our common goals. I would welcome any suggestions about our events or any information that you feel may be helpful to the community. Thank you for your support!

Sincerely,

*Sue Cowell*  
Sue Cowell

HNC Executive Director

## Coming Soon

### Hemophilia Legal Phone Line

Initiated by the Loan Star Chapter and supported through NHF with a grant made possible by Baxter, a program will roll out soon to help provide information that will enable people with bleeding disorders to:

- Gain information on insurance coverage.
- Be informed of your legal rights.
- Learn about insurance programs that may be available.

The legal information is free of charge and confidential. The toll free phone line is manned by a qualified attorney who specializes in consumer rights of people with chronic conditions.

Look for the launch date and more information in our upcoming edition of THE CONCENTRATE.

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or online at:  
[www.medprorx.com/scholarship.php](http://www.medprorx.com/scholarship.php)



CALL US  
24/7

Providing Hemophilia therapy to North Carolina & surrounding areas.





We're now a registered organization on GoodSearch.com. This is a search engine for the Internet. Every time you use it, money goes to Hemophilia of North Carolina. The site is powered by Yahoo!, so you'll get the same quality search results that you're used to.

The more people who use this site, the more money will go to our Chapter to assist the community through programs and assistance. So please spread the word to your friends and family.

Select Hemophilia of North Carolina as your designated charity. Set up instructions are available at:  
<http://www.goodsearch.com>

## Hemophilia of North Carolina Annual Meeting

Saturday, June 2, 2007

9:00am- 5:30pm

[www.cabarrusarena.com](http://www.cabarrusarena.com)

Cabarrus Arena & Events Center

4751 Highway 49 North

Concord, NC 28025

Please save the date to join up at the annual chapter meeting. This year's agenda will be filled with exciting speakers and presentations on the latest topics. In addition, a Feel the Thrill Tour around the track at Lowe's Motor Speedway will be available to the first 100 people who RSVP and register at the event. Space is limited so please contact us as soon as possible.

The winner of our Art Contest will be announced at the meeting along with a free raffle for all who attend.

More detailed information will be mailed shortly to all members.

To RSVP please contact the chapter at (800) 990-5557 or through email at [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org).



## Factor Solutions

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**1. CALL Factor Solutions - 1-800-288-8374**

**2. TALK to a Case Specialist**

**3. RECEIVE Factor at Your HTC**



For more information, please contact your local Bayer HealthCare Account Executive, Spencer Miller, at (803) 319-7114, or by e-mail at [spencer.miller.b@bayer.com](mailto:spencer.miller.b@bayer.com).

\* Based on determination of program eligibility.



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PO Box 70, Cary, NC 27512-0070 • (800) 990-5557 • [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)

## Scholarship Information

### Factor Support Network

**Awards:**

**Mike Hylton and Ron Niederman Memorial Scholarship**

Five \$1000 scholarships for MEN with Hemophilia or von Willebrand Disease and their immediate family members.

**Millie Gonzalez Memorial Scholarship**

Two \$1000 scholarships for WOMEN with Hemophilia or von Willebrand Disease and their immediate family members.

The scholarships can be viewed and downloaded from their website [www.factorsupport.com](http://www.factorsupport.com). All forms must be completed and emailed or postmarked by April 30th. For information call Toll Free: 877 376-4968

### Project Red Flag Provides College Scholarships for Women

The National Hemophilia Foundation's (NHF) Project Red Flag is offering two college scholarships to female students pursuing post-high school studies. Candidates for the Project Red Flag Academic Scholarships for Women with Bleeding Disorders must have been diagnosed with a bleeding disorder, such as von Willebrand disease, or be a hemophilia carrier. Ideal candidates are those who have had some community service experience, particularly within the bleeding disorders community. The scholarship deadline is Friday, May 18, 2007.

The scholarships were inspired by two young women who embody the spirit of giving back to the community—Lindsey Hanson and Josephine Droney.

To download an application, visit: [http://www.projectredflag.org/source/PRF\\_scholarship.doc](http://www.projectredflag.org/source/PRF_scholarship.doc)

*Reprinted from NHF ENotes*

Some scholarship forms and information are available to be mailed to you from the office of Hemophilia of North Carolina. If you need forms or additional information please contact us at 800-990-5557 or by email at [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org).

### Soozie Courter "Sharing a Brighter Tomorrow" Hemophilia Scholarship Program

**Awards:**

- Two \$7,500 graduate scholarships
- Sixteen \$5,000 undergraduate scholarships
- Two \$2,500 vocational scholarships

Scholarships will be awarded to applicants with hemophilia A or B who present the best combination of creative and persuasive essay, excellent recommendations, and superior academic standing.

Deadline: April 17, 2007

Contact: 1-888-999-2349 or on the web site at [www.hemophiliavillage.com](http://www.hemophiliavillage.com)  
Click on Programs & Services  
Program sponsored by Wyeth.

### Hemophilia Health Services

Act now to win your scholarship! The HHS Memorial Scholarship Fund is accepting applications for one of multiple scholarships worth \$1,500.

Apply at: [www.FactorCare.com](http://www.FactorCare.com)  
Open enrollment is until May1, 2007.

For more information, call Sally Johnson at 1-800-289-6501 x5175.



## Remembering America's First Hemophilia Author

Why would anyone skip part of the NHF annual meeting in Philadelphia to visit a cemetery—on Friday the 13th? My compelling reason was the gravesite of Dr. John C. Otto. In 1803, Dr. Otto published the first summary of hemophilia in *Medical Repository*, America's first medical journal. On this early October morning, I drove across the Schuylkill River to Woodlands Cemetery to visit his gravesite out of respect, not mourning.

Born in 1774, Dr. Otto was the son of an eminent New Jersey physician and attended medical school at the University of Pennsylvania. He was elected to the medical staff of Pennsylvania Hospital in 1813, serving there until his retirement in 1835. Oddly, an inaccurate date of death is chiseled into the marble of his tombstone: Otto died in 1844, not 1884. All subse-

quent medical journal articles on hemophilia can be traced to Otto's pioneering article, "An Account of an Hemorrhagic Disposition existing in certain families." In this sense, Otto sparked a scientific revolution by motivating others to write articles for medical journals. His article has been reprinted several times in various journals, most recently in 1996. Otto recognized that people with hemophilia have been a part of US history since our country was founded. The idea of sharing medical information about American hemophilia patients in our own medical journals was an important step in the independence of American medicine. Not only was Otto the first to describe hemophilia in this country, but he was also precise. He accurately depicted not only the bleeding manifestations of individual patients, but also the genetic inheritance pattern over

several generations of "transmitters," now called carriers. In his writing, Otto used the word "bleeders,"<sup>1</sup> a common term that has remained in use for more than 200 years. Significantly, Otto advocated for medical treatment of hemophilia. He recommended sulphate of soda as a "purg-ing" treatment for bleeding episodes—a treatment that was mainly cathartic. From many citations in the medical literature, we know that sulphate of soda gained acceptance in the 1700s, and lasted until about 1900.

I had visited Dr. Otto's gravesite on previous trips to Philadelphia, noting that over time, a coat of green slime was growing. As no one was maintaining the tombstone, I vowed to do something. So on this visit, I arrived early in the morning with a bucket, brush, and can of household cleaner, and I

*continued next page*



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Providing innovative recombinant factor, plasma-derived, and inhibitor management therapies highlights our commitment to choice and illuminates our investment in research and development.

### Through Participation

Offering initiatives for patients, families, physicians, and nurses and supporting local and national organizations and community events, in addition to volunteering.

### Through Progress

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For more information on Baxter programs and services, visit [www.thereforyou.com](http://www.thereforyou.com).

There when you need us

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HEMOPHILIA OF NORTH CAROLINA

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## Get Out the Crayons, Markers and Colored Pencils! HNC is having an Art Contest

We are looking for all the aspiring artists out there to use their talents and design a picture that will be used on our postcards to thank members and other Chapter communications. The original artwork can be any medium and should be a North Carolina theme so put your creative juices to work!

### Rules:

- One original artwork per person.
- Open to ages 4 to 12
- Artist must be diagnosed with a bleeding disorder
- Size should be 4" high x 6" wide (postcard size)
- Artists understand that their entry must be their original artwork and that if accepted will be published in our communications.
- Artwork cannot be returned.
- All entries must be submitted along with Entry Form (below) to Hemophilia of North Carolina by May 1, 2007.
- Please do not write any identifying information on the front of the picture, place name and age on back of artwork.

The artwork will be judged by a committee of community members. The grand prize will be an iPod! All artwork will be displayed at the Annual Meeting on June 2 and the winner will be announced at that time.

Extra Bonus: Anyone who has artwork displayed at the Annual Meeting and is in attendance will have their name placed in a raffle for a special prize!

Entry Form:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Age: \_\_\_\_\_ Type of Bleeding Disorder: \_\_\_\_\_

Parent/Guardian Signature: \_\_\_\_\_

Mail Completed Entry Form & Artwork to:  
Hemophilia of North Carolina  
P.O. Box 70  
Cary, NC 27512-0070

### *Remembering America's First Hemophilia Author cont'd*

scrubbed the tombstone clean. The few joggers on the trail between gravestones didn't notice me; nor did a silent herd of seven deer, who provided an unexpectedly pastoral scene. I was a solitary visitor this Friday, paying homage to John C. Otto, MD, a distinguished figure in the history of hemophilia.

*Author Richard Atwood, MA, MPH, lives in Winston-Salem, North Carolina, where he worked for 17 years at the hemophilia treatment center at Wake Forest University. Currently he serves on the board of Hemophilia of North Carolina.*

*Source: The Parent Empowerment Newsletter, February 2007. To register, visit [www.kelleycom.com](http://www.kelleycom.com)*



Come out, enjoy the game and have fun working a concession stand at the Durham Bulls baseball games on 7/7, 7/27, 8/4, 8/17 & 8/31. As part of our fundraising efforts we will be working a concession stand on these dates and a percentage of all proceeds will be donated to our organization. This is a great opportunity to bring the family, enjoy a night out and meet others in the community. To volunteer, please contact Sue Cowell at [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org) or by calling 800-990-5557.



## Victory Junction Gang Camp

Victory Junction Gang Camp is located south of Greensboro in Randleman, NC. The 2007 summer camp for children & teens ages 7 to 15 with hemophilia is July 30th-August 4th. The theme for this year's camp is Super Heroes.

Sibling week will be held August 7th-August 12th.

Victory Junction is completely funded by donations.

For more information and application forms contact:  
www.victoryjunction.org  
or call 877-854-2267

## Camp Rainbow

Camp Rainbow is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Camp is open to ages K-12 and is sponsored through the Rainbow Services program at ECU. Dates for camp this summer are:

June 10 – June 16

Limited space is available. For more information please contact:  
Jacquelyn Sauls at 252-744-4102 or  
SaulsJ@mail.ecu.edu.

## Camp Carefree

Camp Carefree is located just north of Greensboro in Stokesdale, NC. The 2007 summer camp for children & teens – ages 6 to 16 – with hemophilia and other bleeding disorders is July 22nd-July 28th.

Also offered at Carefree is a camp for well siblings who have a brother or sister with a chronic medical condition. For 2007, this camp will be held June 17th-June 23rd.

This camp is completely funded by donations, there is no charge to attend Camp Carefree. A chili cook off fundraiser will be held at the camp April 21, 2007. This would be a good time to check out and support this 22 acre camp.

For more information and application forms contact:  
Camp Carefree, Inc.  
(336) 427-0966 or on the web  
www.campcarefree.org

## Camp SuperFly III

Go North Carolina Monarchs!!!

Camp SuperFly is an annual, nationwide competition sponsored by Baxter that brings patients, families, chapters and HTC's together to learn more about hemophilia and help chapters earn up to \$30,000 in grants to support summer camp. This is a virtual camp experience where participants are mailed challenges that are designed for three age groups and each challenge is divided into two parts – mental and physical. Challenges will be mailed from the office of Hemophilia of North Carolina and information on participants will be kept confidential. As challenges are completed and mailed in, our chapter receives points toward the grant and will compete with other chapters. Team members may be adults or children of any age. All team members must have a bleeding/clotting disorder. If a child is too young to participate, a parent or guardian may compete for the child.

We are supporting this program because it is a fun, educational way to learn about bleeding/clotting disorders and help people to successfully manage hemophilia and realize their potential to lead full and active lives.

Our team name is the North Carolina Monarchs! The program mailings will begin on April 15 and run through August 15. We are excited about the program and encourage your participation. To be enrolled or for more information on the program please contact Sue Cowell at 800-990-5557 or through the chapter email at [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org).



## Factor: Don't Leave Home Without It

By Maris Santaella, University of Miami Hemophilia Treatment Center

Reprinted from *LIFELINE*, The Official Newsletter of Florida Hemophilia Association – Fall 2006

In a post “9-11” era, traveling by airplane has become more and more involved. This issue becomes even more complicated if you have a bleeding disorder and are traveling with factor. Following are a few tips to make this experience a little bit easier for you and your family.

It is always a good idea to contact your HTC before you travel. By contacting us we can help you update your travel letter, write a letter authorizing you to travel with factor and ancillary supplies, and we can also help you find the HTC nearest to your destination. Knowing where the closest HTC is can be useful in the event of an emergency.

When traveling, always remember that Factor and Stimute are very sensitive to temperature changes and extremes. Carry these medicines with you at all times. Never leave them in the car, and never send them with the rest of the luggage if traveling by air. Cargo compartments in planes are sometimes not pressurized and temperature and pressure may affect the factor's potency and may damage the glass vials in which they are contained.

In an effort to help you get organized and ready for an enjoyable time, we are including a few recommendations for you and your family:

- Make sure you have enough factor and/or other medicines with you.
- Obtain and carry with you and updated “travel letter” from your physician describing your diagnosis and treatment.
- If traveling by air you will also need a letter from your doctor authorizing you to have in your possession factor and infusion supplies.
- Wear your Medic Alert bracelet/pendant.

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For more information, please contact your local Bayer HealthCare Account Executive, Spencer Miller, at (803) 319-7114, or by e-mail at [spencer.miller.b@bayer.com](mailto:spencer.miller.b@bayer.com).

Please consult with your healthcare provider to determine if Kogenate® FS is appropriate for you.

Kogenate® FS is a recombinant Factor VIII treatment indicated for the treatment of hemophilia A. The most frequently reported adverse events were local injection site reactions, dizziness, and rash. Known intolerance or allergic reactions to constituents of the preparation is a contraindication to the use of Kogenate® FS. Known hypersensitivity to mouse or hamster protein may be a contraindication to the use of Kogenate® FS.

For important safety and use information, please see full Prescribing Information at [www.kogenatefs.com](http://www.kogenatefs.com).

\*Compared with conventional vial-to-vial reconstitution

†Butler R, Larson P, Mannix S, et al. *J Outcomes Res.* 2004;8:63-78.

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## Career Planning

By John Jarratt, M.Ed., L.P.C.

With the current retirement age at 65 years, it is probable that most adults will spend approximately 40 years of their lives working. That's a long time! Considering that, choosing a career is one of the most important decisions you make. In our American society, the career that you enter will influence your lifestyle, self-concept, income, choice of friends, and living location.

A career can be defined as a person's progress within an occupation or series of occupations. However, a career is more than just a having a job. The ideal career offers you enjoyment, interest, and meaning. Your career should also offer you a balance of personal, family and social time.

Many people may think that there is only one occupation that best suits them. In reality, most people have many different skills that would be beneficial in more than one profession. Focus your job search and opportunities that best fit your needs and preferences.

Some people may view deciding on a career path as a stressful or frightening prospect. It needn't be. In fact, it can be very exciting. There are many resources available to you. During high school, students often take tests that evaluate their skills and working preferences. The test results can point out

different careers that fit your personality. Your school guidance counselor can offer assistance. Libraries and the internet also often have books about different careers that you can use as a reference. These books give the educational requirements, working conditions, salary range, and future outlook of different occupations.

Regardless of the career you pursue, there are general skills you should acquire. These include the ability to read, write, compute, think critically, and communicate in an effective manner. For the most part, these skills are developed and/or sharpened in general education courses. These skills, along with the ability to cope in a changing environment, will enable you to overcome obstacles throughout your work life.

Prospective employers often look for commitment which translates into dedication, job performance, and retention. You get to experience career and life satisfaction while earning your living, and your employer has a dedicated, effective employee who creates more good morale for others, and is likely to stay. This is a win-win situation.

As a person with a bleeding disorder, examine your employer's insurance benefits thoroughly before accepting an offer. Look specifically for pre-existing clauses, choice

of providers, beginning date of coverage, coverage of blood and blood products, major medical and prescription drug coverage, annual out of pocket costs, and life-time caps.

Today, fewer people are working for just one company throughout their whole career. According to the U.S. Bureau of Labor in January 2004, the median number of years that wage and salary workers had been with their current employer was 4.0 years. It's likely that you may change jobs several times before you retire. In fact, it is not unusual today for many people to change careers completely – transitioning from being a stockbroker to becoming a teacher, for example.

Even if you continue to work in the field of your choice, look into ways to advance your career. This may include additional training, updating your skills, or continuing your education. Business technology advances quickly and being up-to-date will make you attractive to potential employers.

Believe in yourself! Be true to yourself, and follow your bliss! Good luck, spend some time determining what is right for you, and then go after it!

*Source: Bloodstone Magazine –HHS - Summer 2006*

### One person can make a difference – YOU

Washington Days, NHF's annual federal advocacy day and grassroots training, took place March 7-9, 2007. More than 200 members for the bleeding and clotting disorders community were expected to gather in Washington, DC, to educate our elected leaders and their staff about important issues facing the community.

This year, participants advocated for:

- Expanding access to Medigap policies.
- Requesting support for the Genetic Information Non-discrimination Act (GINA)
- Increasing funding for hemophilia treatment centers (HTC's) to expand service to women and others

For information on how to locate your local officials, visit the HNF website at [www.hemophilia.org](http://www.hemophilia.org) and click on Advocacy & Public Policy.



## Bleeding Disorders Educational Conference Call Series for Consumers Presented by Coram

The series is a great way to listen, learn and share about topics that affect you. There is no charge for participating and all information is confidential. If you are interested in participating, simply dial the Coram conference call line at 1-866-213-1962 about 5 minutes before the call, then enter the 7-digit code 2522683 when prompted.

April 25 – 7pm EST

### **Living with Hemophilia –**

How to streamline your factor day

Speaker – Regina Butler, RN and panel – sponsored by Bayer

May 30 – 7pm – EST

### **Preparing parents & children for the camp experience**

Speaker – Matt Stinger – Camp attendee & Camp counselor

June 27 – 7pm EST

### **Community Talks on Rare Bleeding Disorders:**

Hemophilia 101 and Inhibitors

Speaker – HTC Nurse – TBD – sponsored by Novo Nordisk

July 25 – 7pm EST

### **Von Willebrand Disease 101:**

Facts & discussion on the genetic bleeding disorder

Speaker – Susan Zappa, RN, CPN, CPON, Hemophilia Nurse Coordinator (Cook Children's HTC, TX)

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## Increased Access to Medigap Policies

Request: Support legislation that expands access to Medigap insurance plans, by making open enrollment periods available to everyone on Medicare. Join Congressmen Phil English (R-PA) and Bobby Rush (D-IL) in reintroducing the legislation by becoming an original co-sponsor.

Hemophilia is a rare and chronic bleeding disorder affecting about 20,000 people in the United States. Individuals with hemophilia require life-long treatment with costly medication known as factor product. Some hemophilia patients qualify for the Social Security Disability Program as a result of complications due to their bleeding disorder and are eligible for Medicare. Beneficiaries with hemophilia who do not have secondary insurance coverage face

significant, unaffordable co-payments that can threaten access to treatment. While Medicare beneficiaries over the age of 65 can purchase Medigap policies that provide assistance with co-payments during an open enrollment period, beneficiaries who qualify for Medicare due to their disability are denied this opportunity in 26 states.

Legislation that expands Medigap open enrollment to include beneficiaries in all 50 states who qualify as disabled and are under the age of 65 would dramatically reduce the financial burden for people with high-cost illnesses. This legislation would help these beneficiaries obtain assistance with the high costs of their life-saving therapies without placing a significant financial or administrative burden on the Medicare program.

- There are approximately 1,100 Medicare beneficiaries with hemophilia. The annual cost of hemophilia drug therapies can vary widely. The Centers for Disease Control and Prevention (CDC) estimate that the average cost for the most common treatment is \$82,500 a year. A Medicare beneficiary spending \$82,500 would be responsible for a co-insurance of \$16,500 for clotting factor alone. For some patients, the cost of treatment is much higher and therefore the co-payments are much higher.

- Most Medigap policies provide coverage of co-payment amounts, including those associated with Medicare Part B covered drugs like factor product, after the beneficiary meets the \$124 yearly deductible.



The 2007 Uninhibited Achievement Award is the first award dedicated to honoring the exceptional accomplishments of people with hemophilia with inhibitors. The winner will receive a \$5,000 donation to the charity of their choice, a "Night Out on the Town" in Dallas, Texas, and their story published in newsletters and *HemAware*.

**Nominate yourself or someone you know today. To get a nomination form:**

- Visit [uninhibitedachievementaward.com](http://uninhibitedachievementaward.com)
- Send a request to: Uninhibited Achievement Award Program, 302 Carnegie Center, Suite 102, Princeton, NJ 08540

Nominations must be postmarked no later than August 15, 2007, so get your nomination form today. Restrictions apply. Please see nomination form for details.



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HEMOPHILIA OF NORTH CAROLINA

PO Box 70, Cary, NC 27512-0070 • (800) 990-5557 • [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)

- Older beneficiaries currently enrolled in Medicare Part B are granted a six-month open enrollment period to purchase a Medigap policy. During this period a plan cannot deny the beneficiary a Medigap policy, delay coverage or charge more for a policy because of health problems.

- There is no federally mandated open enrollment period for beneficiaries who are eligible for Medicare due to a disability. These beneficiaries are subject to a patchwork of state laws, which may or may not require insurance companies to offer Medigap policies.

- The Medigap Access Improvement Act (H.R. 6175) sponsored by Phil English (R-PA) and Bobby Rush (D-IL) in the previous Congress will be reintroduced later this session.

SUPPORT MEDIGAP ACCESS IMPROVEMENT LEGISLATION

Source: NHF [www.hemophilia.org](http://www.hemophilia.org)

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\*As compared to the original BAXJECT and needles.

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## CSL Behring Reports Progress on Global Implementation of Name Change Change from ZLB Behring to CSL Behring Underway Around the World

King of Prussia, PA — 08 January 2007

CSL Behring today provided an update on its global name change, involving as many as 30 products in each of 70 countries worldwide. The new name, CSL Behring, is now registered in the U.S., Germany, Switzerland and Canada, with other countries following over the next several months.

The renaming program, announced by CSL Behring's parent organization, CSL Limited, last year, will present a consistent and compelling view of the company operating in new and established markets around the world. "CSL has a tradition of innovation with important vaccines and medicines that began 90 years ago and continues to grow," said Peter Turner, President of CSL Behring. "The Behring part of our name originates with Emil von Behring, an innovator with serum therapies who won the

first Nobel Prize in Physiology and Medicine. We have changed our name, but remain strongly committed to the company values of innovation, safety and passion for our customers that we are known for."

The quality, type and volume of products that CSL Behring produces are not impacted by this name change. The company will continue to trade as ZLB Behring in some markets until registration with regulatory authorities is complete. CSL Behring is currently in the process of notifying the respective national health authorities regarding the license transfer. No changes to product names will occur. Throughout the year, company signage, product packaging, Internet sites, e-mail addresses and promotional literature will be updated to reflect the new name.

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Formulated with Sucrose  
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Mix2Vial is a trademark of Medimop Medical Projects Ltd.  
Helixate® FS is manufactured by Bayer HealthCare LLC for ZLB Behring LLC.

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1/2007



HEMOPHILIA OF NORTH CAROLINA

PO Box 70, Cary, NC 27512-0070 • (800) 990-5557 • info@hemophilia-nc.org

The Hemophilia of North Carolina organization gratefully accepts donations in support of its programs and services. Your dollars directly impact the bleeding disorder community by providing education to parents, scholarship opportunities and financial assistance for families in crisis.

**For new members,**  
please complete the following application form.

**For existing members,** we are currently updating our database and would like to make sure we have the most current contact information for you. Please take a moment to fill in the application and check "currently active member – information update".

Please mail completed applications to:  
Hemophilia of North Carolina  
P.O. Box 70  
Cary, NC 27512-0070

Please make checks payable to *Hemophilia of North Carolina*. Your donation may be tax deductible to the extent allowed by law.  
We are pleased to send you a receipt for your donation.



BioRx will be filling 3 summer internship positions. A qualified candidate will be currently enrolled at an accredited college or university. Preference will be given to candidates who have a or marketing/communications. The position will be a paid internship with assistance in applying for additional academic credits.

BioRx is a national provider and distributor of certain specialty pharmaceuticals, related supplies, as well as clinical and reimbursement support services.  
For more information about our company, visit us at [www.biorx.net](http://www.biorx.net)

Interested candidates should contact us at:  
[cclark@biorx.net](mailto:cclark@biorx.net) with an attached cover letter and resume,  
call 866.44.BIORX, or send a resume and cover letter to:  
Human Resources-BioRx, 10828 Kenwood Road, Cincinnati OH 45242

## Membership Application

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

**Check One**

- I am a person with a bleeding disorder. Type \_\_\_\_\_ (ie: VII, IX, VWD)
- I am a family member of a person with a bleeding disorder  
Relationship \_\_\_\_\_  
Type of bleeding disorder \_\_\_\_\_
- I am a medical professional
- I am an interested person
- I am a currently an active member – information update

Annual membership fees, while not mandatory, are at the following suggested rates:

Individual Member	\$10	Supporter	\$100
Family Membership	\$25	Patron	\$200
Contributor	\$50	Benefactor	\$500





# Hemophilia of North Carolina

## Programs and Events:

Call for more details and volunteer opportunities at (800) 990-5557

- Durham Bulls Concession Stand
- Annual Golf Tournament
- Annual Meeting
- Scholarship Opportunities
- Camp Sponsorships & Information
- Regional Workshops
- Legislative/Lobbying
- Chapter Membership & Board Information

## Board Members

Matt Barnes – President  
Richard Atwood – Secretary  
Andrea Brill – Treasurer  
Jason Allen  
Judy Igleman  
Warren Jewett  
Edwin L. Wilson

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HNC is a member of:  
National Hemophilia Foundation  
Hemophilia Federation of America  
Community Health Charities

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*The following committees are being formed to better serve the community.*

*We welcome all volunteers interested in serving on a committee.*

*For more information, contact Sue Cowell at (800) 990-5557.*

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Advocacy Committee \* Education Committee \* Outreach Committee \* Finance Committee \* Fund Development Committee

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