

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2009

Fun for All at the HNC Family Retreat

Despite some very uncooperative weather, the HNC Family Retreat went on from August 12th to the 14th at the Trinity Center in Pine Knoll Shores. It started out under a tornado watch and some very difficult driving conditions for the families but they braved the conditions and all arrived safely!

Our first evening plans of dinner on the beach pavilion were quickly changed to indoor arrangements followed by a time for discussion by the adults and games for the kids. The group was welcomed and had a chance to get acquainted and learn a little something about everyone. We then provided information from the Centers for Disease Control regarding the latest statistics in obesity and how to make better choices for living healthier lives. Did you know that the number of commercials seen by the average American by the age of 65 is 2 million and the average youth spends 1500 hours watching television each year?

Thursday was a full day of programs along with some free time to enjoy the small peek



of sunshine at the beach. Nancy Roy, Senior Clinical Specialist from Baxter Bioscience provided information to the adults on how to Navigate Emergency Care and shared tips on how to communicate your needs. The younger children enjoyed some fun and games with a Camp Superfly session hosted by Baxter and CVS Caremark. The older group of tweens & teens worked interactively with Anne Lowish, RN of MedPro Rx to learn more about self infusion and enjoyed working with the BayCuff self infusion kits provided by Bayer.

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Join Us for the Hemophilia Walk 2009
October 17th, 2009
Lake Crabtree County Park, Morrisville, NC

On Saturday, August 8th the 2009 Hemophilia Walk in NC was officially kicked off with our event held at the Hilton Garden Inn in Morrisville. Information and updates were shared with the group on the progress of the walk, tips for teams and activities that will

take place the day of the walk including chair massages, a photo booth, Stormy and the Slap Shot Booth from the Carolina Hurricanes, our favorite DJ, tasty treats for our four-legged friends and a great scavenger hunt for the kids along the walk route! NBC 17 Health & Fitness

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Latin Union Program
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Raleigh, NC

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NHF Annual Meeting
October 29-31, 2009
San Francisco, CA

HNC Insurance & Health Care Symposium
November 14, 2009
Chapel Hill, NC

HNC Holiday Celebration
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Wilmington, NC

“Hearts for Hemophilia”
Casino Night
January 23, 2009
Raleigh, NC



Hemophilia of
North Carolina

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Cary, NC 27512-0070
(800) 990-5557
info@hemophilia-nc.org
www.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) 319-0014

National Hemophilia Foundation Office
(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America
(800) 230-9797
www.hemophiliafed.org

Community Health Charities of NC
(919) 554-3272(Collect)
www.healthcharities.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**

**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**
Campus Box 7016
Physician Office Building
170 Manning Drive
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736

**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

**Additional Medical
Resources**

**Carolinas Medical Center
Pediatric Hematology/Oncology**
1000 Blythe Boulevard
Charlotte, NC 28203
Phone: (704) 381-6800

**Duke University Medical Center
Hemostasis and Thrombosis Center**
DUMC Box 3422
Durham, NC 27710
Phone: (919) 684-5350
http://htc.medicine.duke.edu/

**Presbyterian Blume Pediatric
Hematology & Oncology Clinic**
1712 E. 4th Street
Charlotte, NC 28204
Phone: (704) 384-1900

Resource Information

American Pain Foundation (APF)
1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
http://painaid.painfoundation.org

**American Society of Pediatric
Hematology/Oncology**
847-275-4716
www.aspho.org

Bleeding Disorders Legal Hotline
1-800-520-6154

Centers for Disease Control & Prevention
1-800-311-3435
www.cdc.gov

**Committee of Ten Thousand
(COTT)**
1-800-488-2688
www.cott1.org

The Factor Foundation of America
1-866-843-3362
www.factorfoundation.org

Inalex Communications
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www.inalex.com

HIV/HCV Newsletter
Hemophilia Association of the Capital Area
www.hacacares.org

Patient Notification System
The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.
1-888-UPDATE U
www.patientnotificationsystem.org

Patient Services Incorporated (PSI)
Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-800-366-7741
www.uneedpsi.org

World Federation of Hemophilia
514-875-7944
www.wfh.org

From the Executive Director

I would like to thank everyone who took the time to complete the HNC Needs Assessment Survey and share your thoughts and ideas. Many key points were taken from the survey including more information on research and insurance along with additional opportunities to share information about bleeding disorders with the medical community. We are working to build this information, along with other programs and services you indicated were very valuable to you, in our upcoming year. It is through this input and the dedication of volunteers who generously give of their time and talent that we are able to develop the chapter and help meet the needs of the community. We are off to a very busy fall with a number of events in September along with our Hemophilia Walk in October. We hope you'll take the opportunity to join us at the Walk for a fun day of activities and a great chance to support the community! We also recognize the importance of up to date information on insurance and changes in health care. On November 14th, HNC will host an Insurance and Health Care Symposium to provide information from local, state and federal speakers, a consumer panel who will share their experiences and the latest information on the changes being proposed in health care. We hope you'll join us for this informative and important symposium.

Sincerely,

Sue Cowell

Sue Cowell
HNC Executive Director

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The Blood Brotherhood Program is an ongoing program that provides opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. Programs held in September include a teleconference on Dental Care, a program on stress management and depression – Mind, Body & Soul and a session on Managing Your Pain. More programs are in the planning and we encourage you to *bring a fellow brother and come on out!* Contact us today for more information (800) 990-5557 or by email at info@hemophilia-nc.org

Look for Your Invitation to...

Hemophilia of North Carolina's Holiday Celebration

Saturday, December 5th 12:30pm-3:30pm
Holiday Inn Resort – Wrightsville Beach



Come join us at the end of year Holiday Celebration on December 5th. There will be food & fun for all ages as we use this opportunity to look back over the past year and get together with old and new friends as the year comes to a close. The celebration will include a visit from Santa & Mr. Claus, buffet lunch and plenty of time to meet & greet! Our celebration will be followed by

tickets to Arlie Gardens. Airlie's holiday light display, *Enchanted Airlie*, is a Wilmington tradition started in 2005; *Enchanted Airlie* is a wonderful opportunity to bring the whole family together to share in the joy of the season. Stroll the gardens at your own pace from 5-7pm, enjoying the beautiful holiday flowers, festive lights, live musical entertainment, and the largest display of model trains running in the Southeast! Look for your invitation to HNC's Holiday Celebration in the mail soon! Registration will also be available online so be sure to Save the Date and come share the holiday spirit!



HNC would like to thank The Hemophilia Alliance for its generous grant that allowed us to purchase new computer equipment and software for the HNC office. The equipment and programs will allow for much more efficient and expansive operations so that we can serve our members better. *Thank you!*



HNC Women's Group

HNC hosted two women's socials in July including a Creating Crepes session in Winston-Salem where we all got to hone our cooking skills and enjoy some delicious

treats. The second program included some budding artists among our members where we created beautiful pottery and enjoyed some great time socializing. Our many thanks to CSL Behring for their continued support of our Women's group. Look for updates on programs coming to your area! If you would like to be involved in the planning for this group or have suggestions to host an event, please contact HNC at info@hemophilia-nc.org or call (800) 990-5557.

SAVE THE DATE

HNC Insurance & Health Care Symposium

Saturday, November 14th

The Friday Center – Chapel Hill, NC

HNC will be hosting this symposium to provide the latest information on insurance and health care reform. The program will include speakers from PSI, HTC's, local & state representatives, a consumer panel and much more. Please join us for this informative and timely opportunity. Look for information on registration soon.



“Hearts for Hemophilia”

CASINO NIGHT

Saturday, January 23rd, 2009

Museum of Natural Sciences, Raleigh, NC

This is a great night of fun! Join us for an exciting night of good fun and fast action for a great cause. Your ticket for the evening will include dinner & music, beer & wine, auction items, great prizes plus “\$10,000” in “funny money” play chips for your to gamble the night away at blackjack, roulette, craps and poker! *For information on helping to plan the event, attend or sponsorships, please contact Sue Cowell at (800) 990-5557 or info@hemophilia-nc.org.*

HNC Needs Assessment Survey Results

We would like to thank all members who took the time and filled out our web based and postal survey. We had 83 individuals who completed the Needs Assessment Survey which was a higher number than we had anticipated! We have had some wonderful comments pertaining to Hemophilia of North Carolina in general, and ways we are able to improve our programs. The Board of Directors has had an opportunity to review the survey results and is working to meet your needs with our programs and services offered for the upcoming year. If you have any questions regarding the survey, please feel free to call HNC at 800-990-5557. Thank you for taking the time to help HNC continue to grow and meet the needs of the community. Again, thank you for your comments and taking the time to complete our survey. It is the member’s suggestions and participation that make the survey results beneficial to reviewing our programs and services.



Hemophilia Walk 2009 *continued*

Reporter, Julie Henry will also be back this year to emcee the event.

At the kickoff, some of our talented young members designed tee shirts that will be part of the scavenger hunt along the route so be on the lookout for these great designs!

We are very excited about the walk and look forward to a great crowd again for 2009! There are lots of opportunities to participate including leading a team, donating and volunteering during the event. For more information about the walk and to see some of the exciting teams that have joined on, visit www.hemophilia.org/walk.

Teams are signing up each day and we’d like to welcome our new and returning teams: MedProRx, Inc, Team South Cows, Bennett’s Buddies, Hemophilia Health Services, UNCTarhealers, Team Novo, Team Grifols, Factor 1 in a Million, Helena’s Children, Walk It Out for Hemophilia, Factor Nine Gang, Walk N’ Roll, Jacob’s Warriors, the National Society of Collegiate Scholars, Carrboro Factor Ones, Rob Co’s Finest, KittyKatKathryn, Zackary and the Factor 8’s, Carolina Walk, Holder’s Tar Heels, Team Andrews, “The Rusty



Joins”, Hemophilia Latin Union, Nick’s Gang, The Duke Factor and Walgreen’s OptionCare.!

We are happy to announce that you have raised over \$54,000 so far on a \$75,000 goal – that’s 72% of the way there! If we reach our goal by walk day, HNC will receive an additional \$10,000 bonus that will go a long way towards our programs and services. For instance, that money would provide assistance to 20 more families and individuals in need of emergency financial assistance during these difficult economic times! If you haven’t had a chance to take a look at the walk site yet, we encourage you to visit and sign

up today for a great day of fun for a very good cause!

Posters, brochures and more information about the walk are available through the HNC office. Please contact Sue Cowell at info@hemophilia-nc.org or call 800-990-5557 if you are interested in receiving materials or have any questions about the walk.

We hope to see you there! ***Remember, every step makes a difference.***

2009 Friends of HNC

We would like to acknowledge the following individuals who generously donated to HNC during the second quarter of 2009. We extend a sincere thank you to our supporters...many of whom contributed several times during this period.

Donations Made In Loving Memory of Kasey E. Frye

Mr. & Mrs. Jim Bostian

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Mr. & Mrs. Kevin Frye

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Mr. Spencer Brill

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Contributions received from July 1, 2008 to June 30, 2009

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Fun for All at the HNC Family Retreat *continued*



Later that morning, the YMCA presented a great program about staying active and tips for getting more exercise and choosing the right foods. Our thanks to Kate Horney, Health and Wellness Director, of the Twin Rivers YMCA for sharing her expertise with us and information on the Fit for All program currently in its pilot program between NHF and some of the YMCA's in other states. We're hoping to see it in NC real soon!

After lunch, we were treated to a presentation by Pete Dyson, CSL Behring Gettin' in the Game Athlete, who spoke about his experiences of participating in a variety of sports. Pete is



Factor IX deficient, lives in Pennsylvania and works as a teacher. His achievements include success in three high school sports: basketball, baseball and golf. Once, he hit two grand slams in one game! We all enjoyed listening to his stories and the tips he shared about managing his bleeding disorder while fulfilling his dreams of participating in sports. Although the weather did not cooperate (once again!) for the pool games that were planned, Pete and Gina Raymond-Duncan of CSL Behring had a perfect Plan B for some fun indoor games.

The rest of the afternoon was free time to enjoy some of the sites in the area and after dinner, everyone enjoyed a visit on family night to the NC Aquarium at Pine Knoll Shores for Pirate Night!

On Friday we got a little messy with our healthy snack making and a great session hosted by Ashley Person, East Carolina University Dietetic Intern. She gave us some great information on how to look for the proper foods, watching the sizes of portions and ways to help develop a plan for the family. Everyone then made some tasty snacks with the assistance of our resident 'chefs' that included Banana Sushi, Berry Smoothies, Veggie Pizzas, Snack Mix and Fruit Kabobs. In surveying the crowd after the taste testing, the Fruit Kabobs and Veggie Pizzas were the biggest hit. If you would like the recipes, please feel free to contact the HNC office for a copy.



Our many thanks to the speakers for their time and information, the Trinity Center and all of our sponsors that made this program a great success. Despite hosting 102 members at this retreat, we are always disappointed that we could not accommodate all of the families who responded to this popular program. The good news is that we are continuing to grow this program and have reserved 44 rooms for next year so that we can host more families and will hold it over Labor Day weekend 2010 so that those people who can not take off work during the week might still be able to attend.

Hemophilia of North Carolina would like to graciously acknowledge our sponsors who made the HNC 2009 Family Retreat possible.

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HNC Member Highlight — A Model Life

By: Spencer Brill

My name is Spencer Brill, I have severe factor VIII hemophilia, and I'm a working model, actor and high school senior. Sounds like the intro to one of those addiction commercials doesn't it?



La Mode au Printemps

I started modeling about two years ago, when I was 15. Like most teenagers, I wanted to make a few extra dollars and thought this would be an easy way to earn extra cash. I was right about the earning extra cash part, but contrary to public opinion, modeling and acting are not easy jobs. Actually, both require a lot of work and discipline. I miss out on being with friends and sometimes I'm absent from school, I've worked 12-hour days and at every casting, I'm evaluated and critiqued about the way I look. Some casting directors are brutal in their comments. This industry is definitely not for the timid or those who are easily offended.

The sacrifices are well worth it because I like being a model and actor and seem to be having some success at both. I prefer acting to modeling and my favorite job is working in film. It's a really great feeling being on set, in character and in front of the cameras. I also travel to a lot of pretty neat places and have met some really interesting people, from casting directors, to make up artists, camera crew to producers and gaffers, and even a few TV and movie stars.

I'm currently signed with one agency and one management company. The first agency I signed with was a small agency in



North Carolina. A few months later, I was picked up by a larger agency and place with their print division and just recently with their TV/Film board. In August, my parents, managers and I are meeting with a rather prominent agency and I anticipate signing a contract with them as well. Models and actors are under contract to agencies. The

agencies send us out on go-sees (auditions) and hope we book (are hired for) jobs. My managers promote me to agencies, casting directors and others in the entertainment industry and along with my parents, help supervise and direct my career and education.

I recently did a photo shoot in downtown Winston Salem for a photographer who will use my photos in her print advertisements. I had a great time shooting with her. We shot in and around a lot of historic buildings including the still impressive, though deserted, RJ Reynolds tobacco plant.

A few of the other jobs I've booked include:

- A television commercial for North Carolina's Jordan Lake
- Tyler Perry's "Meet the Browns", filmed in Atlanta, Georgia
- La Mode au Printemps, modeling clothes for a runway event and aired on CBS
- "Liberating Jessie," a movie filmed in Charleston, South Carolina
- "One Last Sunset, a movie filmed in Granite Falls, North Carolina
- An editorial in AllYou, a Wal-Mart magazine
- A Paul Mitchell Charity live runway event
- La Mode au Printemps live runway event
- Various print and web ads

My first acting job was the Jordan Lake commercial. I booked it last May. I was really surprised the producer cast me, because, at the time, I didn't have any acting experience. Since that job, I've worked



in two films and enrolled in an acting class. My instructor is a principal actor on "Army Wives", and "One Tree Hill". He's also been in a number of Hollywood movies: "Remember the Titans" and "The Reaping" are examples.

I recently auditioned for Columbia Pictures', *Battle Los Angeles*, starring Aaron Eckhart. This movie is being filmed in Louisiana and is about a marine platoon fighting off an alien invasion. I auditioned for the part of a marine named Private Imlay. My acting instructor read the sides, (movie lingo for script) with me during my audition. So far, this is my favorite casting. My manager worked with the above mentioned agency to get this casting for me. I also auditioned for a movie being filmed in North Carolina called, "Pitch Black Milk."

My next booking is a campaign for a clothing company. A campaign consist of various types of advertisements: print, TV, radio, billboards, etc. This campaign includes a magazine cover, prints ads and features me as the company spokes model. This is my first magazine cover and campaign. I'm not 100% sure what being a spokes model entails, but I'm always up for new challenges.

I've really enjoyed all the jobs I've worked on and look forward to working on many more. If you're interested in learning more about modeling and acting or just want to keep tabs on what's happening in my career, check out the blogs: "Headshots and Comp Cards: My Journey Into the World of Modeling and Acting" at: <http://headshotsandcompcards.blogspot.com/> and "Starring Spencer Brill" at: <http://starringspencerbrill.blogspot.com/>



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January 2009

244118-01

Aging Hemophilia Patients Experience Clinical Challenges

A recent article published in the journal *Haemophilia*, describes the health complications facing aging hemophilia patients. The lead author of the article was Barbara A. Konkle, MD, Director, Penn Comprehensive Hemophilia and Thrombosis Program, Hematology/Oncology, University of Pennsylvania.

While historically, the life expectancy of a person with hemophilia has been significantly lower than unaffected individuals from the general population, that trend has been reversed over the last few decades. Life expectancy has risen to the point where a person with hemophilia can reasonably expect to live into middle age and beyond. The availability of effective antiviral drugs to treat HIV and hepatitis C virus (HCV), the production and widespread availability of safer factor concentrates and the creation of a comprehensive care model provided through the hemophilia treatment center network – are considered the major contributors to this trend.

“Today, increasing numbers of persons with haemophilia (PWH) are middle-aged and older, and they face the same age-related health issues as the general population. The impact of these risks on PWH is unclear, however, and there is a paucity of information about how to manage co-morbidities in this patient population,” explained the authors.

Konkle and coauthors reviewed prior research studies, eventually identifying five co-morbidities (co-existing medical conditions in addition to the initial hemophilia diagnosis) commonly seen in aging hemophilia patients: cardiovascular disease (CVD), liver disease, cancer, renal disease and joint disease.

Previously, patients with hemophilia A (factor VIII deficiency) were thought to be protected against CVD – the leading cause of death in U.S. males since the 1950s. The study data present enough conflicting reports to not only call that theory into question but support the opposite conclusion. “Several coagulation proteins have been implicated as possible CVD risk factors, FVIII among them. Results from the prospective atherosclerosis risk in communities (ARIC) study, which included 12,681 participants from four U.S. communities, showed that the FVIII level progressively increases with age and is one of the established risk factors for CVD. Whether FVIII deficiency offers protection from CVD is unclear, however, and the literature contains conflicting reports,” stated the authors.

While HIV, HCV and joint disease are well-understood major complications facing the hemophilia community, the authors expressed particular “surprise” at the mortality rates associated with renal (kidney) disease. Findings from a prior study suggest that adults with hemophilia showed a 50-fold increased risk of death from renal disease when compared to the general population. Hypertension (high blood pressure), as the second most common cause of end-stage renal disease (ESRD) in the elderly, was mentioned specifically. The authors suggest that hypertension may be even more prevalent

in the older hemophilia population, leading to bleeding in the kidney. They also cited HIV, HIV/HCV co-infection and the presence of inhibitors in hemophilia patients as other factors contributing to renal disease. Other possible complications linked to renal disease are anemia, kidney failure and uremia, a toxic condition in which there is retention in the bloodstream of waste products normally excreted in the urine

The authors suggested multiple management strategies for each of these co-morbidities to help clinicians care for these aging patients. “The growing number of ageing persons with hemophilia is a testament to advances in haemophilia care that have occurred over the last two decades. Yet this newfound longevity carries with it the increased risk for age-related health issues not previously recognized in PWH, such as cardiovascular disease and cancer. Research efforts are increasingly being focused on the identification of optimal strategies to treat co-morbidities in older haemophilia patients,” concluded the authors.

Source: Konkle B, Kessler C, Aledort L, Andersen J, Fogarty P, Kouides P, Quon D, Ragni M, Zakarija A, Ewenstein B. Emerging Clinical Concerns in the Ageing Haemophilia Patient. *Haemophilia* (2009); Volume 15 (Issue 4): pages 926-931.

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EDUCATING GYNECOLOGISTS: NEW INFORMATION, BETTER TREATMENT

BY HEATHER BOERNER

The first time doctors told Sherri Revard that she couldn't have a bleeding disorder because she was a girl, she was 5 years old and had just had her tonsils out.

But it wasn't the last time.

Now 41, the hospice admissions nurse from Brownstown, Michigan, bled excessively as a teen, when severe pain and heavy periods made her miss two days of school a month. And it lasted into her 20s, when the birth of her three children—two of them twins born by Cesarean section—led to unexplained bleeding that lasted for days.

Eventually, Revard's gynecologist urged her to visit a specialist. At age 29, doctors discovered that her symptoms fit with many types of bleeding disorders, including hemophilia A and symptomatic carrier—but they diagnosed her with probable type 2 von Willebrand disease and a platelet dysfunction.

Across the U.S., women like Revard tell their doctors of heavy and painful periods, childbirth complications and other reproductive tract problems. And just as people in the bleeding disorders community are becoming more aware of women's unique experience with bleeding disorders, a movement is under way to educate their doctors.

"Only five to seven years ago, gynecologists lacked awareness about women and bleeding disorders," says Rezan Kadir, MD, OB/GYN and member of the obstetrics and gynecology department at the Royal Free Hospital in London.

When Kadir surveyed 500 gynecologists on their knowledge of bleeding disorders, only 5% to 6% said they would arrange appropriate testing to determine if their patient had a bleeding disorder. More than half suspected nothing when a woman presented with very heavy periods and said they would not take steps to rule out a bleeding disorder.

In reality, about 15% to 20% of women with heavy and painful periods have bleeding disorders.

An April 2009 monograph on the subject published in the journal *Treatment of Hemophilia* brings the point home. "Reproductive Health in Women with Bleeding Disorders" filters all the latest research on women with bleeding disorders and lays out appropriate diagnosis and treatment methods.

It reveals:

- Adolescent girls and perimenopausal women are likely to have the most reproductive tract symptoms from their bleeding disorders because they're least likely to ovulate and therefore experience erratic and longer periods.
- Women with bleeding disorders may have no symptom other than very heavy periods, including so-called "flooding" and passing of large blood clots.
- Painful periods are more common in women with bleeding disorders than in other women. In addition, some over-the-counter pain medications, chiefly non-steroidal anti-inflammatories, can worsen bleeding.
- Between 2% and 25% of women with bleeding disorders experience more bleeding with ovulation and hemorrhaging ovarian cysts than women without bleeding disorders.

Today, experts and organizations worldwide are drawing attention to women with bleeding disorders, including the National Hemophilia Foundation's Project Red Flag. Andra H. James, MD, director of the Women's Hemostasis and Thrombosis Clinic and associate professor of obstetrics and gynecology at Duke University Medical Center,

Continued on page 13



T Cells are Key Players in Immune Tolerance of Clotting Factor

Researchers from the University of Florida (UF) in Gainesville recently reviewed data that provide convincing evidence that regulatory T cells, called Treg, play a vital role in the prevention of inhibitor antibodies to clotting factors. Treg are a special type of T cell that suppress activation of the immune system. The findings could have positive implications for both factor replacement therapy and potential gene therapies for hemophilia. The lead author of the study was Ou Cao, MD, PhD, Assistant Professor, Division of Cellular and Molecular Therapy at UF.

Inhibitors are a major complication in the clinical management of hemophilia. It is both costly and difficult to treat. Approximately 10% to 30% of hemophilia A patients and 1%-4% of hemophilia B patients develop inhibitors, which occur when the body's immune system recognizes infused clotting factor as a foreign substance and releases antibodies to it. These antibodies attack the factor, neutralizing its therapeutic effects.

Cao and colleagues explained that Treg are an important part of the mechanism by which inhibitor formation can be prevented and tolerance to clotting factor could be ensured. Investigators concluded that whether naturally occurring or induced, these cells are “invoked” in the suppression of antibody responses to clotting factor. Treg is therefore crucial to tolerance, according to the authors.

While the risk of inhibitors with genetically triggered factor production is not fully understood, investigators believe Treg could apply to gene-based therapies as well, adding that the cells could become a key component in establishing tolerance to clotting factors in “gene- or protein-based therapies.” Cao and fellow authors explained that novel therapies and immune tolerance induction protocols could be developed with this insight into the workings of immune regulation.

Source: Cao O, Loduca P, Herzog R. Role of Regulatory T Cells in Tolerance to Coagulation Factors. *Journal of Thrombosis and Haemostasis* 2009; 7 (Suppl. 1): 88-91.

“Sleeping Beauty” Helps Correct Hemophilia A in Mice

Researchers from the University of Minnesota (UM) successfully increased factor VIII levels in mice with hemophilia A through a type of gene therapy that targets cells in the liver. The study was published in the *Journal of Clinical Investigation*. The lead investigator was Betsy T. Kren, PhD, Department of Medicine, UM Medical School, Minneapolis.

Kren and colleagues took nanocapsules (submicroscopic drug carrier systems made of an oily or watery core surrounded by a thin membrane) and coated them with hyaluronan, or hyaluronic acid, which helps cells bind more readily. They then enhanced the nanoparticles by encapsulating segments of DNA known as transposons. Also known as, “jumping genes,” transposons can move independently to different positions in the genome of a single cell, making them ideal for carrying therapeutic genes into targeted cells.

Investigators used the so-called *Sleepy Beauty* transposon, which was first discovered more than 10 years ago when a laboratory found that the seemingly outmoded gene could be “awakened” to become a key vehicle for transporting genetic material into the nucleus of a cell.

The hyaluronan-coated/*Sleepy Beauty*-encapsulated nanoparticles, further customized with the FVIII therapeutic gene, were then delivered to the liver. Measurements taken 5 and 50 weeks after the injection showed that FVIII levels and clotting ability improved significantly in the mice with hemophilia A. In addition, no inhibitor antibody response was reported. Researchers hope that these successful animal studies will eventually lead to human trials of this type of gene therapy.

Source: Kren T, Unger G, Sjeklocha L, et al. Nanocapsule-delivered Sleeping Beauty mediates therapeutic Factor VIII expression in liver sinusoidal endothelial cells of hemophilia A mice. *The Journal of Clinical Investigation*, June 2009.

co-authored the monograph with Kadir. The two have also published several studies on women with bleeding disorders in major North American and European gynecological medical journals.

“Gynecologists should have a low threshold of suspicion,” James asserts. “They should ask appropriate questions, help sort it out and consult a hematologist who has experience in hemostasis or a hemophilia and thrombophilia center for knowledge.”

“I hold my gynecologist up on a pedestal because it was a learning experience for both of us,” Revard says. “It’s something he didn’t have to take on, to learn. And I think it opened his eyes to other bleeding disorders people have.” ●



Project Red Flag
Real talk about women's bleeding disorders



NATIONAL HEMOPHILIA FOUNDATION

Project Red Flag: *Real Talk About Women's Bleeding Disorders* is NHF's public awareness campaign. The program is made possible by support from the Centers for Disease Control and Prevention (CDC) and CSL Behring. For more information about Project Red Flag, contact Kathleen Roach, NHF Director of Chapter Services: kroach@hemophilia.org.

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To Learn More...

- Contact HANDI, NHF's information resource center: 800.42.HANDI or handi@hemophilia.org.
- Read “Only the Beginning: First Decade Defines NHF's Women's Programs,” *HemAware*, May/June 2008, page 38.
- Read “Young Women Carry the Flag,” *HemAware*, July/August 2009, page 40.
- Read “The Diagnosis, Evaluation and Management of von Willebrand Disease” at the National Heart, Lung, and Blood Institute Web site: www.nhlbi.nih.gov/guidelines/vwd/index.htm.
- Read “MASAC Recommendations Regarding Women with Inherited Bleeding Disorders” on the National Hemophilia Foundation Web site: www.hemophilia.org/NHFWeb/MainPg/MainNHF.aspx?menuid=57&contentid=1192.
- To get involved in Project Red Flag in your community, contact Kathleen Roach, NHF Regional Director of Chapter Services: kroach@hemophilia.org.

Source: *HemAware Magazine*, September/October 2009, volume 14, issue 5.



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Hemophilia Alliance Endorses MASAC Pharmacy Standards

Acting on behalf of its member organizations, the Hemophilia Alliance has formally endorsed Recommendation 188 of NHF’s Medical and Scientific Advisory Council (MASAC), MASAC Recommendations Regarding Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients With Bleeding Disorders. The Hemophilia Alliance is an organization made up of 71 hemophilia treatment centers that either have or are seeking to have factor delivery programs under Section 340B of the Public Health Service Act. Recommendation 188, which was approved by MASAC on November 15, 2008 and adopted by the NHF Board of Directors on November 16, 2008, outlines a series of standards that all pharmacies that supply clotting factor directly to people with bleeding disorders are expected to meet. The standards cover things like knowledge and experience expected of pharmacy staff, ability to supply all clotting factor products and ancillaries, appropriate delivery of products within specified time frames, and many others.

In their letter of endorsement, Hemophilia Alliance President Joe Pugliese reported that “all 71 members of the Alliance meet or exceed the minimum requirements of MASAC 188.” The statement is in keeping with NHF’s request that all pharmacies that provide fac-

tor to report whether or not they meet the standards. NHF maintains and periodically updates a list of all pharmacies who have so reported. A copy of the list, along with the standards themselves, are available on the NHF Website at www.hemophilia.org under the MASAC section of “Researchers and Healthcare Providers.”

Specialty Pharmacies Self-Reporting Having Met or Exceeded MASAC Recommendation #188 Standards:

Accredo’s Hemophilia Health Services, AHF, Inc., ARJ Infusion Services, BioRx BioScrip Infusion Services Bleeding Disorders Resource Network, LLC, Care For Life, Chartwell Midwest Indiana CoaguLife Pharmacy, Coram, CVS Caremark, FactorSource America, Factor Support Network Pharmacy, The Hemophilia Alliance (71 HTC-based 340B Programs)*, Herdon Pharmacy, Matrix Health Group, MedPro Rx, Inc., National Cornerstone Healthcare Services, Inc., PrecisionRx Specialty Solutions, Specialty Therapeutic Care, Walgreens-OptionCare.

Member of the Hemophilia Alliance
University of North Carolina at Chapel Hill

Source: www.hemophilia.org



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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
Improving current therapies and developing new and better ways to manage hemophilia A—innovations inspired by listening to you.

For more information on Baxter programs and services, visit www.thereforyou.com. There when you need us **Baxter**

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Michelle's Law (H.R. 2851) signed by George W. Bush on October 9, 2008 becomes federal law effective **October 9, 2009**. College students are often covered under their parent's health insurance as long as they maintain full-time status (over 12 hours). Under Michelle's Law, a student, age 18-22, may take a **medical leave of absence** from school for up to twelve months without losing their full-time student status, ensuring a continuation of their insurance coverage. **Michelle's Law** prohibits insurance companies from dropping coverage on otherwise eligible students who are unable to stay in school full-time due to a serious illness or injury. The student's treating physician is responsible

for verifying the illness or injury and the necessity of the medical leave of absence.

H.R. 2851 was named in memory of Plymouth State University student, Michelle Morse, who passes away in 2005 at the age of 22. During her battle with cancer, Michelle was forced to remain a full-time student in order to keep her medical insurance coverage in effect. Michelle's Law – *"Because college kids should not have to make a choice between their education and maintaining health insurance."*

References: National Hemophilia Foundation, Advocacy Center, News: www.hemophilia.org, Michelle's Law: www.michelleslaw.com



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Healthcare Reform - National Hemophilia Foundation

Since 1948, NHF has worked to improve medical care, services, education, and safety and surveillance of blood and blood products. We've made tremendous progress since then. People with bleeding disorders in the U.S. have access to one of the best models of coordinated care through hemophilia treatment centers (HTCs), a model replicated all over the world and by several other disease groups. And though this community has undergone some dark periods, we've emerged with safe and effective life-saving treatments that have given future generations options their parents and grandparents never had.

Unfortunately, not everyone has the same access to care and treatment. For many individuals with bleeding disorders and their families, it has become an increasingly difficult struggle to get insurers to cover someone with a bleeding disorder outside of a large group health plan. As anyone who has encountered this situation knows, when an insurer eventually offers a policy to a person with a bleeding disorder outside of a large group health plan, often that policy is inadequate to cover their basic needs, too expensive, or includes restrictions such as lifetime insurance caps and pre-existing exclusion clauses that allow the insurer to not have to pay for the individual's care.

We have a chance to change the existing system to prevent insurers from denying health coverage to those who need it most--people with hemophilia and other bleeding disorders, and other chronically ill individuals.

Right now the debate over healthcare reform is taking center stage in our nation's capitol. Over the next several months, things will be moving at an accelerated pace as lawmakers attempt to restructure the healthcare system. Although NHF has not endorsed any specific legislative proposal, our public policy team is working to shape the policies that most impact the bleeding disorders community. Specifically, we are working to ensure health reform legislation include provisions that:

- Cover everyone,
- Curb costs responsibly,
- Abolish exclusions for pre-existing conditions, and
- Eliminate lifetime caps on health benefits.

NHF believes it's important that the community remain informed as the debate progresses, so we've created this Web site to provide regular updates on various healthcare reform issues.

We also want to hear from members of the community. Please feel

free to contact us with any questions and concerns about healthcare reform, or share your stories with us through our website at www.hemophilia.org.

Reliable information about healthcare reform can be found on the following Web sites:

- Kaiser Family Foundation (www.kff.org)
- Kaiser Health News (www.kaiserhealthnews.org)
- Families USA (www.familiesusa.org).
- "Thomas," the official Congressional Web site named for Thomas Jefferson (www.thomas.gov)

Source: National Hemophilia Foundation website, www.hemophilia.org

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Health Care Reform – Hemophilia Federation of America Statement on Health Care Reform

The Hemophilia Federation of America (HFA) strongly supports healthcare reform to ensure individuals affected by bleeding disorders have access to a healthcare system that provides high-quality, affordable, comprehensive and preventative health care services to all. The current system is both costly and inefficient, and does not provide care to all, particularly those with the greatest need. We believe Americans deserve a better health care system and that includes Americans with bleeding disorders!

HFA seeks to ensure the needs of the bleeding disorders community, in partnership with the broader rare disease community, is considered in any health reform discussion. The voices of the rare disease community must be heard and recognized during the health care reform debate!

HFA has been working with the rare disease community to develop health care reform principles in response to health care reform and are actively reaching out to congress and the administration to en-

sure our needs have the opportunity to be addressed.

HFA actively monitors pending and existing legislation as it relates to the bleeding disorders community and is committed to sharing this information with the community. You are invited and encouraged to read HFA's statement and position papers listed on their website at www.hemophiliafed.org. These documents are provided as education and background on some of the most pressing current legislative and policy issues today that could impact this community and include information on:

- Health Care Reform
- Single Source Provider
- PUC Principles (Plasma Users Coalition)
- Comparative Effectiveness Research (CER)

Source: Hemophilia Federation of America website, www.hemophiliafed.org

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- **Kaiser Daily Health Policy Report** summarizes the top health policy stories and opinions. It is usually sent by 10:15 a.m. ET each weekday;
- **Afternoon Edition** includes the latest updates to news summaries and KHN original stories, sent when news merits;
- **Breaking News** alerts you on major health policy news, as soon as it happens.

If you'd like to subscribe to any of these emails, please log in at www.kaiserhealthnews.org

Families USA's Health Action Network

The Families USA Health Action Network is comprised of organizations and individuals working towards the goal of high-quality, affordable health care for everyone. Sign up for e-mail updates on Medicaid, Medicare, prescription drugs, access to health care, pri-

vate insurance, minority health, global health, faith-based resources, and other important health care developments by choosing the topics and subscriptions you're most interested in. To sign up and learn more about Families USA visit their website at www.familiesusa.org



Important Medicare Dates

The open enrollment period for the Medicare Part D Prescription Drug Plans (PDP) is November 15 through December 31, 2009. Medicare beneficiaries can join, switch, or drop a PDP during this time period, and changes will take effect January 1, 2010. The Medicare Prescription Drug Plans are provided by private companies that sell drug plans approved by Medicare. The "Medicare & You" handbook beneficiaries will receive this fall will include information about the Prescription Drug Plans in North Carolina. The NC Seniors' Health Insurance Information Program (www.ncshipp.com) can provide enrollment assistance to Medicare beneficiaries of all ages by calling 800-443-9354. Information is also available by going to the Web site: www.medicare.gov and selecting "Compare Medicare Prescription Drug Plans" under "Search Tools."

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.

Calendar of Events

We have a busy year planned and thought we would share some of these HNC dates in advance so that you can mark your calendars. We anticipate adding more programs as we continue to plan our event. As those dates become available, we will let you know.

- Latin Union - Hispanic Heritage Month - September 26th*
- Blood Brotherhood - Managing Pain - September 26th*
- HNC on the Go - Pain Management*
- September 30th (Durham) & October 1st (Wrightsville Beach)*
- Latin Union Program - Raleigh - October 3th*
- 2009 Hemophilia Walk - October 17th*
- NHF Annual Meeting - October 29th-31st, San Francisco, CA*
- HNC Insurance & Health Care Symposium - November 14th*
- HNC Holiday Celebration - December 5th*
- "Hearts for Hemophilia" Casino Night - January 23rd, 2010*

The best resource for the latest information, registration and event updates is to visit the web site at www.hemophilia-nc.org.

Membership Application

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Cell Phone: _____

Email: _____

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



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Hemophilia of North Carolina is a chapter of the National Hemophilia Foundation, a chapter member of the Hemophilia Federation of America, a member agency of Community Health Charities of North Carolina, and a member of the NC Center for Nonprofits.