

THE CONCENTRATE



THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2007

“The best ever!”

“The best ever!” was heard repeatedly about the HNC Annual Meeting on June 2 at the Cabarrus Arena & Events Center in Concord. Over 100 members of the bleeding disorders community were in attendance as were representatives of 17 pharmaceutical companies and care provider groups. There was universal praise for the speakers and the special programs for old and young alike.

In the morning sessions we heard from two professional individuals, both severe hemophiliacs,

doctors, a hematologist, a pediatrician or internist, an immunologist, a hepatologist, etc. If any of your physicians are unwilling to be in frequent communication with you as well as with each other then Val says, “Fire them”.

Rich Colvin is a physician at Harvard University conducting research on inflammatory diseases and treating patients in his specialty of infectious disease. He shared with us the things which he had found in his own life to be the most important in achieving the goals he had set for him-



Val Bias and Dr. Rich Colvin. Val spoke to us about the importance of taking effective command of your disease and treatment. “No one knows better than you what works best for you. So, set goals and objectives with practical routes to their accomplishment and you will achieve.” Organize your life in ways that will facilitate ease and continuity in the things you do, even to such simple things as repackaging your meds in baggies for each day of the month. That way when you travel or go about any task, a baggie in your pocket, you can keep to your drug regime. Val also pointed out the great importance of being certain that your physicians are team players. Most members of our community have multiple

self. First among these, is the need to remain physically fit, which means participating in activity and exercise to the greatest extent possible. It is equally important to develop and maintain emotional and psychological wellness. In his concluding remarks Rich pointed out the tremendous value to him of his family and children in all of his endeavors.

During the morning sessions for the adults there were special programs for the children. A great favorite was “Reptile Rap”, a presentation of Discovery Place Museum on Wheels with an introduction to “Garcia” for an up close and personal meeting with the kids.

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On the Health Front

On the National & Legislative Front

Save The Date

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

Camp Carefree
July 22 – 28
Phone 336-427-0966

Victory Junction Gang Camp
July 30 – August 4
Phone 877-854-2267

CEO Young Adult Program
Ages 15-20 & Parents
August 14, 2007
Durham, NC

Mom's Night Out
August 18, 2007
Morrisville, NC

Women's Retreat
September 28 – 30
Lake Junaluska, NC

Junior National Championship
October 6, 2007
Glen Allen, VA

HNF 59th Annual Meeting
November 1 – 3
Orlando, FL



HEMOPHILIA OF
NORTH CAROLINA
PO Box 70, 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) 460-1536

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

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

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

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

Resource Information

LA Kelley Communications

Parent Empowerment Newsletter (PEN)
1-800-249-7977

www.kelleycom.com

Tools and information for families and individuals. PEN Newsletter provided free to our members of HNC.

Patient Notification System

1-888-UPDATE-U
www.patientnotificationsystem.org

This organization informs people when a blood product has been withdrawn or recalled. Free of charge but you must register.

World Federation of Hemophilia

514-875-7944
www.wfh.org

Centers for Disease Control & Prevention

1-800-311-3435
www.cdc.gov

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

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



From the Executive Director

Spring is almost behind us and we've been very busy with office moves, our Annual Meeting and preparing for this edition of The Concentrate. It's always amazing to me how fast time goes and there just never seems to be enough time in the day to get everything done. One of our projects this spring was to select the recipients of the BioRx/HNC Scholarships this year. As I was reading through the essays submitted, I was in awe of the accomplishments of the applicants. Despite their responsibilities with school and jobs, many also volunteered for multiple organizations. I was reminded about how important it is to get involved and how rewarding it can be to help someone in their time of need. In closing, I would just like to encourage everyone to take a step, no matter how small, toward getting involved with HNC and help the community we care so deeply about. We'd love to hear from you and talk about your ideas, stories and suggestions!

Sincerely,

Sue Cowell
HNC Executive Director



We are now a registered organization with the Food Lion Shop & Share Program. Each time you use your MVP card, a portion of your grocery purchase will be donated to Hemophilia of North Carolina. Please register your card today at www.foodlion.com or by calling 704-633-8250 x 3810. Our organization is listed as Hemophilia of North Carolina in Cary.

HNC 2007 Annual Charity Golf Tournament

Our tournament was a great success this year! The golfers and volunteers enjoyed a great day at The Preserve at Jordan Lake on June 22. Look for the upcoming article and pictures in our next edition of The Concentrate. Many thanks go out to our sponsors and volunteers who made this event such a success for HNC.

SUMMER CAMP SURVIVAL LIST

By Dale Michael Brisson

Maybe you're on your way to camp, or just got back, either way... here are some crucial tips to improve your next camp experience. As a seasoned counselor, I know it's never too early to start planning for that first day. After extensive research, a panel of experts has developed the following list of items guaranteed to enrich your week at hemophilia camp:

BALLOONS: Don't leave home without them. They should be first on everyone's list. Without these rubbery friends - you are defenseless against water projectile attacks from other campers. Standard size balloons are easiest to fill, aim, and throw. Water pistols may serve as an alternative.

YOUR FAVORITE LIMP: Everyone will have one. If you walk straight - you'll feel left out. If you don't have the standard limp, practice in front of a mirror before leaving home. Develop a gimpiness with style and flair.

A FRAMED PICTURE OF ANGELINE JOLIE: Sign it, place it by your bed and tell everyone she's your girlfriend.

FLASHLIGHT: Great for shining in the face of sleeping campers! Also, useful for those late night, illegal walks in the woods.

OLD CLOTHES: NEVER, NEVER bring new articles of clothing. It's no fun if you're clean all the time. Prepare to be muddy, sweaty, and dirty.

CAMERA: You'll want pictures of new and old friends. Additionally, a useful tool for blackmail purposes.

THE LATEST SLANG: You'll be a dorky geek if you can't word up. Chill.

SARAN WRAP: The most perfect product ever developed for secretly covering the women's commode. (Oooops! You didn't know that was me, did you?)

BOOKS WITH STORIES, SONGS & SKITS: A must for good camp productions on skit night.

RUBBER SNAKES, SPIDERS, VOMIT, ETC: The old stand-bys. Ideal for dropping in a roommate's bunk, cereal, or government lunch.

BIOGRAPHICAL RESUME: In case you have so much fun you forget who you are.

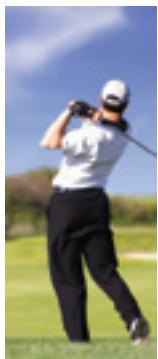
SENSE OF HUMOR: By far, the most important aspect of making any camp experience a complete success!

Dale Michael Brisson is a former HNC board member who's been living with hemophilia for more than half a century. His articles, stories, essays and poems have been published worldwide. Dale Michael Brisson is a writer from Salisbury, NC. DMB@2007



6th Annual Gettin' In The Game Junior National Championship

Presented by ZLB Behring



Are you interested in learning to play a new sport or looking to improve your baseball or golf skills? Do you just want to get outside for a day of fun with your family?

This regional event is being held this year on Saturday, October 6, 2007 beginning at 10:00am.

It will take place at the Virginia Crossings Resort in Glen Allen VA. Event activities for families and children include:

- Golf and baseball clinics for all skill levels
- A chance to meet with two Gettin' In The Game athletes – Perry Parker, Professional Golfer & Jesse Schrader, Professional Baseball Player.
- Family games and activities
- Complimentary lunch, refreshments and awards ceremony.

To register for this event please contact HNC at 1-800-990-5557 for a registration form or go online at www.CSLBehring.com. You must register before September 28, 2007.

MOM'S NIGHT OUT

Calling all Mom's! HNC will host a Mom's Night Out on Saturday, August 18th at the Breckenridge Development Clubhouse in Morrisville from 4pm-7pm. NuFACTOR and HNC cordially invite you to take some time off to enjoy yourself and other women of the North Carolina hemophilia community at our Mom's Night Out. Please join us for an afternoon of greeting card creation and then relax over dinner, dessert & conversation. For more information on this event or to RSVP, please contact Sue Cowell at 1-800-990-5557 or by email at info@hemophilia-nc.org.

Scholarship Information

BioRx Educational Scholarship Awards

After a very thorough review of the 36 applicants for the BioRx Educational Scholarships, the committee of three HNC board members chose the winners. The recipients of the awards are:

Celeste Schimmels of Kentucky;
Michael Weintraub of New Jersey and
Craig Wright of Tennessee

Each of the winners will receive a \$2000 scholarship pursue their education in healthcare related fields. Our thanks to BioRx for making this opportunity available to these individuals.

For the latest information on scholarship opportunities, please visit the National Hemophilia Foundation at www.hemophilia.org and the Hemophilia Federation of America at www.hemophilafed.org.



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H.R. 154: Ending the Medicare Disability Waiting Period Act 2007

Reprinted from the HFA website: www.hemophilafed.org

A number of advocacy groups have begun to lobby the U.S. Congress to revise a law that requires a two-year waiting period for disabled persons to become eligible for Medicare after they begin to receive Social Security disability benefits. Presently, the only exceptions to this rule are individuals with end-stage kidney disease or amyotrophic lateral sclerosis. An estimated 400,000 uninsured U.S. residents with disabilities are waiting to become eligible for Medicare.

When an individual with a chronic illness such as hemophilia reaches a level of disability which makes it no longer possible for him or her to continue working, there is a two-year waiting period before that person can begin to receive Medicare disability benefits. During this waiting period, the disabled person may not have access to adequate health insurance coverage, resulting in impoverishment and/or worsening of the disabling condition.

Rep. Gene Green (D-TX) has introduced a bill that seeks to eliminate the Medicare disability eligibility-waiting period. H.R. 154, known as "Ending the Medicare Disability Waiting Period

Act of 2007," would amend Title II of the Social Security Act to "(1) phase out the waiting period for disabled individuals to become eligible for Medicare benefits under SSA title XVIII (Medicare); and (2) eliminate the waiting period for individuals with life-threatening conditions to become eligible for such benefits." The Act also "Directs the Secretary of Health and Human Services to request the Institute of Medicine of the National Academy of Sciences to study the range of disability conditions that can be delayed or prevented if individuals receive access to health care services and coverage before a condition reaches disability levels."

Take action now to contact your U.S. Representative, urging him or her to support H.R. 154, the **Ending the Medicare Disability Waiting Period Act of 2007**.

For more information and to send an email to your representative, log on to www.hemophilafed.org, click on Advocacy, click on Legislative Action Center and then Legislative Alerts & Updates.



World's First Book on Inhibitors

Families of children with hemophilia and inhibitors have long been ignored educationally in the bleeding disorders community. Attending the first Novo Nordisk Inhibitor Summit meeting in the fall of 2005, author and mother Laurie Kelley witnessed their deep pain and need for education and mutual connection. "I had not seen such collective anguish in over ten years in our community," she says. "It was like a well kept secret." Even good friends who had children with inhibitors had managed to hide their struggles. The Summits bring education to the many who can attend, and Laurie knew it was time to reach everyone with inhibitors, everywhere. This year, Laurie will begin writing the world's first parenting book about inhibitors, called *Raising a Child With Inhibitors*. Funded with an unrestricted grant from Novo Nordisk, this book will cover all aspects of inhibitors, from diagnosis to teen years, from the medical to the psychosocial, in a language parents can understand. The book will be chockfull of practical information, advice, actual stories from families, and resources.

Laurie is requesting stories—and she would like any parent of a child with an inhibitor or patient with an inhibitor, to contact her to share their story. These collective stories will form the backbone of the book, addressing directly what parents want and need to know, based on what parents and patients tell her. If you'd like to be a part of this groundbreaking project, contact her at once at laurie@kelleym.com or 800-249-7977. Now's your chance to tell the world your story and share what you've learned for future parents and generations, so no parent or patient ever feels isolated or helpless again.

Authors on Staff

Our congratulations go out to two HNC Board Members on their recent accomplishments as authors in the community.

Richard Atwood, MA, MPH, is the newest columnist for PEN Newsletter and will be a regular contributor. Richard has written several articles for the publication including his most recent, "Bleeding Hearts" in the May 2007 edition. Richard serves as Secretary on the HNC Board of Directors.

Andrea Brill was recently contacted by Laurie Kelley, President of LA Kelley Communications that her story she documented on parenting experiences will be included in Laurie's upcoming book, *Raising A Child With Hemophilia* (Fourth Edition), which should be available at this year's NHF Annual Meeting. Andrea serves as Treasurer on the HNC Board of Directors.



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"The Best Ever" continued from page 1

During lunch HNC's new Executive Director, Sue Cowell, was introduced by our acting president Matt Barnes. Reports were presented on finances and chapter plans for the coming year. Ed Wilson, head of the nominating committee, presented the slate of Officers and Directors and called for additional nominations from the floor. Matt Barnes was elected president; Andrea Brill, Richard Atwood, and Warren Jewett are directors for the coming year. An invitation was put forward for participation by any of the attendees as volunteers or board members of the chapter.



The afternoon was crammed with presentations and activities. Anita Smith presented, "Living with Hemophilia", a program on practical tips for the family and dealing with some of the challenges they may face. Penni Perez spoke on the A.C.C. E.S.S program with information on insurance options and how to best manage your health care. Keith and Janice Slack, members of our community, were available for a book signing of their new book "NASCAR's Hidden History". Chris Barnes was busy crafting with all the kids during the Buddies Program and making lots of fun items to take home.

At intervals during the afternoon groups left for a special Lowes Motor Speedway event, a thrill ride around the track. Returning to the Events Center from the ride people could see, up close, the Rahmoc Race Car in which each kid got a chance to sit in the driver's seat for pictures. Virtually everyone got a chance to take home a souvenir picture of them behind the wheel.

At the end of the afternoon 10 door prizes were awarded including Ipods, a portable DVD player, a luggage set and gift cards. The announcement of a tie was made on our first ever Art Contest. Casey & Bennett Barnes both were first place winners for their artwork and received tickets to Carowinds Amusement Park. It was, indeed, a wonderful day and for Hemophilia of North Carolina the best ever.



We gratefully acknowledge the pledge of support from the following sponsors for the 2007 HNC Annual Meeting

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Building A Better Site!

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We would like to acknowledge the generous donation of a \$4000 grant by Wyeth to assist the Chapter in developing our website and publications. This grant will allow us to create a more interactive site with updated information and resources. Also, our goal this summer is to create some additional resources for distribution through the HTC's and other facilities to new families affected by bleeding disorders. Our thanks to Wyeth for their continued support and efforts to help build the new HNC!



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 or by calling 800-990-5557.

CEO Program & Durham Bulls Game *Career, Education & Opportunities*

On Tuesday, August 14, 2007, HNC will host this program designed for young people (15-20 years of age) that are affected by a bleeding disorder and transitioning from adolescence to adulthood. The program will be held in Durham near the Durham Bulls ball park.

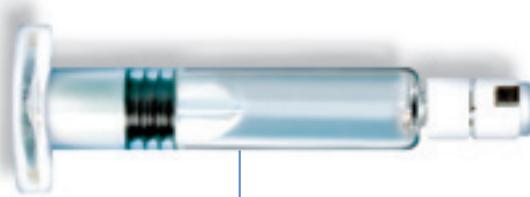
Young Adults and their parents/guardians are encouraged to attend this day-long program that is packed with fun interactive activities that help young people learn about their individual strengths and interests. During the CEO event, adolescents will focus on goal setting, career planning & financial understanding. Parents will have their own track

that runs concurrently with the young adult program.

The CEO program is professionally facilitated and made available to us by Baxter. At the conclusion of the program all attendees will enjoy a dinner and a ballgame at the Durham Bulls Park sponsored by HNC beginning at 7:00pm.

For more information on this program or the RSVP for the event, please contact Sue Cowell at 1-800-990-5557 or by email at info@hemophilia-nc.org. Space is available on a first come, first serve basis.

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Change in the Marketplace...

More Consumers will have to get Factor Product from Specialty Pharmacies in 2007

By David Linney

The following article pertains primarily to individuals with employer-sponsored insurance plans. Medicaid specialty pharmacy programs are not addressed in this article. This article appeared in the September/October 2006 issue of HemAware, a publication of the National Hemophilia Foundation.

In 2007, insurance companies will require more consumers with bleeding disorders to obtain their factor products from specialty pharmacies. In 2008, those numbers will be even greater.

Specialty pharmacies provide biotechnology drugs that are very expensive. Most biotech drugs are either infused (intravenous) or injected (intramuscular). As a category, these drugs are commonly referred to as "specialty pharmacy drugs". Factor products are specialty pharmacy drugs.

Specialty pharmacies sometimes are associated with drug plans known as pharmacy benefit managers (PBM's) and a limited number of health plans. Specialty pharmacy services which focus on the effective cost management of high-cost specialty pharmacy drugs (through efficient purchase, supply and programming), are marketed to payers.

Payers, including employers and insurers who pay for pharmacy bills, have become very interested in using specialty pharmacies to try to reduce their overall drug costs. Interest has risen in direct response to the large number of specialty pharmacy drugs expected to enter the marketplace over the next few years. Payers are concerned that their drug costs will increase dramatically as these new therapies become available.

Until a few years ago, factor products were

covered almost exclusively as a health plan benefit. While this is still common today, there is a strong, growing trend to change factor products coverage to a separate drug-plan benefit. Many payers have determined that it is easier to manage drug costs through a drug plan than through a health plan because it is quite difficult to track and manage specialty pharmacy costs through the medical claims review process of a health plan.

Type of Specialty Pharmacies **PBM Specialty Pharmacies**

A PBM is a pharmacy benefits manager. For consumers, a PBM is a drug plan that provides pharmacy benefits separate from the health plan.

PBM's contract with employers and insurers to be the fiscal managers of drug benefits for the group's members. They develop and manage formularies (listings of approved drugs). PBM's typically have a network of retail pharmacies to supply prescription drugs and a mail order pharmacy that may supply up to several months' worth of regularly prescribed drugs.

As more PBM's pop up in the marketplace, a number of them either have or are developing a specialty pharmacy to supply drugs like factor products. The three largest PBM's, in order of size based on covered lives, are Caremark, Medco and Express Scripts. Together, they service more than 200 million policyholders, or approximately two-thirds of the marketplace. Each has its own specialty pharmacy.

Caremark's self-named specialty pharmacy

became an even more significant force after it acquired AdvancePCS in 2004. Medco acquired Accredo Health, Inc., in 2005 to create its current specialty pharmacy services, including Hemophilia Health Services, which is dedicated exclusively to hemophilia care. Express Scripts acquired CuraScript Pharmacy and CuraScript PBM Services in 2004 and Priority Healthcare in 2005, creating CuraScript, its specialty pharmacy.

Having a drug plan, though, does not mean it will automatically cover your factor products. Currently, factor products remain more commonly covered under health insurance plans.

The sponsor of the health insurance plan—commonly, the employer or an insurer—decides if it will include specialty pharmacy drugs, including factor products, as a benefit of the drug plan (If the sponsor does not include specialty pharmacy as a drug-plan benefit, then the factor products usually will be covered under the health plan). The outlook for 2007 is that more employers and insurers will contract with PBM's to supply specialty pharmacy drugs, including factor products.

So if you have a drug plan in 2007, it's very important to verify coverage and supply of factor products for the coming year. Look at your insurance card(s) and call the drug plan number on it. (Most of us have either a health insurance card with a drug plan listed or a separate drug plan card). For further assistance, contact your hemophilia treatment center (HTC), physician or factor product vendor.

Continued on page 10



Changes in the Marketplace

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Health Insurance Plan Specialty Pharmacies

Some health insurance plans that provide pharmacy benefits in addition to health benefits have established their own specialty pharmacies. Three of these are Aetna, Cigna and WellPoint. Aetna requires the use of its own specialty pharmacy or an Aetna-approved HTC factor product. Cigna urges—but does not exclusively require—the use of its specialty pharmacy, Tel-Drug. WellPoint's specialty pharmacy, Precision Rx, is its exclusive option.

If you have Aetna, Cigna or WellPoint, be sure to check out the company's required use of specialty pharmacies associated with the health plans in 2007. Call the plan number on your health insurance card. For further

assistance, contact your HTC, physician or factor product vendor.

Impact for Consumer

The trend toward coverage of factor products as a drug benefit brings both positive and negative changes for consumers.

PROS OFTEN INCLUDE:

- No lifetime limit.
- Low out-of-pocket expenses (many drug plans only have a co-payment).
- Potential use of a PBM that provides high-quality service supplying factor products to consumers.

CONS MAY INCLUDE:

- Decreased ability to select a factor product vendor (i.e., a homecare company), as payers

likely will increasingly require the use of specialty pharmacies.

- Little or no recourse in having to use a specialty pharmacy (unless, perhaps, quality of service is below accepted standards).
- Decreased ability to use current factor product vendor if that vendor is an HTC factor product program or another factor product that is not a PBM.
- Newer specialty pharmacies with little experience supplying factor products. Follow up with your HTC or physician to advocate for a reputable, high-quality service and contact both your local chapter and the National Hemophilia Foundation.
- HTC factor product programs likely will lose some of their customer base, which will decrease critical revenue used to support essential HTC services.

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Women's Retreat

This educational retreat is open to women with bleeding disorders and will take place Friday afternoon, September 28, through Sunday morning, September 30. It will be held at the Lake Junaluska Conference & Retreat Center in Lake Junaluska, NC (near Asheville). All transportation, lodging and food costs for the women in attendance will be covered. The retreat will be open to about 25 women from North Carolina, South Carolina, Kentucky and Tennessee. For more information on the retreat, contact Steve Humes, Regional Coordinator – UNC at shumes@email.unc.edu.



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For important safety and use information, please see full Prescribing Information at 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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Meeting Health Challenges

*This article appeared in the Accordant Care Connections – Hemophilia
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You may have recently learned that you or your child has hemophilia. Or you may have lived with it for some time. Either way, you've probably faced one or more of the many challenges or changes that can come with having a chronic health condition. And you may already have tried one or more ways to "cope" or adapt to meet these challenges. Some ways may have worked well, others not so well.

Unfortunately, there is no magic formula or one best way to cope that works every time for every person. You must find ways that fit well with your own style and situation. Here are some tips that others have used and found helpful in meeting their health challenges:

- Think about ways you've used to meet challenges – in the past – that worked well for you. Consider using them again.
- Health challenges may require you to give up control over some parts of your life.
- Adopt a positive approach. Focus your attention on what you can do.
- Set realistic goals that you know you can meet.
- Accept help and support from those who care about you.

Know that it's OK to ask for help when you need it.

- Speak openly with your doctors, program nurse and other members of your healthcare team about your needs and feelings.
- Look for healthy ways to express feelings and emotions that may surface. Find a support group in your community. Or talk to your doctor or program nurse about other options.
- Learn as much as you can about your hemophilia from trusted sources such as your doctor or program nurse. This way you'll have the information you need to make plans and decisions that are right for you.
- Time spent in activities such as prayer, inspirational reading or meditation may offer solace, comfort and stress relief.
- Find a balance in your life. Look for and spend time in activities that give you pleasure and allow you to be creative.
- Keep a hopeful outlook and sense of humor.
- Reflect on ways you have grown as a person or on relationships that have deepened as a result of meeting your health challenges.

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Advice For Managing Heavy Periods

By Bruce Goldfarb

This article appeared in the March/April 2007 issue of *HemAware*, a publication of the National Hemophilia Foundation.

For the more than 2.5 million women in the US with bleeding disorders, birth control pills are a double-edged sword. While drugs such as desmopressin acetate (DDAVP) or amino-caproic acid (Amicar) are helpful for many women, combined hormone contraceptives are often the first choice of treatment to control heavy or prolonged menstruation, also known as menorrhagia. Although they remedy the symptoms of menorrhagia, hormone contraceptives interfere with reproductive decisions and in some cases put women in a moral quandary.

Troubled with prolonged menstrual periods her whole life, Amy McFarland wasn't diagnosed with type 1 von Willebrand disease (VWD) until after the birth of her youngest daughter, now three years old. The 33-year-old mother of two, who works as an event planner in suburban Philadelphia, had periods that often persisted for nine days each month – a nuisance she prefers that her daughters, both of whom have VWD, not face in the future.

For some, menorrhagia is more than a nuisance-anemia is one of the most common physical effects of this condition. Women with menorrhagia should have regular blood tests to make sure they aren't anemic. Tests for anemia include the hematocrit and measurement of levels of hemoglobin and ferritin, which assess the body's stores of iron. In general, anemia is considered a hematocrit below 31%, a hemoglobin level below 12.1%, or a ferritin level below 12 ng/ml.

Iron supplements can help correct anemia. University of Pennsylvania hematologist Barbara Konkle, MD, says that all women with menorrhagia should take over-the-counter

dietary iron supplements or choose iron-fortified foods. The biggest risk of iron supplements is taking too much, which can lead to problems such as abdominal distress and constipation. Konkle suggests that women who experience side effects from iron supplements should either try a lower dose or a different brand.

Managing Menorrhagia

Prolonged or heavy period can deeply affect a woman's self-image, compounding the physical aspects with isolation and depression. "As a teenager, you're always worried and self-conscious," says McFarland. She says it made her wonder, "Will I have to get to a bathroom in a hurry? It's very awkward."

Fortunately, many women with VWD and other bleeding disorders are helped by combined hormone contraceptives. Although commonly referred to as "the pill", hormone contraceptives are also available as a patch and in a vaginal ring. A newer type of oral contraceptive, called a seasonal contraceptive, limits menstruation to four times a year. Another recently introduced product, an intrauterine device (IUD) that releases low levels of hormones, may be helpful to control menorrhagia for women past their childbearing years. Your doctor is the best source of information about options for menorrhagia.

Hormone contraceptives work by preventing ovulation and thinning the lining of the uterus, interfering with the implantation of a fertilized egg. By stopping the menstrual cycle, the problem of heavy or prolonged periods is kept in check.

Hormone contraceptives also increase the level of clotting factors in the blood, which

raises the risk of blood clots in some women, but is a beneficial effect in those with bleeding disorders.

Planning for Baby

In many cases, hormone contraceptives raise more questions than answers.

Although hormone contraceptives can control menorrhagia, they must be stopped when couples, such as McFarland and her husband Joseph, decide to have a baby.

"With the exception of fibrinogen deficiency or factor XIII deficiency, most women with bleeding disorders can carry a pregnancy," says Andra H. James, MD, a hematologist at Duke University Medical Center. "With fibrinogen deficiency or factor XIII deficiency, they tend to miscarry. Women with other bleeding disorders are usually successful, but they may need some help during the pregnancy."

Once a woman becomes pregnant, menorrhagia is no longer an issue. But the bleeding disorder can still present problems during pregnancy, says James.

"Generally, we believe that if your bleeding disorder is so severe that we have to give you prophylaxis during menstruation or ovulation, you're at risk of bleeding during pregnancy," she says. "And if not during pregnancy, then there is a risk of bleeding after delivery."

Coming off hormone contraceptives is relatively easy—a woman simply stops taking the pills. Fertility can return almost immediately.

To reduce the risk of problems during preg-

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nancy, a woman with a bleeding disorder should consult with members of the hemophilia treatment center (HTC) team first.

"Getting pregnant has to be a planned process," says Dawn von Mayrhauser, MSW, social worker at the University of Connecticut Hemostasis and Thrombosis Center in Farmington, Connecticut. "An unplanned process sets you up for a pregnancy with bleeding afterward, or termination, which can be dangerous for a person with a bleeding disorder."

If a woman has a bleeding disorder, a delivery or termination of pregnancy should be done at a medical center affiliated with

an HTC, with the involvement of a hematologist, Ob/Gyn, anesthesiologist and other health providers who are experienced with bleeding disorders.

Moral Issues

Aside from squelching troublesome menstruation, hormone contraceptive therapy can raise moral or value-based issues that can make patients and parents uncomfortable. Some religions frown upon contraceptives. Many parents, including McFarland, are also concerned about the unsavory reputation that may be linked to a young girl who uses contraceptives.

McFarland says that her older daughter, now five, will likely need hormone con-

traceptives when she reaches puberty. "My husband would probably cringe if I told him that," she says. "Do I explain the other effects to her? You don't want the stigma attached to contraceptives. I don't know how to address that. Fortunately, we have a few years to think about it."

Health providers and patients may find it helpful to call the drug "hormone therapy" rather than use a hot-button term like "contraceptive." Also, women who take hormone contraceptives, whether to manage menorrhagia or not, must keep in mind that they offer no protection against sexually transmitted diseases.



NHF's 59th Annual Meeting

Get Your 2007 Travel Grants Soon

Now is the time for the first-time attendees at this year's 59th Annual Meeting to apply for one of NHF's 5th Annual Travel Scholarships.

The program provides funding for the event, which will be held November 1-3, 2007, at the Orlando World Center Marriott Resort in Florida. Applications are available online at the NHF website: www.hemophilia.org. New: This year NHF has funding for 1st time families and individuals who are dealing with inhibitors to attend. This year's meeting includes a special three-hour inhibitor symposium for families and individuals on Thursday, November 1. For more information contact NHF Education Coordinator, Sonia Roger: sroger@hemophilia.org or call (800) 42-HANDI. *Hurry, applications should be postmarked by Friday, June 29, 2007.*



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Meeting with NC Department of Health and Human Services

On Wednesday, May 30th, members of HNC had a meeting with Secretary Carmen Hooker Odom and members of her staff including, Patti Forest, MD, MBA, Director's Office – Medical Director and Thomas D'Andrea, RPH, MBA, Section Chief – Pharmacy & Ancillary Services.

Present at the meeting from HNC were Sue Cowell, Executive Director and Kathy Register, longtime member and advocate for HNC. The meeting was made possible and also attended by Mr. Jim Haase, Bayer-Senior Regional Manager, State Government Affairs.

We were fortunate to have the opportunity to discuss the high risk pool pending in the legislature at this time, insurance topics and the resources available through the NC Department of Health and Human Services. Follow up meetings have been scheduled to further discuss the Vocational Rehabilitation programs and other opportunities that may be available to members of HNC. We would like to take this opportunity to thank Secretary Hooker Odom and her staff for taking the time to meet with us.

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Bills to Create a High Risk Pool Pending in the North Carolina General Assembly

The North Carolina General Assembly is considering bills that would eliminate guarantee issue policies in the state but would create a high risk pool for those that can not find health insurance. There are several bills pending: House Bill 265, Senate Bill 163 and Senate Bill 177. The House bill has been moving thru committees and this issue will eventually be considered in the Senate.

Hemophilia of North Carolina and various factor manufacturers and home care companies are lobbying the General Assembly to incorporate a few measurers in the bill that would help those with bleeding and clotting disorders.

1. Eligibility: We are advocating for the automatic inclusion into the high-risk pool for any person with a diagnosis of a bleeding disorder. This would help eliminate having to jump through all the hoops for those with hemophilia to qualify.
2. Lifetime Cap: We are concerned that although there is no lifetime benefits cap in the legislation, the Board

could impose a cap at some later point in time. The Board could ultimately be faced with the dilemma of either imposing a lifetime benefits cap on existing enrollees or limiting new applicants admission to the plan. We are seeking an amendment to the bills that would say: "The rules shall not include a lifetime limit for covered individuals with congenital or acquired chronic illnesses."

Hemophilia of North Carolina has been to the capitol twice to lobby on these amendments, once to testify in the House Finance committee and another to lobby key Senators on the measure. We will be working diligently during the summer to try and solidify these amendments to the bills in an effort to protect insurance access for the community.

If you have any questions about the bills or the process please feel free to contact Sue Cowell, HNC Executive Director at 1-800-990-5557 or Elizabeth Stoll with Baxter Healthcare at 404-217-7618.

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A Successful Day!

We had a wonderful turn out at our Hemophilia Awareness Day event in the Legislative Building on May 15, 2007. The day began with a wonderful lunch (compliments of Bayer) where we had a chance to chat and talk about the days events. After that, we had a private audience with the Speaker of the House, Representative Joe Hackney and Representative Bob England, M.D., who was the primary sponsor of the bill.

In our meeting we discussed the current status of the High Risk Pool Bill (HB 265), the need for adequate healthcare coverage



for all, challenges facing the community and additional funding needed for HTC's. We were very impressed with the questions that Representative Hackney posed and his interest in hemophilia. Representative England has treated patients with hemophilia in his practice and has long been a advocate for the community.

At the conclusion of the meeting, we moved to the Legislative House Chamber where the Speaker of the House acknowledged those in the audience from the hemophilia community. The bill that is going for signature to law will designate May as Hemophilia Awareness Month in North Carolina each year.

Our next opportunity to celebrate this milestone will be when the Governor signs the bill into law. We should, once again, use that as an opportunity to discuss items of interest to the community and acknowledge the recognition we are receiving. As soon as the date is available, we will send it out.

We also would like to thank Mr. Jim Haase, Bayer - Senior Regional Manager, State Government Affairs, for his efforts in guiding this act through the process.

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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:

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We are actively seeking individuals who have an interest in serving on the HNC Board of Directors. Responsibilities of a board member are:

- Attend monthly board meetings by phone conference and quarterly face to face board meetings – different locations.
- Elected for two-year terms.
- Disclosure of the following information –
 - Candidate's particular relationship to hemophilia or other bleeding disorder;
 - Whether the candidate, or any member of the candidate's immediate family (parent, spouse, sibling or child) works for any industry catering specifically to the hemophilia or bleeding disorders community;
 - Other organizations within the hemophilia and bleeding disorders community to which the candidate belongs or serves as an officer or director;
 - Whether any member of the candidate's immediate family serves on, or is also a candidate for, the Board of Directors, and;
 - Any other matters that the candidate believes to be relevant to his or her ability to serve on the Board of Directors.

If you are interested in making a difference in the community and can dedicate an average of 3-4 hours per month (mostly by phone), please give us a call at (800) 990-5557.

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HNC is a member of:

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Community Health Charities

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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