Refresher & Renewed — Couples Retreat Huge Success!

Twenty-five couples attended the recent HNC Couples Retreat in Concord, NC on March 1st & 2nd. During the program we enjoyed a delicious breakfast and lunch prepared for us by the staff at Embassy Suites. The group had a chance to visit with our sponsors and then attended a workshop presented by Inalex Communications and their speaker, Jack Kakolewski.

The program included introductions and warm-ups, which were very enlightening. We then explored relationships, dealing with differences, disappointments, failures and finding ways to repair and heal disconnects. Topics and exercises also included emotional dependency and connectedness, intimacy and most of all, renewal and hope.

The workshop was filled with fun, humor and lots of opportunities for the couples to rediscover

Continued on page 4

NHF is On the Road to Durham!

A Celebration of 10 Years of Activism on Behalf of Women in the Bleeding Disorder Community

Project Red Flag: Real talk about women’s bleeding disorders Durham, NC — May 16-17, 2008

2008 marks the tenth anniversary of NHF’s outreach, education and activism for women with bleeding disorders. It is indeed a cause for celebration and we are fortunate to have it take place in our state.

The NHF On the Road conference will take place on Friday and Saturday at the Sheraton Imperial Hotel and Convention Center located at 4700 Emperor Blvd in Durham, NC. The

Continued on page 5
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.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 & Medical Resources

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

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

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

**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

**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**
201-493-1399
www.inalex.com

**HIV/HCV Newsletter**
Hemophilia Association of the Capital Area
www.hacacares.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 couldn’t be more proud than to be standing in Washington, DC at the recent HNF Washington Days conference with eight other individuals who represented North Carolina. We were no doubt one of the largest contingencies represented at the event. It was energizing to hear from all of the other states and their progress in advocating for the needs of their members and being able to meet with representatives to discuss important issues. That being said, we know we have a long way to go and an uphill challenge with health care reforms and having our issues heard over the loud cries of many organizations.

It is now time to focus our efforts on a local level and make our voices heard in Raleigh! Our Legislative Day is scheduled for June 10th where we will have an opportunity to meet with our local representatives, share our stories and let them know how important their support is to the community. We have an exciting day planned and need everyone to come out and join us for the wonderful opportunity.

We are also excited to announce an expansion of the Chapter to form regional groups. Efforts are underway now to identify locations around the state to host the meetings. We realize the difficulties that some members face in traveling to the events and hope that the regional groups will be more convenient and another opportunity to meet other individuals and families in their area. With our membership expanding rapidly, this is a great time to expand. If anyone is interested in coordinating a group in their area, please contact me. Look for upcoming announcements on this initiative.

Sincerely,

Sue Cowell
Sue Cowell
HNC Executive Director

THE CONCENTRATE

Winter 2008
Couples Retreat Huge Success! Cont.

their relationships.

At the conclusion of the workshop, everyone had a chance to get settled in their room at the beautiful, new Embassy Suites and enjoyed a beverage at the Manager’s Cocktail Reception in the lobby. That was followed by a wonderful dinner in their private dining facility, The Rocky River Grille. The evening came to a conclusion with an amazing performance by Adrian the Magician who wowed everyone with his close up card tricks and parlor show where the whole audience got involved!

Our many thanks to Joe Caronna, President & Co-Founder of Inalex Communications, a non-profit organization that conducts workshops for the community, for an outstanding program for our members. The presentation from Inalex Communications was made possible through a grant by Baxter BioScience.

We would like to graciously acknowledge our sponsors who made this program possible:

EVENT SPONSORED BY:

HNC Awarded Project Red Flag Grant

Women’s Task Force Now Forming

HNC has been awarded a grant from Project Red Flag to provide outreach and education about women and bleeding disorders in the state. A Women’s Task Force is now forming and the initiatives of this group will be to present information at educational symposiums, collect data and increase awareness in the medical community and general public. We encourage you to get involved with this wonderful opportunity and welcome all members. If you are interested in joining the Women’s Task Force, please contact HNC at (800)990-5557 for more information.
The Concentrate

Winter 2008

Chapter News & Information

NHF is On the Road to Durham

conference will include a focus on where we started, what we’ve achieved over the course of the last ten years and what we plan to do going forward. On Saturday, we will explore the state of art in screening, testing and treatment, how to effectively use the new NHLBI guidelines, look across the lifespan at challenges specific to women in the bleeding disorders community and examine cause marketing strategies and activism campaigns for women’s causes. Also addressed will be issues for carriers and women with low levels of clotting factor. A special dinner is planned for Saturday to pay tribute to five individuals who paved the way for Project Red Flag.

All members, male & female, are welcome to attend the conference and we encourage you to join us for this wonderful opportunity. Registration forms are available through HNC by calling (800) 990-5557 or email us at info@hemophilia-nc.org. There is no charge to attend the conference. Travel grants may be available for hotel rooms if needed, ask HNC for more information.

Men’s Program & Fishing Trip

Saturday, June 28th
Lake Norman

Look for information shortly on an upcoming men’s program and half-day fishing trip on Lake Norman in Charlotte, NC. The day will begin with breakfast followed by a presentation. Then the group will head to the boats for a great time on the water where all the equipment will be provided. This trip will be available for all men 18 years of age or older who have a bleeding disorder or are a parent of a child with a bleeding disorder. Registration forms will be available very soon for this exciting event so save the date!

For more information, please contact your local Bayer HealthCare Account Executive Spencer Miller, at (803) 319-7114, or by e-mail at spencer.miller@bayer.com.
It may take a village to raise a child but, it takes an army to host a walk! We are excited to announce our walk-a-thon that will be held this fall at Lake Crabtree County Park in Morrisville, NC. The walk is an inaugural collaboration between the National Hemophilia Foundation and Hemophilia of North Carolina. This is a great opportunity for our local chapter, a chance to educate people about the bleeding disorders community and an event where every member can get involved!

You can start or join a team, sponsor a walker, volunteer, become a Team Captain, sponsor the walk or organize a group from your local area to participate! The opportunities to help support the walk are endless and will be very rewarding.

Walkers will receive complete support during their scenic walk along the lake with rest stops, traffic control and lots of activities. The park welcomes strollers, pets, wheelchairs and all trails are nicely paved for easy access!

We invite you to join us for our initial information/volunteer meeting on Wednesday, May 7th at Luther Café located at Christ the King Lutheran Church, 600 Walnut Street – Cary, NC, 7:00pm-9:00pm.

At the meeting, you will hear all about the walk site, how to start a walk team and become a Team Captain, sponsorship opportunities and many other details! Come join us, enjoy a beverage & dessert, relax and get inspired for what is sure to be a wonderful event!

For more information about the upcoming meeting or the Hemophilia Walk 2008, please contact Sue Cowell at (800) 990-5557 or info@hemophilia-nc.org. More information and walk registration will be available on our web site shortly.

Matrix Health
Dedicated to Making a Difference in the Lives of People with Hemophilia and Other Bleeding Disorders

When you are ready for homecare services that go beyond the ordinary...

Contact Your Regional Care Coordinators:
Matt Igelman 919-699-1972
migelman@matrixhealthgroup.com
Matthew Compton 919-931-1761
mcompton@matrixhealthgroup.com
Donna Compton 919-270-8382
dcompton@matrixhealthgroup.com

Visit Our Website! www.matrixhealthgroup.com
HNC 4th Annual Charity Golf Tournament

Friday, April 25th
The Preserve at Jordan Lake
Chapel Hill, NC

Come join us for a fun day of golf at the HNC 4th Annual Charity Golf tournament! The course is great, food is excellent and it is a great opportunity to support the Chapter. Registration forms and sponsorship opportunities are available on the web site at www.hemophilia-nc.org or by calling (800) 990-5557.

We are excited to announce our guest player, Perry Parker, who will be on hand for a Beat-the-Pro contest and other great activities! Perry is a PGA Professional and Gettin’ in the Game athlete that has worked with the bleeding disorders community for years at the Junior National Championships. This is a wonderful chance to bring the kids along and learn from the best!

In addition to players, we are also looking for volunteers on the day of the event and donations towards our gift basket raffle!

When Only the Best Homecare Will Do!

Since 1989, AHF has set the standard for quality bleeding disorders home care. The AHF pharmacy works exclusively with bleeding disorders...you are our only business. Our specialists will design a care program that is personalized for you. As a result, AHF receives a rating of nearly 100% satisfaction from our clients. Remember, it is your right to choose the very best home care company to meet your family’s needs.

- Delivering overnight with 24 hour-a-day client services support
- Providing the full range of clotting medications and ancillaries
- Answering your calls with a real person, round-the-clock
- Arranging home infusion nursing services
- Negotiating insurance reimbursement

Returning a large percentage of all proceeds back to the bleeding disorders community.

For further information contact:
Shirley Moorehead  866-243-4621

www.AHFinfo.com

Setting the Standard of Homecare for the Bleeding Disorders Community

31 Moody Road, P.O. Box 985, Enfield, CT 06083  800-243-4621  AHF@AHFinfo.com
The “Bloody” Ring Tone
By Laurie Kelley

I’ve rediscovered ring tones. It happened a few weekends ago at the home of Kerry Fatula, executive director of the Western Pennsylvania Chapter of the NHF, who I was interviewing for my newest book. While chatting in the kitchen we heard a ring tone and everyone went silent, wondering whose cell phone it was. It was the dinosaur in “Jurassic Park III” (on TV), you know, the one who swallowed the cell phone and then... well, if you know the movie you will know the outcome. We all acknowledged that has to be the most famous ring tone in history.

Kerry Fatula and I thought it would be funny if she and I had our own ring tone and we began listing tunes we like and which would make us laugh when we think of each other. I’ve been using the odd little pings and rings provided by Apple, which are kind of lame. When I use them, I can hear a distinctive noise come on and know immediately who I do not want to answer. (Kerry is not one of those.)

So I thought it would be fun if I selected ring tones for each member of my family. This gets to be very fun and creative, and addictive. I am still trying to find one for Kevin. Hmm, a long, long time ago (21 years to be exact) we each suggested songs for our wedding. I picked Tina Turner’s “Better Be Good to Me” while he chose the Rolling Stones’ “Under My Thumb.” Now, I would choose the latter for Kevin, but the Stones don’t allow their songs as ring tones, at least not through iTunes.

Now Tommy: what to use for the young man in my life? Kevin, as a joke, suggested looking for something with bleed in it. I logged on to iTunes and typed in “bleed.” Popular name for songs, apparently.


A good ring tone for hemophilia, with the widest assortment of artists and genres. Something for everyone, which is good because many of the songs are heavy metal and the lyrics aren’t so nice.

Factor Solutions
Factor Support During Loss of Insurance*

1-800-288-8374

1. CALL Factor Solutions - 1-800-288-8374
2. TALK to a Case Specialist
3. RECEIVE Factor at Your HTC

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

* Based on determination of program eligibility.
But if these don’t strike your fancy, try these:

“Bleed it Out” — by Linkin Park
This is what happens when you don’t infuse fast enough.

“Bleed Alone” — Haste the Day
A good ring tone for all the single guys with hemophilia.

“Bleed and Blister” — Moneen
A ring tone for when you wear shoes that are too big.

“Bleed Black” — AFI
A ring tone for when you have an upper GI bleed?

“Bleed Forever” — Super Furry Animals
A ring tone for while we wait for a cure.

“Bleed from Within” — The Music
A ring tone for those prone to joint bleeds.

“Bleed Me an Ocean” — Acid Bath
A ring tone for when you forget your factor.

“Bleed Together” — Lovedrug
A ring tone for hemophilia camp!

“Bleed, Everyone’s Doing It” — Spill Canvas
Could be the ring tone theme song for all with hemophilia?

“Born to Bleed” — Dirty Sweet
A ring tone for those who inherited their hemophilia.

“Brother Bleed Brother” — Finch
A ring tone for your sibling.

“Let it Bleed” — The Rolling Stones
Not good advice, but you can’t get it in a ring tone anyway.

“Let it Bleed Again” — God or Julie
Still not good advice, which we don’t want to be reminded of in a ring tone.

“As I Bleed” — Bipolar
A ring tone for an infusion.

“Please Bleed” — Ben Harper and the Innocents
A ring tone for when you want to stay home from school.

“Punch Me I Bleed” — Children of Bodom
A ring tone for those who don’t have lifetime caps.

“Bloody Nose” — Earlimart
A ring tone for when you say the above to someone.

“Bleeding” — Ignite, Prom Kings, Todd Rundgren, Sixpence None the Richer, Five Finger Death Punch, Delerium, Sprung Monkey, Tiger Lillies [very weird], One King Down, Jacksom Rohm, Venom, Raindancer, Cord, Raunchy
A ring tone for when you first get diagnosed.

“Done Bleeding” — Sebastian Bach
A ring tone for those on prophylaxis.

“Bloody Reunion” — Molly Hatchet
At last, a ring tone theme song for NHF meetings.

“Through His Blood” — Bloody Sunday
A ring tone for grandchildren of those with hemophilia.

“Only Women Bleed” — Alice Cooper
A ring tone for those, of course, who have VWD.

“Bleeding” — F5
A ring tone for those with Owren’s disease (factor V deficiency)?
And my favorite... “You’re Bleeding” by NOFX, as in no factor X?
And what about Tommy? What ring tone did I finally choose? Well, he’s a musician, loves heavy metal rock and is picky. He chose Slipknot. Yes, Slipknot. Those weird, carnival-faced, mutant KISS-like boys who like to scream. The song?

“Wait and Bleed.” Yikes.

Laurie Kelley is a mother of a child with hemophilia and president of LA Kelley Communications, Inc., a worldwide provider of educational resources on bleeding disorders. For more information, visit www.kelleycom.com to order free books about hemophilia, subscribe to PEN, the quarterly newsletter and to read HemaBlog.

---

HNC Resource Guide Coming Soon!

Through a generous grant by Wyeth Pharmaceuticals, HNC is developing a Resource Guide for all members and the medical community. Included in it will be information on insurance, financial assistance, education, recreation, product assistance and much more. Look for the guide to be complete by early this summer!
HNC Annual Meeting
May 31st, 9:00am registration
Lawrence Joel Veterans Memorial Coliseum Complex
Winston-Salem, NC

Past • Present • Future

This year we are celebrating 35 years of Hemophilia of North Carolina with a look at our past, present and future. We have an exciting panel of experts ready to present their insight into the different eras. The panel includes Harold R. Roberts, M.D. – Distinguished Professor of Medicine (UNC-CH), Warren R. Jewett, Sc.D. (Biomedical Engineer & HNC Board Member), Sally Owens, BSN, RN – Health Scientist, Division of Hereditary Blood Disorders (CDC), Roberta Smith (Utah – Women’s Bleeding Disorders). Our keynote speaker will be Ms. Jeanne White-Ginder, the mother of Ryan White, who will share her story of courage and determination. In addition, the afternoon will be filled with workshops on the latest topics and we will also have lots of activities for the kids, including a visit from the Children’s Museum in Winston-Salem and a trip to the Game Frog Café for the kids 10-17.

We are also pleased to offer tickets to a race that evening at Bowman Gray Stadium which is only minutes from the meeting site. The stadium is the official site of NASCAR’s longest running weekly race track. This is sure to be a family favorite!

This is an exciting opportunity to hear the latest information affecting the bleeding disorders community, network with other members and enjoy a great day with new and old friends. Registration forms are being mailed and available on the web site at www.hemophilia-nc.org or by calling (800) 990-5557.

Registration forms due by May 12, 2008.

Celebrating 35 Years of HNC

from the Children’s Museum in Winston-Salem and a trip to the Game Frog Café for the kids 10-17.

We are also pleased to offer tickets to a race that evening at Bowman Gray Stadium which is only minutes from the meeting site. The stadium is the official site of NASCAR’s longest running weekly race track. This is sure to be a family favorite!

This is an exciting opportunity to hear the latest information affecting the bleeding disorders community, network with other members and enjoy a great day with new and old friends. Registration forms are being mailed and available on the web site at www.hemophilia-nc.org or by calling (800) 990-5557.

Registration forms due by May 12, 2008.
2008 Friends of HNC

We would like to acknowledge the following individuals who generously donated to HNC during the first quarter of 2008. 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

Ms. Penny Corpening
Ms. Monteen Fox
Mr. & Mrs. Bob Green
Mr. & Mrs. Richard Greene
Baley Gofarth
Ms. Linda Hedrick
Ms. Ruby Herman
Mr. & Mrs. Jeff Johnson
Mr. Kevin Lawson
Mr. & Mrs. Eric Lineberger
Mr. & Mrs. Harold Lineberger
Mr. William McCabe
Ms. Michelle Simmons
Mrs. Bertie Smith
The ChildHealth Center, PA
Mr. & Mrs. John Vinciguerra

Donations Made In Loving Memory of Keith Slack

Mr. Richard Durkee
Hemophilia First – Mr. Larry Cline
Lucian & Robie Neal
Ms. Madonna Neal
Mr. & Mrs. Monroe Poplin

Donations Made In Loving Memory of Mable Louise McLaurin Strickland

Ms. Sharon Welker

Donations Made In Loving Memory of Joe Summey

Mr. & Mrs. Bob Williams

Additional Donors

Mr. & Mrs. John Bond
Mr. & Mrs. Fletcher Gist
Mr. & Mrs. W. Allen Heafner
Mr. Eric Hill

Thank You to Our Honor Roll of Corporate Sponsors
First Half of Fiscal Year 2008

DIAMOND ($15,000 OR MORE)
Baxter
CSL Behring

PLATINUM ($10,000 - $14,999)
MedPro Rx

GOLD ($5,000 - $9,999)
Bayer
Wyeth

SILVER ($1,000 - $4,999)
AHF, Inc.
BioRx
CVS Caremark
Hemophilia Caremark
HRF, Inc.
Matrix Health
Novo Nordisk

BRONZE ($500-$999)
Coram
Factor Health Alliance
New Life Home Care

FRIENDS OF THE COMMUNITY
(Up to $499)
CoAg
Grifols
OptionCare
Kaiser Daily HIV/AIDS Report

**Public Health & Education | HIV/AIDS Experts, Doctors**

**Voice Concerns About Health Problems Seen Among Long-Term HIV/AIDS Survivors**

Jan 07, 2008

Some experts and doctors recently have voiced concerns that people who were diagnosed with HIV/AIDS in the early years of the epidemic are experiencing “premature” or “disproportionate numbers” of ailments associated with aging, the New York Times reports. CDC estimates show that the number of people ages 50 and older living with HIV increased by 77% between 2001 and 2005 and that this population now represents more than 25% of all HIV/AIDS cases in the U.S. The “graying of the AIDS epidemic” has raised interest in the link between AIDS and cardiovascular disease, certain cancers, diabetes, osteoporosis and depression, the Times reports.

Cardiovascular disease and diabetes are associated with lipodystrophy, which results in fat redistribution that can leave the face and lower limbs gaunt, the stomach swollen and the back humped. Lipodystrophy also raises cholesterol levels and causes glucose intolerance, which could be particularly harmful to black people, who are predisposed to heart disease and diabetes. According to the Times, there are no data that compare the incidence, age of onset and cause of aging-related diseases in the general population with long-term survivors of HIV. However, experts say they do not see HIV-negative people in their mid-50s with hip replacements associated with vascular necrosis, heart disease or diabetes related to lipodystrophy, or osteoporosis without the usual risk factors.

The most comprehensive research has come from the AIDS Community Research Initiative of America, which has studied 1,000 long-term survivors in New York City. The ACRIA study, published in 2006, found unusual rates of depression and isolation among older people living with HIV.

The NIH-funded Multi-Site AIDS Cohort Study -- which has followed 2,000 subjects nationwide for the past 25 years -- will examine the effects of HIV/AIDS and aging over the next five years. MACS investigators and other researchers say the slow pace of research on HIV/AIDS and aging is a result of numbers. They note that the first generation of people diagnosed with HIV/AIDS in the mid-1980s had no effective treatments for 10 years and died in large numbers, leaving few people to participate in studies.

Charles Emlet -- an associate professor at the University of Washington-Tacoma and a leading HIV and aging researcher -- said HIV/AIDS and aging research has been slow to start because of "the rapid increase in numbers." CDC’s most recent data, from 33 states that meet certain reporting criteria, showed that the number of people age 50 and older with HIV or AIDS was 115,871 in 2005, compared with 64,445 in 2001. In addition, the “routine exclusion” of older people from drug trials by large pharmaceutical companies has undermined such research, the Times reports. The studies are designed to measure safety and efficacy but not long-term side effects of drugs. The lack of research also limits a patient’s care, the Times reports.

“AIDS is a very serious disease, but longtime survivors have come to grips with it,” Emlet said, noting that although some patients experience unpleasant side effects from the antiretroviral drugs, a vast majority find a regimen they can tolerate. “Then all of a sudden they are bombarded with a whole new round of insults, which complicate their medical regime and have the potential of being life threatening. That undermines their sense of stability and makes it much more difficult to adjust,” he added (Gross, New York Times, 1/6)
New guidelines for von Willebrand disease

Medical Condition News
Published: Sunday, 2-Mar-2008

The National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health, has issued the first clinical guidelines in the United States for the diagnosis and management of von Willebrand Disease (VWD), the most common inherited bleeding disorder.

The guidelines include recommendations on screening, diagnosis, disease management, and directions for future research. An extensive article on the guidelines is published online Feb. 29 in the journal Haeomophilia.

In VWD, low or absent levels of a blood protein called von Willebrand factor affect the blood’s ability to clot. Von Willebrand factor also carries with it clotting factor VIII, another important protein that helps blood clot. VWD is typically milder but more common than another bleeding disorder, hemophilia. However, for some people with VWD, the condition can pose serious health risks, especially during surgery, following an injury, or during childbirth. VWD affects 1 out of every 100 to 1,000 people - both males and females. Hemophilia mainly affects males.

“These are the first guidelines on von Willebrand Disease published in the United States and we are pleased to offer clinicians science-based recommendations in the evaluation and treatment of patients,” said NHLBI Director Elizabeth G. Nabel, M.D. “The disease can be difficult to diagnose, especially in women of child-bearing age and in children, and the danger of excessive bleeding is often under-recognized.”

In consultation with the American Society of Hematology, the NHLBI convened an expert panel on VWD whose members were selected for their scientific and clinical knowledge and experience, including specialists in hematology as well as family medicine, obstetrics and gynecology, pediatrics, internal medicine, and laboratory sciences. A draft of the guidelines was posted on the NHLBI Website for a 30-day public comment period in September 2006.

Screening recommendations in the guidelines call for physicians to take a complete medical history and physical examination, and order a sequence of blood tests to evaluate persons whose history suggests VWD or any bleeding disorder.

The symptoms of VWD include frequent large bruises from minor bumps or injuries, frequent or hard-to-stop nosebleeds, extended bleeding from the gums after a dental procedure, heavy bleeding after a cut or after surgery, and heavy or extended menstrual bleeding in women. “The guidelines provide physicians with recommendations for diagnosing and treating the three major types of VWD,” said William L. Nichols, Jr., M.D., associate professor of medicine at the Mayo Clinic in Rochester, Minn., and chairman of the NHLBI expert panel that developed the guidelines. “While von Willebrand Disease cannot be cured, it can be treated. Proper diagnosis is important, and with the

Continued on page 15
Transplanted Liver Lining Cells May Cure Hemophilia

U.S. News and World Report, February 14, 2008
By Steven Reinberg

Scientists have shown that transplanting healthy liver cells into mice with hemophilia enables the animals to produce a critical clotting factor missing in humans with type A hemophilia.

The breakthrough finding may lead the way to a cure for type A hemophilia, the most common type of the disease, researchers believe.

“We were able to verify what cell type in the body can make factor VIII, which is deficient in hemophilia A,” said lead researcher Dr. Sanjeev Gupta, a professor of hepatology at Albert Einstein College of Medicine in New York City.

“In addition, we were able to replace the cells that line the liver and, in that way, we were able to cure the disorder in mice,” Gupta said.

In the study, Gupta’s team worked with a mouse model of hemophilia. They transplanted healthy liver endothelial cells into the livers of these mice, according to the report in the Feb. 14 online issue of the Journal of Clinical Investigation.

Three months after transplanting the cells, the number of healthy cells had increased and were producing factor VIII in amounts sufficient to cure their hemophilia, the researchers found.

Given these results, researchers can start to focus on where factor VIII is made in the human body and how things can go wrong with its production, Gupta said.

“From the treatment point of view, we can now begin to direct our attention to these particular cells and find the most effective way to cure this disorder in people,” Gupta said.

There are several different ways to treat hemophilia A, Gupta said. These include injecting the missing clotting factor, replenishing blood from time to time, or correcting the gene through gene therapy or cell transplantation.

“What we have done in this work seems to be more promising than any of the other modalities,” Gupta said. “This is the first time a cure has been achieved with cell therapy. That opens up new directions in treating the condition.”

Hemophilia A affects one in 10,000 males and can cause uncontrolled bleeding that can lead to disability or death. It has commonly been associated with British and Russian nobility but affects many others. Cures for hemophilia have ranged from faith healing by the Russian monk Rasputin in the early 20th century to clinical trials using gene therapy, but none of these approaches have amounted to a cure.

One expert thinks a lot more study is needed before this technique can be tried in patients.

“If successful in other animal models, this approach could add another option of treatment for patients with severe hemophilia, though one would have to weigh the risk-benefit ratio,” said Dr. Prasad Mathew, from the Ted R. Montoya Hemophilia Center at the University of New Mexico.

NHF Enotes - 2/15-2/21
New guidelines for von Willebrand disease

continued from page 13

right treatment plan, even people with type 3 VWD, the most serious form, can live active lives.”

The guidelines address the three types of von Willebrand disease.

* In type 1 VWD, patients have a low level of the von Willebrand factor, and may have lower than normal levels of factor VIII. This is the mildest and most common form of VWD. About three out of every four people with VWD have type 1 VWD.

* In type 2 VWD, the von Willebrand factor does not work the way it’s supposed to. Type 2 VWD is divided into subtypes 2A, 2B, 2M, and 2N. Each type is caused by different gene mutations and treated differently.

* In type 3 VWD, patients usually have no von Willebrand factor and low levels of factor VIII. Type 3 is the most serious form of VWD, but is very rare.

People with type 1 or type 2 VWD may not have major bleeding problems, according to Nichols, and, as a result, they may not be diagnosed until they have heavy bleeding after surgery or some other trauma. On the other hand, type 3 VWD can cause major bleeding problems during infancy and childhood. As a result, children with type 3 VWD are usually diagnosed during their first year of life.

Since heavy menstrual bleeding is the most common symptom of VWD in women, the guidelines suggest that a full gynecological exam be performed before diagnosis of VWD is made. In addition, the guidelines address the challenges that pregnancy and childbirth present for women with VWD.

“Even before conception, VWD patients should consult with a hematologist and an obstetrician who specializes in high-risk pregnancies,” said Andra James, M.D., assistant professor of obstetrics and gynecology in the Division of Maternal-Fetal Medicine at Duke University and a member of the NHLBI expert panel. “Once pregnant, women with VWD should consider using a center that specializes in high-risk pregnancies.”

Treatment for VWD depends on its type and severity and this makes knowing the exact type of VWD a patient has very important. Most cases of VWD are mild, and may require treatment only for surgery, tooth extraction, or injury. Medicines may be prescribed to replace von Willebrand factor, or increase the release of it into the bloodstream (desmopressin), to prevent the breakdown of clots (antifibrinolytics) or to control heavy menstrual bleeding in women (oral contraceptives).

According to the guidelines, it is important for people with VWD to avoid over-the-counter medicines that can affect blood clotting, including aspirin, ibuprofen, and other nonsteroidal anti-inflammatory drugs (NSAIDs). Those with VWD should talk to their dentist to determine if medicine is needed before dental work to reduce bleeding. Anyone over two years of age with VWD should be immunized against hepatitis A and B to decrease risks of complications from blood transfusions. It is important to exercise regularly and maintain a healthy weight. Safe exercises include swimming, biking, and walking. Football, hockey, wrestling and lifting heavy weights are not recommended for people with VWD.

The NHLBI von Willebrand Disease Expert Panel was established in spring 2004 in response to a recommendation from the FY 2004 Congressional appropriations conference committee. The committee urged NHLBI to work with medical associations and experts in the field to develop a set of treatment guidelines for VWD. For more information visit the NHLBI web site at http://www.nhlbi.nih.gov/.
NHF 60th Annual Meeting

November 13-15, 2008
Denver, CO

Register early and save! If you register online before Monday, May 5, 2008, you will receive a 15% discount on registration fees. Parents and caregivers will want to register early for the popular Baby Care Program and Activity Program for Kids & Teens. For information on the meeting please visit the web site at www.hemophilia.org or call (900) 42-HANDI.

HFA Symposium 2008

Destination Little Rock: May 1-4, 2008

The HFA 2008 Annual Educational Symposium will be held May 1-4th, 2008 at the Peabody Little Rock, in the heart of downtown. The weekend will be full of education and entertainment for young and old alike! For more information and to register, please visit the web site at www.hemophiliafed.org or call (800) 230-9797. Registration is due no later than April 15, 2008.
Some states looking to reduce the number of uninsured residents have passed laws that allow young adults to stay on their parents’ coverage longer, the AP/Houston Chronicle reports. Nearly all states, when regulating insurance plans for small- and medium-sized companies, set a maximum age for coverage of dependent children -- usually 19 for non-students and 23 for full-time college students. However, in the past two years, 11 states have passed laws allowing young adults to remain on their families’ policies up to age 25, according to the Commonwealth Fund. Delaware, Indiana and South Dakota also passed laws allowing young adults up to age 24 to remain on their parents’ coverage, and the limit has been increased to 30 years old in New Jersey.

The National Conference of Insurance Legislators is expected to vote in two weeks on a policy recommendation that would support allowing dependents to receive benefits up to age 25. According to the AP/Chronicle, an endorsement of the recommendation would be important because lawmakers across the country look to the organization for guidance on insurance issues. The Commonwealth Fund estimates that if all states extended dependent coverage to at least age 23, an additional 1.4 million people would have health insurance. Laura Tobler, director for health programs at the National Conference of State Legislatures, said, “This is one way states can address a specific age group and not have to expend a lot of state resources to extend health coverage.”

Mohit Ghose, a spokesperson for America’s Health Insurance Plans, said that increasing dependent age limits usually adds less than 1% to the cost of health policies. However, over time, the mandate will increase costs and could make coverage too costly for some employers and their workers, Ghose said. Ghose and Susan Laundicina, director of state research and policy for the Blue Cross Blue Shield Association, said a better solution would be to allow insurers to sell plans that would appeal to young adults, such as coverage that includes low monthly premiums and high deductibles (Freking, AP/Houston Chronicle, 2/21).
HNC Well Represented at NHF Washington Days


The group had an opportunity to meet with representatives or their aides from districts throughout North Carolina, including the offices of Senators Elizabeth Dole (R-NC) and Richard Burr (R-NC). In total, we attended 7 meetings during the day on the hill. Topics discussed included lifetime caps, medigap coverage and additional funding for the HTC’s. We were fortunate that a bill was introduced by Senator Dorgan (D-ND) the night before our visit that addresses lifetime caps (S.2706 - Health Insurance Coverage Protection Act). We asked all of our representatives to help support the bill and other legislation that is pending. During the three days the NC contingent attended training workshops, legislative briefings and a State Advocacy Workshop where we were honored to be able to speak about initiatives in NC.

Our thanks to Leonard Poe, Vice President and Advocacy Chair of HNC, for coordinating a well represented contingent from the state, preparing information on the program and scheduling the group for our many meetings.

It is now time to move on to NC Legislative Day on June 10th and initiatives for our state. As a follow up to a productive trip to Washington, HNC will be setting up meetings between constituents and their representatives around NC. If you are interested in being a part of the growing group of active participants in the advocacy arena, please contact Leonard Poe at leonard.poe@hemophilia-nc.org or by phone at (828) 713-6246. You can help to make a difference!
Let Your Voices Be Heard!

HNC Legislative Day
Tuesday – June 10, 2008
Raleigh, NC

HNC will be hosting its Legislative Day at the NC State Legislative Building in Raleigh, NC on Tuesday, June 10th. The day’s events will include a Talking Points session where we will discuss the latest topics and how best to communicate our needs to the legislators. This will be followed with an opportunity to meet with our legislative representatives and share your personal stories. We encourage everyone to come out and bring pictures, copies of your EOB’s and other information that will help to communicate our important message!

Included in the program will be all the information needed to make an effective presentation to your officials, meals and transportation assistance!

This event creates a wonderful opportunity for the North Carolina bleeding disorder community to participate in the policy decision-making process that impacts our day-to-day lives. We encourage you to take advantage of this exciting opportunity! We are currently working on setting up meetings with the representatives and space for our group. If you are interested in attending, please contact HNC at (800) 990-5557 or by email at info@hemophilia-nc.org by May 19th.

When you need us, Baxter will be there.

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

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

Through Progress
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.theforyou.com. There when you need us

Baxter

Baxter, Adley, Camp Superfly, Factor Assist, and www.theforyou.com are trademarks of Baxter International Inc.

©Copyright (January 2007), Baxter Healthcare Corporation. All rights reserved. HY12652

Winter 2008
CDC To Identify Inhibitor Risk Factors

By: Patrick Hayes
HemAware, March/April 2008

In 2007, the Centers for Disease Control and Prevention (CDC) approved additional funding to add four more centers to its multi-state study to identify the risk factors for developing an inhibitor to hemophilia medication.

The Division of Blood Disorders (DBD) at the CDC is heading the inhibitor project, which is being conducted in conjunction with the Universal Data Collection (UDC) project. The UDC project gathers information about the complications of bleeding disorders. People enrolled in the UDC project are eligible enroll in the inhibitor study as long as they have hemophilia A or B with a factor level below 50%. Participation is voluntary: People who meet the criteria, or parents of minor children, give informed consent to be a part of the study. Some of the data collected include age of first bleed, the drug used to treat the bleed, race and ethnicity. Investigators believe that these factors contribute to inhibitor development.

Researchers will also study genetic data to see if a person’s genes contribute to inhibitor development. The four added centers – Children’s Healthcare of Atlanta, Mountain States Regional Hemophilia and Thrombosis Center in Denver, Phoenix Children’s Hospital Hemophilia Center, and Children’s Hospital and Regional Medical Center in Seattle – will investigate these factors as well as collect information on children less than two years old.

For more information about the CDC, visit their web site at www.cdc.gov
Share your stories, ideas & photos with HNC!

Do you have a story to tell or a photo to share? How about an idea or suggestion? We’d love to hear from you. We are your organization and would be interested in learning more about what is happening in your lives, what suggestions you might have and how we can help. Please take a moment and share your thoughts with us. Let us know if there is a particular program or article you would like to hear more about, a story you’d like to tell or a message you would like to communicate to the public. We look forward to hearing from you!

Please mail or email your stories, ideas, photos or comments to:

HNC Executive Director
Sue Cowell
PO Box 70
Cary, NC 27512
info@hemophilia-nc.org

We understand the challenges of living with hemophilia.

Developed by Jeff Harper and Ed Wilson—designed for young people in the community seeking resources for:

- A Hemophilia Friendly Job
- Benefit Counseling
- High School Diploma
- College or Trade School

The Carolina Pathways Challenge
Making a Difference!

A MedPro Rx, Inc.
Sponsored Advocacy Program

Upcoming event schedule:

Charlotte, NC – April 19
High Point, NC – May 10
Wilkesboro, NC – June 21
Asheville, NC – July 19

Call to confirm seating and locations 888-571-3100 or visit www.medprorx.com
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.

Membership Application

Name:__________________________________________

Address:_________________________________________________________________________________

City:___________________________________________ State:_____________ Zip:___________________

Check One

____ I am a person with a bleeding disorder.

Type ______ (ie: VII, IX, VWD)

____ I am a family member of a person with a bleeding disorder

Relationship _____________________

Type of bleeding disorder ____________________________

____ I am a medical professional

____ I am an interested person

____ I am a currently an active member – information update

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

Individual Member $10  Supporter $100
Family Membership $25  Patron $200
Contributor $50  Benefactor $500
How You Can Help

It is now possible to make a donation from the HNC website at www.hemophilia-nc.org.

Double Your Dollars! Many companies match their employee’s donation to registered non-profit organizations such as HNC. If your employer provides matching donations, please do let us know. This is an easy way to double your donation. All you will need to do is mail in the matching contribution form from your company with your employment identification. We will provide the details on HNC and also send in our tax exempt status.

Please consider remembering HNC with a bequest in your will, a gift from your stock portfolio or as a beneficiary of your life insurance or retirement plan. For additional information, you may wish to consult with an attorney.

Honor the memory of a loved one with an In Memory donation to HNC. Remember someone special by giving a gift in their memory. HNC will send a letter acknowledging your thoughtful donation to the person of your choice.

Give a gift to honor someone close to you for a birthday, an anniversary, a wedding, to celebrate the birth of a baby, or other special occasion. HNC will send a card acknowledging your thoughtful donation to the person of your choice.

Shop & Search to Help. HNC is a registered participant of the Food Lion Shop & Save Program. Each time you use your card, a portion of your purchase will be donated to HNC. Register your card today! Set your search engine to GoodSearch.com. We are a registered organization on this search engine and every time you use it, money goes to HNC. Select HNC as your designated charity.

Host Your Own Fundraiser. Do you have an idea for a fundraiser? Programs hosted by members of other chapters include a Bowl-A-Thon, Texas Hold’Em Tournament, Flea Market and BBQ. HNC will assist with the set up, communications and any support needed.
Opportunities for Programs & Participation:
Please tell us if you or a family member would be interested in assisting with any of the following programs or opportunities that are taking place in 2008:
Call for more details and volunteer opportunities at (800) 990-5557

• HNC Annual Meeting (May 31)
• HNC Legislative Day (June 10)
• Family Retreat (August 13-15)
• Tennis Tournament (September 20)
• Hemophilia Walk (October 18)
• Holiday Celebration (December)
• Casino Night (January)
• Advocacy - chaired by Leonard Poe
• Education & Women’s Task Force - chaired by Jeannie Adair
• Outreach - chaired by Andrea Brill & Warren Jewett
• Finance - chaired by Kathy Register
• Fund Development - chaired by Richard Atwood & Matt Barnes

All chairpersons are available through the HNC website or by phone at (800)990-5557.

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