Casino Night at the Museum!

Hemophilia of North Carolina (HNC) hosted our second annual “Hearts for Hemophilia” Casino Night event on Saturday, January 10th at the ever impressive Museum of Natural Sciences in downtown Raleigh.

It was a great night where guests were greeted with $10,000 in ‘funny money’ play chips to test their luck at the tables, delicious hor d’oeuvres and an open bar of beer & wine. Our menu for the evening included a delicious fare of glazed pork tenderloin, a mashed potato bar, almond chicken and a Middle Eastern dipping station. For dessert, we were treated to Bananas Foster (which was brought back by popular demand) and petit confections.

Throughout the evening, we were entertained by a fabulous quintet from the UNC-CH Jazz Band!

As with our first event, we had the whole first floor of the museum to ourselves where guests were able to dine amongst the exhibits in the North Carolina Natural Treasures area and then move on to the two story high Coastal Carolina section for an exciting night of gaming at the blackjack, roulette, craps and poker tables!

The dealers were terrific and happy to help those of us who needed some instruction at any of the seven tables that were offered. By the end of play, we had lots of winners who exchanged their chips for raffle tickets and a chance to win some great prizes that included gift certificates, overnight hotel stays, gift baskets, wine & much more! We then announced the winner of our 52 Pick Up 50/50.

Mr. Terry Lamb, our professional auctioneer for the evening, then took over the microphone for another exciting live auction event! We had a full slate of items to auction including sports

A Wonderful Women’s Retreat

Women and their daughters traveled from points farthest east and west to attend HNC’s Women’s Retreat from March 6-8th at the beautiful Umstead Hotel & Spa in Cary. The retreat was open to women with bleeding disorders, women who are carriers and teen daughters of both groups.

Throughout the weekend, the women attended presentations and workshops on topics including an overview of bleeding disorders, genetics, treatment & research, stress & emotional management, public health surveillance and communication tips on making themselves heard. Breakout groups took time to share thoughts and bond with others who face similar challenges.

After a warm welcome by Sally Wright, MSW, LCSW (UNC-CH), the group had a chance to share their stories and then take in a show at the Carolina Theatre.

Other speakers at the retreat included pioneers and leaders in the field of women with bleeding disorders including Dr.
Hemophilia of North Carolina is a non-profit organization whose goal is to assist, involve and educate persons affected by bleeding disorders and to educate the medical community and the public about bleeding disorders.

### Contact Numbers

**Hemophilia of North Carolina**
(800) 990-5557

**Executive Director, Sue Cowell**
(919) 319-0014

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

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

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

### About This Publication

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

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

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

### Hemophilia Treatment Centers

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

**University of North Carolina**
At Chapel Hill
School of Medicine
Campus Box 7016
Physician Office Building
170 Manning Drive
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736

**Wake Forest University Baptist Medical Center**
The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27517-1081
Phone: (336) 716-4324
Fax: (336) 716-3010

### Additional Medical Resources

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

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

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

### Resource Information

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

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

**Bleeding Disorders Legal Hotline**
1-800-520-6154

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

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

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

**Inalex Communications**
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
Well, we’re off to a very busy year and have been traveling quite a bit. One of the HNC groups I accompanied was the contingency that went to NHF’s Washington Days in February. This experience is always very empowering and shows each of us what a difference one voice can make. If you have never experienced Washington Days or a state Legislative Day event, I would encourage you to take advantage of the opportunity to share your story, speak for the community and feel the difference you’ll make. Another conference I attended with HNC President, Richard Atwood, was the NHF Leadership Weekend where members of chapters from all over the country get together to share ideas and learn from experts in the field. One of the sessions that was presented by Pat “Big Dog” Torrey, Physis, Inc., involved volunteerism and spoke about why people get involved. Along with other reasons, it is to meet their “fun needs” and embrace their passion. This passion can lead to hosting a fundraiser for the cause, donating time to community service, designing a community program to meet the needs and helping to develop the organization. *We’re here to meet your fun needs, so please get involved!*

Sincerely,

**Sue Cowell**

Sue Cowell

HNC Executive Director

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**FORM A LASTING CONNECTION WITH YOUR COMMUNITY!**

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HNC’s On the Go program is a series of educational meetings held in different regions of the state. The topics will vary and will include the latest information on treatment, research, and issues important to the bleeding disorders community. We welcome your input. If you suggest a topic of interest to you and your community, we will do our best to offer it in your area.

If you have questions about this program or would like to be involved in the planning of this series for your region, please contact Sue Cowell, HNC Executive Director, at (800) 990-5557 or by email at info@hemophilia-nc.org. We look forward to seeing you soon!
A Wonderful Women’s Retreat continued

Andra H. James (Duke University), Dr. Alice D. Ma (UNC-CH) and Sally Owens (CDC). Also presenting was Dr. Tamison Jewett (Wake Forest University) who gave a fascinating description of the genetics of bleeding disorders and made this difficult topic easily understood. Our breakout groups were moderated by Kimmy Walsh-Ebsworth, Lori Kunkel, Jeannie Adair, PhD, LPC, NCC (HNC Board Member) and Alex Boeving-Allen, PhD (Wake Forest University) who taught everyone some excellent relaxation and stress relief techniques.

The weekend wasn’t without some fun and relaxation. Those sessions included a greeting card creation segment and a fun pamper party on Saturday night. Sunday morning started with a brisk walk around the beautiful lake behind the hotel followed by a terrific health & fitness presentation by Carol Ryner who took us through exercises with a band that can be done anywhere. If you see someone stretching on their shopping cart at the checkout line, you’ll know they’ve had a session with Carol!

The hotel was first class, the food delicious and the presentations enlightening but the best thing about the weekend were all the people who made new friends. It was an opportunity for the women and their daughters to learn about each other, talk about things that often go unsaid and leave with the knowledge that nobody has to be alone during a time of need.

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

Cat Out of the Bag

Tim Ochoa is a hemophilic young man who applied for a food service position, confident that his hemophilia would not prevent him from performing the responsibilities of the job. During his interview, Tim disclosed that he had hemophilia. Suddenly the tone of the interview changed, and Tim was asked to obtain documentation from his doctor stating that he was fit to work. As requested, Tim obtained the letter. But he did not get the job. Being a novice and an honest applicant, Tim told a potential employer that he had hemophilia prior to being offered the job. Like scores of hemophilic young people, he simply wasn’t prepared to address his hemophilia in an interview setting. Bobbie Kincaid, community advocate with Acreedo’s Hemophilia Health Services, said that Tim isn’t alone when it comes to spilling the beans about hemophilia during an interview: “We’re not doing enough to educate job seekers on this front because she sees firsthand the positive effect holding a job has on the lives of young people. “Getting that first job — regardless of what it is — is an important step that starts young people with hemophilia on their way to realizing their dreams,” says Bobbie. “And it’s a shame when a young man is excited about a job, is a good fit for the job, and then doesn’t get it because he innocently discloses that he has hemophilia.”

Confusion Over Rights

“There’s definitely a lack of education on the subject of employment rights in the hemophilia community,” observes Beth Sufian, an attorney who runs the Bleeding Disorders Legal Information Hotline. With respect to employment issues, she notes, many of the people she speaks with either don’t know or have serious misconceptions about their legal rights. Of the calls Beth fields, those involving employment discrimination are surpassed only by those relating to insurance. Many job applicants with hemophilia are at least vaguely aware that they may receive some protection under The Americans with Disabilities Act (ADA). But what they may not realize is that protection under the act is as much about the employer as it is about the applicant. For instance, in order for a company to be covered by ADA, it must have at least fifteen employees. As for the applicant, ADA defines an individual with a disability as a person who

- has a physical or mental impairment that substantially limits one or more major life activities;
- has a record of such an impairment¹; or
- is regarded as having such an impairment.

Assuming both the company and applicant are covered by ADA, then certain aspects of the act are particularly important to people with hemophilia: “Employers may not ask job applicants about the existence, nature, or severity of a disability. Applicants may be asked about their ability to perform specific job functions.”¹ In other words, an employer covered by ADA can’t ask if you have a disability, but can ask if anything prevents you from doing the job for which you’re interviewing. If you’re asked whether anything would inhibit your ability to perform specific job functions, responding with a simple “no” is appropriate. But the situation gets muddled if you’re asked directly whether you have a medical condition the employer should know about. Legal or not, if you push back on this issue, you’re likely to raise red flags. Again, your response can be simple: “No, I don’t have any condition that would prevent me from performing the job.” Once the company offers you a job, you can be asked questions that might reveal a disability — as long as the same questions are asked of all applicants. At this point, if you decide to disclose your hemophilia, the company cannot withdraw its offer unless it determines that your condition prevents you from performing essential job functions or that you would pose a risk of injury to yourself or others. As you can see, the interview process can become a game of semantics. The bottom line? Be prepared. Have a response ready if the subject of hemophilia surfaces. Worst-case scenario? You’re not prepared for the question, and you’re caught like a deer in headlights.

When In Doubt, Seek Help

The subject of discrimination in the hiring process involves complex legal issues. If you think you’re a victim of discrimination, seek legal assistance and consider filing a claim with the Equal Employment Opportunity Commission (EEOC). Bear in mind that there are time limitations for filing claims, and that legal action far from guarantees a satisfactory outcome. Obtaining representation is difficult, and according to Beth Sufian, only 3% of ADA cases are won by the employee. If you decide to pursue legal remedies, the Bleeding Disorders Legal Information Hotline is a sound place to start. The toll-free number is (800) 520-6154. There’s no way to predict if the subject of your hemophilia will arise during a job interview. In any case, you should be prepared to address it. Handling the issue with poise could end up landing you the job.

¹For the full text of the The Americans with Disabilities Act of 1990, Titles I and V: www.ada.gov
²Emphasis added. This excerpt is from the Equal Employment Opportunity Commission’s website, a good resource for questions employers are allowed to ask: www.eeoc.gov

Casino Night at the Museum! continued

memorabilia, a week’s stay at High Rock Lake, a 1913 Rooster 20 Franc gold coin, an overnight stay and spa treatment at The Umstead Hotel & Spa and collector’s edition model cars.

The night concluded with thanks to our sponsors and guests. Each attendee received a chocolate favor in the design of a playing card as a thank you for being our guest and participating in this great event that raised over $20,000 for Hemophilia of North Carolina! The proceeds from the event will help to provide crucial support for individuals and families affected by a bleeding disorder. Specifically, support will include the need for emergency financial assistance, transportation costs for treatment and continued health education.

We are especially grateful to the many individuals, organizations and companies for their generous support of our event:

Casino Night Sponsors

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For more information on Baxter programs and services, visit www.thereforyou.com.
2009 Friends of HNC

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

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- Ms. Evelyn Carson
- L.E. & R.L. Strickland
- Mr. Joseph Welker, Jr.
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*Donation Made In Honor of William R. Swiler*

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CAMP CAREFREE

By Matt Igelman

Growing up with hemophilia, I had a fun place where I could meet other kids just like me every summer. That place was Camp Carefree. Founded in 1986 by Gib and Anne Jones, Camp Carefree offers a free weeklong camping experience for children suffering from chronic illness. The beautiful thirty acre camp in Stokesdale, NC offers a range of your normal camp activities including fishing, hiking, horseback riding, high ropes course, canoeing, rock climbing wall, and many other activities. Camp Carefree focuses on the ability to bring kids together and providing them with a “care-free” experience.

“At Camp Carefree kids get the opportunity to enjoy everything camp has to offer,” informs Michelle Richardson, Program Director. Programs and facilities are designed to encourage and enable the roughly 450 campers that attend camp to safely conquer and enjoy all activities. Medical staff from local health organizations including UNC Hospitals, Moses Cone Health System, and Wake Forest University Baptist Medical Center ensure a safe environment. I remember my own feelings of being truly care free; any worries about hemophilia quickly faded away with the excitement that camp offered.

In addition to weeks that focus on specific disorders, the camp also includes a week for siblings of children suffering from chronic health problems. “We saw the need for this when some of the kids came with their parents to an adult weekend program,” Michelle commented. “The responsibility that these children take on in the home year-round was really apparent and that was the inspiration behind our Well Children week.”

Camp Carefree continues to make additions to their programming and facilities. “In the last five years we have expanded our ropes course and horse back riding programs, and through the wonderful volunteers efforts of Living Rhythm, included and African drumming program.” Through the effort of all the volunteers, Camp Carefree continues to make a year-round difference in the lives of their campers. “We are always looking for new volunteers – currently we hope to include yoga and other alternative beneficial activities to our campers,” Michelle added.

Running primarily on volunteer efforts with only one paid staff position, the camp continues to change the lives of every child that attends. As a nonprofit 501c3, every dollar goes a long way. “It’s the small donations throughout the year that really make a difference and keep the camp thriving,” Michelle commented. Volunteer efforts in the community also drive fundraising opportunities that range from motorcycle rides to chili cook-offs. The camp is also available for everything from company outings to family reunions. For more information regarding fundraising, contributions, or facility rental, please contact Michelle Richardson, Program Director at 336-427-0966.

The World Federation of Hemophilia’s Twinning Program – Part I

By Nigel S. Key, MD,
Director, Harold R Roberts Comprehensive Hemophilia Diagnostic and Treatment Center,
University of North Carolina – Chapel Hill

In 2013, the World Federation of Hemophilia (WFH) will celebrate its 50th anniversary. Headquartered in Montreal, Quebec, WFH was founded by Frank Schnabel, a Canadian who was born with severe hemophilia. WFH is a non-profit organization that is officially recognized by the World Health Organization. Its mission is to advance the care of persons with hemophilia (PWH) and other bleeding disorders worldwide through a variety of time-tested programs, educational conferences and printed materials, and personal interactions with PWH, physicians and other medical professionals, and selected politicians who have the power to improve the lives of affected individuals in their countries. The success of WFH is entirely dependent on the efforts of a large number of unpaid volunteers, who lend their expertise and time to promote the mission.

One of the most successful WFH initiatives has been the Twinning Program. Established in 1994, the Twinning Program has been an outstanding success. By linking emerging and established hemophilia organizations (HOT twins) and Hemophilia Treatment Centers (HTC twins), the program has become one of the cornerstones of the WFH organization. Over the past 15 years, about 140 twinning partnerships have been completed. Every year, about 45 twinning partnerships are funded by the WFH, and in 2008, there were 44 active twins in 53 countries. The HTC twinning program pairs emerging HTCs with established HTCs to improve the diagnosis and treatment of persons with hemophilia and other bleeding disorders. Likewise, the HOT twinning program links emerging and established patient organizations to improve patient education, outreach, and fundraising and other advocacy activities, such as the establishment of summer camps for children and adolescents with bleeding disorders. Each twinning is endorsed and monitored for up to 4 years, but more often than not, the relationships that are established continue well beyond the official closure date. WFH support comprises a modest annual twinning payment and grants to address specific objectives, but inevitably, twins seek and find additional resources to support their projects. Twins are coached by and work collaboratively with the excellent WFH Programs staff, so that they do not have to ‘re-invent the wheel’ for want of the appropriate experience at the outset of their collaboration. Notably, there is a relatively high rate of experienced HOT and HTC twins who seek a second – and sometimes a third – twinning after completion of their first venture. Anybody interested in learning more about the deep commitment that is the rule (rather than the exception) among the Centers that have immersed themselves in their twinning should visit the WFH website (http://www.wfh.org/index.asp?lang=EN) to view the powerful documentary video that was made to highlight the accomplishments of the 2008 HTC ‘Twinning of the Year’ between the Fort Worth Comprehensive Hemophilia Center and the Center in Lima, Peru.

I have been fortunate enough to be associated with the Twinning Program since 1998, when my former HTC at the University of Minnesota began a Twinning with the National Institute of Hematology and Blood Transfusion in T’bilisi, Republic of Georgia. We assisted the Center to set up a coagulation diagnostics laboratory, a registry for patients with bleeding disorders, and a national tender to begin the purchase of clotting factor concentrates. Subsequently, armed with a sense of the steps needed to approach the problems in this, a typical emerging nation, we undertook a second twinning with neighboring Armenia. Both twinnings were life-changing experiences for me, and I was therefore delighted to find that my colleagues at UNC were anxious to undertake their first WFH twinning which is now just getting launched, and is described by Dr Alice Ma. For my part, I continue to be involved with the WFH as a member of the Executive Committee, and the Chair of the HTC Twinning committee. I am scheduled to travel with the WFH this year to Peru and to China, but I look forward to hearing great things about the accomplishments in our UNC twinning with Ethiopia.
The World Federation of Hemophilia’s Twinning Program – Part II

By Alice Ma, MD,
Associate Professor of Medicine, Harold R. Roberts Comprehensive Hemophilia Diagnostic and Treatment Center
University of North Carolina – Chapel Hill

On November 17, 2008, members of the Harold R. Roberts Comprehensive Hemophilia Treatment Center from the University of North Carolina traveled to Addis Ababa, Ethiopia to begin a twinning partnership under the auspices of the World Federation of Hemophilia.

Dr. Paul Monahan, a pediatric hematologist, Dr. Herb Whinna, a pathologist who directs the coagulation laboratory at UNC and I, an adult hematologist made the trip as our initial assessment visit to the Tikur Anbesse (Black Lion) Hospital. We were charged with determining what care was available to persons with hemophilia and how best to help the providers at the Black Lion hospital develop into a comprehensive hemophilia center.

During our visit, we met the doctors and nurses charged with providing hemophilia care. Dr. Khalid Asrat is a pediatrician who treats all children in Ethiopia with blood and cancer. Dr. Amha Gebremedhin is the only hematologist for the entire nation of 12 million people, and he is joined by Dr. Abdulaziz Sherif, who is an internist who will soon start a hematology fellowship in South Africa. Sister Ayalech Tekelu directs the blood bank and supervises infusions of plasma, cryoprecipitate and the rare doses of clotting factor that are donated by organizations from more developed countries. Sister Birhane Gebre was recently hired to be the nurse for the hemophilia center, and she has both experience and motivation, since her 12 year old son has hemophilia.

Ethiopia is a country accustomed to getting by with limited resources supplemented by external donations. There, patients with hemophilia come to medical attention usually because of the death of an older child in the family from bleeding after circumcision. A family history of bleeding and a prolonged PTT assay labels the child as a hemophilic, but assays for Factor VIII and IX can not be done, so it is unknown whether these boys have Hemophilia A or Hemophilia B. In fact, one young man was given 7 precious doses of factor VIII for an elbow bleed when he turned out to have Factor IX deficiency. Needless to say, the Factor VIII treatment was unsuccessful! At the moment, 37 persons with hemophilia are identified (based on aPTT and family/clinical history). The physicians note that 10-15 years ago there were 70 identified patients with hemophilia, but that most of these were lost to follow-up as government resources for health care declined. No genetic counseling is offered, since it is a stigma to have a PWH within the family.

During our visit, we asked to see some patients with hemophilia, and with only 2 days notice, 15 patients and their families presented on Thursday morning. With the exception of two patients age 26 and 42 years (each of whom was found upon our testing to have mild hemophilia B) the patients were less than 20 years old. We were told this age distribution is consistent with the total hemophilia population and with the greatly decreased life expectancy of PWH in Ethiopia. They all came up 8 flights of stairs (or were carried by their parents—since the elevators in the medical school are in poor repair and “killed 2 people” the last time they were used). All but one had severe joint disease. One was having an acute right ankle bleed. No one was in a wheelchair. Many could have benefited from crutches but had none. It was not clear how crutches could be procured for this child’s use.

Dr. Whinna solicited a donation of reagents from Stago Inc, and he worked diligently to set up the assays and run tests on these patients, so now all 15 boys and young men have accurate diagnoses—which can only help the doctors provide better care.

The joint endeavor between the established hemophilia center at UNC and the emerging hemophilia center at Black Lion Hospital was recently approved as twinning project by the World Federation of Hemophilia. Goals for this year include setting up and maintaining a patient registry so that an accurate count of PWH can be used to lobby the government for services, sending a lab technician for training in doing assays for Factor VIII and Factor IX, and sending a nurse for specialized hemophilia training. A 4-5 year span of projects is planned to establish the Black Lion Hospital as a center for excellence in providing comprehensive care for hemophilia in Ethiopia.
Signs of Variant Creutzfeldt-Jakob Disease Found in a UK Patient with Hemophilia; No Added Risk Seen for U.S. Patients

Source: NHF - MASAC Medical Advisory #409, www.hemophilia.org

Wednesday, February 18, 2009

Health authorities in the United Kingdom have announced that a man with hemophilia A who died of unrelated causes was found at post-mortem examination to have evidence of infection with the agent causing variant Creutzfeldt-Jakob disease (vCJD), the human form of “mad cow disease.” The discovery was made when a biopsy was performed on the patient’s spleen as part of an ongoing UK surveillance study, and signs of abnormal prion proteins, the infectious agent causing vCJD, were detected. This is the first time that a person with hemophilia has been found to have any evidence of vCJD infection.

Eleven years ago, this patient infused UK-produced clotting factor concentrate, which was later identified as having been made from plasma from a donor who developed vCJD after making the donation. Health authorities in the UK have identified this clotting factor exposure as the likely source of prion transmission to this patient, although it is not the only possible source, and the follow-up clinical research is not yet complete.

It is important to note that only individuals exposed to UK-sourced plasma infused between 1980 and 2001 are considered to be at elevated risk for vCJD compared to the general population. These products were used primarily by patients in the UK, although some products were exported to Brazil, Brunei, India, Jordan, Oman, Singapore, Turkey, and United Arab Emirates. A few individuals in the US used a UK-produced FXI product during this time, but no vCJD-implicated plasma was used in its production.

Currently, UK-sourced plasma is not used in any product worldwide, and it has never been used in products licensed for use in the United States. In the US, plasma donors who have spent time in the UK are deferred from donating blood or plasma. Therefore, there should be no change in the safety profile of US-licensed products or in any treatment recommendations.

The Medical and Scientific Advisory Council (MASAC) and the Blood Safety Working Group of NHF are working closely with relevant U.S. and international agencies to monitor this issue and distribute any new information that becomes available. Additional information about this case is available from these UK Web sites: Health Protection Agency press release (17 February), Health Protection Agency Website, UK Haemophilia Society, UK Haemophilia Centre Doctors’ Organisation. Information about vCJD and other blood and product safety issues is also available on the NHF Web site, and on the Web site of the World Federation of Hemophilia (WFH).

Patients with individual concerns should contact their treatment center physician.

Please sign up for the Patient Notification System (PNS) to be notified directly about the latest recall or withdrawal of recombinant and plasma products. The system is confidential and time sensitive. It is administered by an independent third-party organization and is free of charge. To enroll in the PNS online, please go to: http://www.patientnotificationsystem.org/
Blood and Product Safety: Everyone’s Responsibility

In this day of very safe products, it might be tempting for some to let complacency take over and either not think about product safety at all, or mentally chalk it up as “someone else’s responsibility.” However, products are only safe today because consumers demanded it, and it remains everyone’s responsibility to ensure that blood and products remain safe.

One crucial step that anyone with a bleeding disorder can take is to register for the Universal Data Collection (UDC) project (UDC) of the Centers for Disease Control and Prevention. The UDC collects and monitors important patient data, including information on blood-borne pathogens and joint complications. It is one of the best indicators we have that current products are safe from viral pathogens, and will be an important warning system if a problem emerges in the future. You can learn more about the UDC from the CDC’s Web site. To participate in the UDC, talk to the staff at your local hemophilia treatment center (HTC).

Another basic thing everyone can do, is to register for the Patient Notification System (PNS). PNS was established by the Plasma Protein Therapeutics Association (PPTA), an industry trade group representing manufacturers of plasma-derived therapies and their recombinant analogs, in cooperation with patient organizations that serve on an advisory panel. The system allows any user of these therapies, or any interested party, to sign up for alerts notifying them when a product is either withdrawn or recalled because of a safety concern or other issue. Participants may receive notifications by e-mail, telephone or fax, and they also receive a copy of the notification by first class mail.

Some discussions have taken place about the possibility of adding other notification methods, such as text to phone or PDA. Although PNS is under the auspices of industry, it is operated by an outside contractor and no personal information from those who register is ever shared with PPTA or any of the manufacturers. Patient groups such as NHF and our chapters often redistribute notifications via other means including medical advisories, NHF eNotes and our Web site. However, the best way to insure that you get timely information about a product withdrawal or recall is to register for PNS or call 1.888.873.2838.

While PNS lets you know if there is an actual product withdrawal or recall, it does not provide other types of information about blood safety issues. However, much of this type of information can be found through NHF’s communication vehicles, our chapters and other community organizations. For example, on NHF’s Web site, visitors can find information on a variety of blood-borne pathogens such as HIV, hepatitis C, West Nile Virus, variant Creutzfeldt-Jakob disease (vCJD) and others, including their potential impact on blood and product safety. Community organizations like the Committee of Ten Thousand (COTT) and the Hemophilia Federation of America (HFA) also discuss blood safety issues on their Web sites. Information about these issues is also available on the Web sites of government agencies that share in the responsibility of ensuring the safety of the nation’s blood supply. For example, a lot of information is available on the Web site of the Center for Biologics Evaluation and Research (CBER) of the U.S. Food and Drug Administration (FDA.) Additional information can also be found at the Web site of the U.S. Department of Health and Human Services’ (HHS) Advisory Committee on Blood Safety and Availability (ACBSA). Some very good information is also available on the Web site of the World Federation of Hemophilia.

This article was excerpted from the Fall 2008 issue of Blood & Product Safety News, a new quarterly newsletter published by the National Hemophilia Foundation.

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Patient Services Incorporated to operate the A.C.C.E.S.S. Program

Midlothian, Virginia, February 20, 2009 — Patient Services Incorporated (PSI), a leading health advocacy non-profit will begin operating the A.C.C.E.S.S. (Advocating for Chronic Conditions, Entitlements and Social Services) effective February 19, 2009. The A.C.C.E.S.S. program has become a 501 (c)(3) non-profit under PSI and will be known as the “PSI A.C.C.E.S.S. Program”. The program, which will be based in Tampa, Florida, will provide Social Security and disability representation to patients diagnosed with Bleeding Disorders, Alpha1, Chronic Inflammatory Demyelinating Polyneuropathy, Pulmonary Arterial Hypertension, Amyotrophic Lateral Sclerosis and Primary Immune Deficiency. You may still reach the PSI-A.C.C.E.S.S. Program at 1-888-700-7010.

“I am excited to include this value added service among our existing programs,” said PSI President and Founder Dana Kuhn. “It is just one more step closer to meeting the total needs and challenges of patients with expensive illnesses. Helping patients navigate and obtain Medicare/SSDI is a service that will help our organization become the premier patient assistance foundation.”

For additional information about the PSI ACCESS Program, contact Mandy Herbert or Jon McNamara by phone at (804) 744-3813, or by email at uneedpsi@uneedpsi.org.

About A.C.C.E.S.S.:

Founded by the late Rachel Warner, Advocating for Chronic Conditions, Entitlements and Social Services (A.C.C.E.S.S.) is dedicated to helping find solutions to many of the social and economic problems that confront families facing chronic conditions. With a full staff of credentialed attorneys, A.C.C.E.S.S. can provide legal advice and assistance with insurance related concerns, Medicare, Medicaid, and Social Security Disability issues. A.C.C.E.S.S. also helps patients explore eligibility for continuation of health insurance under federal law (COBRA and HIPAA), as well as alternative sources of coverage, such as state high-risk insurance pools.

About PSI:

PSI is the “ground breaking” 501(c)(3) non-profit, charitable organization of its kind. Founded in 1989, the Midlothian, Virginia based company has helped people who live with specific chronic illnesses or conditions locate suitable health insurance coverage and access ways to satisfy expensive co-payments. PSI provides assistance with the cost of health insurance premiums associated with COBRAs, State High Risk Pools, Open enrollment, Guaranteed Issue policies, HIPAA conversion policies; and prescriptions co-payments associated with private insurance as well as with Medicare Parts B and D.

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Kathy Robinette-Stoneberg
National Director, Community Advocate
(866) 528-4963

Providing Hemophilia therapy to North Carolina & surrounding areas.
Let Your Voices Be Heard!
HNC Legislative Day
Tuesday – June 9, 2009
Raleigh, NC

HNC will be hosting our Legislative Day in Raleigh on Tuesday, June 9th. We will begin with a breakfast meeting at the Hilton Garden Inn in Morrisville followed by transportation and meetings at the Legislative Buildings in Raleigh. The days 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 25th.

NYLI Retreat for Teens

By Spencer Brill

Friday the 13th, what a day for flying. Oh well, I signed on the dotted line and now I’m committed. This past February, I joined 44 other teens from across the nation and headed to the National Hemophilia Foundation’s, National Youth Leadership Institute’s, retreat in Texas. This was an experience I will always remember.

The Timeline…

Day 1 – I woke up at 4:30 that morning, eager, anxious (due to the Friday the 13th part) and ready to meet everyone in Texas. My parents and I drove to our local airport, checked in and waited for my flight to be called. After I arrived at the Texas airport, I was met by my chaperone. He rounded up me and a bunch of other teens and led us away. We lounged in a huge hotel room and did a meet and greet while waiting for the rest of the pack to arrive. The time was passed in a variety of ways: from Jenga smack downs, to fierce card games, to eating cookies out of unsupervised box lunches.

At precisely two o’clock, the alarm went up; we headed for our tour bus and onto camp. The remainder of the first day was spent organizing groups and cataloging what seemed like an endless supply of medication, rubs and salves we, teens had brought along. We also participated in some group activities/games that helped us get to know each other.

Day 2 – The rap sessions and peer mediation groups we participated in on day two were probably the most meaningful aspects of the retreat for me. We just sat down and talked about things that troubled us and shared common problems that we deal with on a regular basis.

The mini rap sessions we held in our cabins every night are noteworthy as well. I think the small, familiar group setting put everyone at ease and created opportunities to open up and share. It was very interesting to hear everyone’s story and where they came from, and how their bleeding disorders shaped and molded them into who they are today. I was inspired by tales that ranged from being local celebrities, to dreams of military careers to those who are still figuring out who they are and who they want to be. Everyone really opened up during these group meetings; there were no judgments, no shame, just our raw emotions. These were my favorite sessions.

Day 3 – The last day was rather dreary, as I prepared to leave my newly made friends. We collected our belongings, loaded onto the tour bus and made the long trek back to the airport. Once again we lounged in the same hotel room where just a few days ago we spent so many hours becoming acquainted. Periodically, names were called and those individuals hurried off to claim their boarding passes, amid shouts of “Good bys” and “See ya laters.”

Final Thoughts – I had an amazing experience at the NYLI 2009 and I’m really glad I was chosen to attend. In the past I have not thought too much about having hemophilia, because it plays such a minor role in my life. Since attend NYLI I have thought about hemophilia in a different aspect. First, it was really great talking to other teens that have hemophilia. And second, I’m now able to view hemophilia and other bleeding disorders from various perspectives, not just through my myopic view. We all have stories to share and to tell. I hope I’m able to attend next year and if not, I hope the teen that goes in my place will come away with a new perspective on life.

Spencer and his family are active members of Hemophilia of North Carolina and we thank Spencer for sharing his NYLI experience with us.
NHF Appoints 3rd Regional Director of Chapter Services

By Val Bias, NHF CEO

We are delighted to announce the appointment of Michelle Rice as NHF Regional Director for Chapter Services, effective April 6, 2009.

Michelle needs no introduction to our community, having served as Executive Director for Hemophilia of Indiana since 2000. Within that role, her accomplishments include the following:

- Created a coalition to advocate for a change in Indiana Medicaid coverage for inpatients resulting in a state plan amendment authorizing the implementation of reimbursement for inpatient clotting factor.
- Helped craft legislation insuring access to Indiana Hemophilia Treatment Center (IHTC), inclusion of all drugs used to treat Hemophilia, HIV/Aids and Hepatitis C on any established Preferred Drug List and preventing the implementation of a life time cap for the state high risk insurance pool.
- Collaborated with the IHTC and Delta Dental to develop a dental insurance plan for people with bleeding disorders and their families in the state of Indiana.
- Restructured the organization by identifying and prioritizing key initiatives and developing strategies to generate funding to support their implementation.
- Identified and cultivated relationships with key funders converting a $60,000 budget deficit into a $642,000 budget within six years.

Her positions with other organizations include her present role as President of the Chapter Staff Organization (CSO); Secretary of the Indiana Comprehensive Heath Insurance Association; and Member of the Indiana HTC Patient Advisory Board.

Michelle will be joining Dawn Rotellini and Kathleen Roach as Regional Directors for Chapter Services, within the Department led by Vice President Joe Kleiber. We are sure that you will join us in welcoming Michelle to her new role, as we continue to build the level of service provided by NHF to our member chapters.

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Some of our friendships go back 30 years…

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Hemophilia of North Carolina
PO Box 70, Cary, NC 27512-0070 • (800) 990-5557 • info@hemophilia-nc.org • www.hemophilia-nc.org
Fact Sheet: COBRA Premium Reduction

Source: U.S. Department of Labor, Employee Benefits Security Administration, February 26, 2009

The American Recovery and Reinvestment Act of 2009 (ARRA) provides for premium reductions and additional election opportunities for health benefits under the Consolidated Omnibus Budget Reconciliation Act of 1985, commonly called COBRA. Eligible individuals pay only 35 percent of their COBRA premiums and the remaining 65 percent is reimbursed to the coverage provider through a tax credit. The premium reduction applies to periods of health coverage beginning on or after February 17, 2009 and lasts for up to nine months.

COBRA gives workers who lose their jobs, and thus their health benefits, the right to purchase group health coverage provided by the plan under certain circumstances.

If the employer continues to offer a group health plan, the employee and his/her family can retain their group health coverage for up to 18 months by paying group rates. The COBRA premium may be higher than what the individual was paying while employed but generally the cost is lower than that for private, individual health insurance coverage.

The plan administrator must notify affected employees of their right to elect COBRA. The employee and his/her family each have 60 days to elect the COBRA coverage, otherwise they lose all rights to COBRA benefits.

Note: COBRA generally does not apply to plans sponsored by employers with less than 20 employees. Many States have similar requirements for small plans providing benefits through an insurance company. The premium reduction is available for plans covered by these State laws.

Changes Regarding COBRA Continuation Coverage Under ARRA

Premium Reduction: The premium reduction for COBRA continuation coverage is available to “assistance eligible individuals”.

An “assistance eligible individual” is the employee or a member of his/her family who:

- is eligible for COBRA continuation coverage at any time between September 1, 2008 and December 31, 2009;
- elects COBRA coverage; and
- is eligible for COBRA as a result of the employee’s involuntary termination between September 1, 2008 and December 31, 2009.

Those who are eligible for other group health coverage (such as a spouse’s plan) or Medicare are not eligible for the premium reduction. There is no premium reduction for premiums paid for periods of coverage prior to February 17, 2009.

ARRA treats assistance eligible individuals who pay 35 percent of their COBRA premium as having paid the full amount. The premium reduction (65 percent of the full premium) is reimbursable to the employer, insurer or health plan as a credit against certain employment taxes. If the credit amount is greater than the taxes due, the Secretary of the Treasury will directly reimburse the employer, insurer or plan for the excess.

The premium reduction applies to periods of coverage beginning on or after February 17, 2009. A period of coverage is a month or shorter period for which the plan charges a COBRA premium. The premium reduction starts on March 1, 2009 for plans that charge for COBRA coverage on a calendar month basis. The premium reduction for an individual ends upon eligibility for other group coverage (or Medicare), after 9 months of the reduction, or when the maximum period of COBRA coverage ends, whichever occurs first. Individuals paying reduced COBRA premiums must inform their plans if they become eligible for coverage under another group health plan or Medicare.

Special COBRA Election Opportunity: Individuals involuntarily terminated from September 1, 2008 through February 16, 2009 who did not elect COBRA when it was first offered OR who did elect COBRA, but are no longer enrolled (for example because they were unable to continue paying the premium) have a new election opportunity. This election period begins on February 17, 2009 and ends 60 days after the plan provides the required notice. This special election period does not extend the period of COBRA continuation coverage beyond the original maximum period (generally 18 months from the employee’s involuntary termination). COBRA coverage elected in this special election period begins with the first period of coverage beginning on or after February 17, 2009. This special election period opportunity does not apply to coverage sponsored by employers with less than 20 employees that is subject to State law.

Notice: Plan administrators must provide notice about the premium reduction to individuals who have a COBRA qualifying event during the period from September 1, 2008 through December 31, 2009. Plan administrators may provide notices separately or along with notices they provide following a COBRA qualifying event. This notice must go to all individuals, whether they have COBRA coverage or not, who had a qualifying event during the period from September 1, 2008 through December 31, 2009.

Individuals eligible for the special COBRA election period described above also must receive a notice informing them of this opportunity. This notice must be provided within 60 days following February 17, 2009.

 Expedited Review of Denials of Premium Reduction: Individuals who are denied treatment as assistance eligible individuals and thus are denied eligibility for the premium reduction (whether by their plan, employer or insurer) may request an expedited review of the denial by the U.S. Department of Labor. The
Fact Sheet: COBRA Premium Reduction continued

Department must make a determination within 15 business days of receipt of a completed request for review. The Department is currently developing a process and an official application form that will be required to be completed for appeals.

Switching Benefit Options: If an employer offers additional coverage options to active employees, the employer may (but is not required to) allow assistance eligible individuals to switch the coverage options they had when they became eligible for COBRA. To retain eligibility for the ARRA premium reduction, the different coverage must have the same or lower premiums as the individual’s original coverage. The different coverage can not be coverage that provides only dental, vision, a health flexible spending account, or coverage for treatment that is furnished in an on-site facility maintained by the employer.

Income limits: If an individual’s modified adjusted gross income for the tax year in which the premium assistance is received exceeds $145,000 (or $290,000 for joint filers), then the amount of the premium reduction during the tax year must be repaid. For taxpayers with adjusted gross income between $125,000 and $145,000 (or $250,000 and $290,000 for joint filers), the amount of the premium reduction that must be repaid is reduced proportionately. Individuals may permanently waive the right to premium reduction but may not later obtain the premium reduction if their adjusted gross incomes end up below the limits. If you think that your income may exceed the amounts above, consult your tax preparer or contact the IRS at www.irs.gov.

This fact sheet has been developed by the U.S. Department of Labor, Employee Benefits Security Administration, Washington, DC 20210. It will be made available in alternate formats upon request: Voice phone: 202.693.8664; TTY: 202.501.3911. In addition, the information in this fact sheet constitutes a small entity compliance guide for purposes of the Small Business Regulatory Enforcement Fairness Act of 1996.

Record Representation at NHF Washington Days

Both a record number of participants and a record number of states were represented at this year’s NHF Washington Days held February 25-26, 2009 including representatives who joined us from NATT (The National Alliance for Thrombosis and Thrombophilia). Sixteen representatives from North Carolina attended this year and were successful in meeting with most of the NC legislators or their assistants on our day ‘on the hill’. NHF has reported congressional activity on our issues, and that is thanks to the advocacy efforts on Washington Days.

Aside from sharing some very powerful personal stories, we discussed the need for additional funding to the HTCs’s with a request to maintain federal funding and sign the letter to the Appropriations Committee and legislation that was introduced to increase the lifetime caps. All representatives were asked to support Senate Bill 422/House Bill 1085, the Health Insurance Coverage Protection Act. A number of additional co-sponsors signed on as a result of the visits.

Some updates since Washington Days are:

Funding for HTC’s – At this point, one member, Rep. James McGovern, has already agreed to co-sign the letter that Rep. Tammy Baldwin is sending to the House Appropriations Committee.


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 9th 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!

Matt, Reid, LaQuenta & Jacques Meet with Rep. Bob Etheridge
The Hemophilia of North Carolina organization gratefully accepts donations in support of its programs and services. Your dollars directly impact the bleeding disorder community by providing education to parents, scholarship opportunities and financial assistance for families in crisis.

For new members, please complete the following application form.

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

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

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

### Calendar of Events

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

- 5th Annual HNC Charity Golf Classic – April 24th
- HNC On the Go – VWD Presentation – April 30th
- HNC On the Go – Cinco de Mayo Celebration – May 2nd
- Hemophilia Walk Information Meeting – May 21st
- HNC Annual Meeting – May 30th
- HNC Legislative Day – June 9th
- Family Retreat – August 12th-14th
- Teen Retreat – September 19th-20th
- 2009 Hemophilia Walk – October 17th
- NHF Annual Meeting – October 29th-31st
  
San Francisco, CA

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

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### Membership Application

Name:______________________________________________

Address:____________________________________________

City:___________________________________________ State:_____________ Zip:__________________

Home Phone:______________________________________ Cell Phone:________________________________

Email:______________________________________________

Check One

- I am a person with a bleeding disorder.
  Type ______ (ie: VII, IX, VWD)

- I am a family member of a person with a bleeding disorder
  Relationship __________________

- Type of bleeding disorder ____________________________

- I am a medical professional

- I am an interested person

- I am a currently an active member – information update

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

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SAVE THE DATE
Saturday, October 17th, 2009
Lake Crabtree County Park ♦ Morrisville, NC

Join us at the *Walk Information & Volunteer Meeting* being held on **Thursday, May 21st** from **6:30pm-8:00pm** at the *Nantucket Grill in Chapel Hill* to hear all about the new web site, walk details, team incentives and lots more! Representatives from HNC and NHF will be on hand to answer all your questions and provide some highlights on what’s to come for this year’s exciting 2009 Hemophilia Walk!

*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.*