

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2008

A Great Time at the HNC Family Retreat

After a bit of blustery weather, the HNC Family Retreat that took place from August 13th to 15th, was off to a good start with a Mystery Boat Treasure Hunt trip from Beaufort. We took a tour of the area before landing on a private island where the kids searched for hidden treasure with the pirates, argh!!! Fortunately, the storm broke by then and we were successful in finding some delicious treasures for all. After the hunt, we were given a tour of the island and saw the wild horses that roam the dunes.

After returning back to solid ground, the group of 21 families checked into the Trinity Center in Pine Knoll Shores. Following the official orientation, Gina Raymond-Duncan (CSL Behring) presented "The Clot that Binds Us". This was a fascinating look at the differences and similarities of bleeding disorders. Although our campfire plans were rained out for the evening, we were entertained by resident folk teller and songwriter, Ray Mendenhall, who involved the whole audience in his world of storytelling.

On Thursday morning the sun was shining beautifully! The families broke into different programs with the children attending the Knight's Crossing Program presented by Rich McLaughlin (Baxter) and the adults attended a presentation by Anne Lowish, RN (MedPro Rx) on School Tips and Emergency Prepared-



ness. The kids had fun in their program that took place at the beach. The highlight was the team competition for the egg drop off the beach pavillion!

After lunch, Ed Burke, President of the Factor Foundation of America spoke to the group about advocacy and the importance of getting involved. Ed has been active in pursuing legislation to eliminate lifetime caps and stressed the need for members to contact their legislative representatives, learn the issues and speak up! Everyone then attended The Strength of Life program, presented by Chad Brown, Sports Advocate Consultant to the Factor Foundation of America. Chad is 30 years old, has severe hemophilia and is a professional wake boarder. He shared his personal story and the importance of following your passion while being safe and staying healthy. Then we all joined Chad at the pool for some aquatic exercises and games – great fun!

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Save The Date

Hemophilia Walk 2008
October 18
Lake Crabtree County Park
Morrisville, NC

Election Day
November 4

NHF Annual Meeting
November 13-15, 2008
Denver, CO

HNC Holiday Celebration &
Tanglewood Festival of Lights
December 6
Village Inn Golf &
Conference Center
Winston-Salem, NC

"Hearts for Hemophilia"
HNC 2nd Annual Casino Night
January 10, 2009

Note: change of date
Raleigh, NC

NYLI Teen Retreat (NHF)
February 13-15, 2009
Burton, TX



Hemophilia of
North Carolina

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The deadline to register to vote in NC is Friday, October 10th

**MISSION
STATEMENT**

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

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557

Executive Director, Sue Cowell
(919) 319-0014

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

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

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

About This Publication

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

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

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

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Brody School of Medicine**
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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

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Charlotte, NC 28203
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**Duke University Medical Center
Hemostasis and Thrombosis Center**
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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

From the Executive Director

It's been another busy quarter getting ready for the 2008 Hemophilia Walk in October along with our other events this fall. Although much of my time is focused on those programs taking place for the remainder of this year, I am very excited about 2009 and the initiatives being planned for this upcoming year.

The HNC Board of Directors has been busy over the past couple of months preparing the 2009 Strategic Plan with lots of great ideas on new programs and services. We will continue to host our regular events including the 5th Annual Charity Golf Tournament, the Annual Meeting & HNC Legislative Day in the spring, the ever popular Family Retreat in August, the 2nd Annual Hemophilia Walk and our expansion of regional programs. In addition to these programs & services, other areas of focus include a mentoring program, women's & men's retreats, new family connections, fitness and our continued efforts to expand the services for our Latino community members.

The programs mentioned above are just a small part of what we hope to accomplish in the upcoming year. We hope that you will consider giving some of your time and expertise to assisting with a project or initiative. Do you feel passionate about an area of education, advocacy or outreach? Do you have time to give one hour per month to share your ideas on a conference call? Do you have an idea for a fundraiser in your area or would like to help with one that is ongoing? If so, please call me! I'd love to hear your thoughts and ideas on how we are doing and welcome you to join me in helping to grow and expand Hemophilia of North Carolina to meet your needs.

Sincerely,



Sue Cowell

HNC Executive Director

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A Great Time at the HNC Family Retreat Cont.



The families enjoyed some free time in the afternoon to go to the beach or travel around the area and take in the sights. That evening, we enjoyed a delicious dinner at the Beach Pavillion on a beautiful summer night. After dinner, a representative from the NC Aquarium presented “Scaly Skins, No Fins” and brought along a few of her favorite scaly friends for the kids (big and small) to enjoy! Following the presentation, we took at Night Trek on the beach with flashlights and learned all about the habitat and living creatures that make the area their home. We had fun looking for ghost crabs (they are real crabs!) and had a special treat in visiting the nesting site of sea turtles that were getting ready to hatch. On Friday morning, we all checked out and concluded the retreat activities with a visit to Fort Macon where we heard information about the history of the Fort and saw a musket firing demonstration.

Our many thanks to the speakers, the Trinity Center and all of our sponsors who made this program a wonderful success. We were disappointed that we could not accommodate all the families who responded to this popular program but the good news is that we’ve reserved the Trinity Center again for next year at the same time and have held 30 rooms so we can fit more families!

Hemophilia of North Carolina would like to graciously acknowledge our sponsors who made the HNC 2008 Family Retreat possible.

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A Special Thanks to
Factor Foundation of America for
presenting their Strength of Life Program



HEMOPHILIA WALK 2008

October 18th, 2008

Lake Crabtree County Park, Morrisville, NC

If you haven’t already signed up – now is the time! Teams and walkers are registering daily as the excitement builds towards Walk Day on Saturday, October 18th at Lake Crabtree County Park. Be a part of this inaugural event by coming out to walk, help to fundraise, donate or volunteer!

Our goal for the NC Walk is \$50,000. So far, we have raised over \$40,000, with 29 teams and hundreds of walkers ready to go. The day will be filled with fun activities for everyone including a Halloween theme nature hunt along with walk trail for the kids, pet stops for our four-legged friends and lots more. So bring your friends, family, co-workers & pets along for a great day!

For information, please visit the web site at www.hemophilia.org/walk or call Sue Cowell at 800.990.5557. We hope to see you there and remember, *Every Step Makes a Difference!*

A Successful Voyage for the Children's Passport Program!

On Tuesday, August 5th our young members of HNC and their families joined together for the Children's Passport Program at Jillian's in Charlotte. During the evening, the group was treated to delicious food and drink along with great entertainment (really, it was very educational but shhh... don't tell the kids!). Dr. Paulette Bryant and Alisha Davis, both of the Presbyterian Blume Pediatric Hematology & Oncology Clinic in Charlotte, did an outstanding job in explaining about the care & treatment of bleeding disorders with a variety of fun, interactive games and sing-a-longs. They even showed us how to make Blood Soup - yum!

The staff of Hemophilia Health Services then showed everyone the proper steps for infusion. The kids had a blast learning everything



about their bleeding disorder and earned stamps in their passports for each activity. At the end, the kids showed their completed passports and received a game card good to play the arcade games at Jillian's.

Our many thanks to Megan Mauk (HNC Region South Coordinator), Dr. Paulette Bryant, Alisha Davis, Sue & Allen Heafner and Hemophilia Health Services for coordinating a terrific program for the Charlotte region. We look forward to many more events in this area and if anyone would like to be involved in the planning for this region, please contact HNC at 800-900-5557.

This program was made possible through the generous support of **Hemophilia Health Services**. We would also like to acknowledge the generosity of **Jillian's** who provided the appetizers and game cards for the program.



because **curiosity** is in his nature...



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A Place Where Everybody Really Knows Your Name

By Spencer Brill

There is a place where everybody is somebody. A place where kids laugh, learn and explore. A place where everyone feels valued and appreciated for who they are. That place is Camp Carefree.



Even though I'm just sixteen, I already look back at my weeks spent at hemophilia camp as influential periods in my life. I made many friends and challenged myself in activities I had not competed in before. I also learned a lot, not only about myself but also about teamwork, camaraderie and leadership. This year was my first opportunity to give back a small fraction of the support I received from the volunteers at Camp Carefree.

This past summer one of the more rewarding events in my life began when I was selected to be a Counselor In Training (CIT) at Camp Carefree. For two weeks I had the privilege to mentor kids who have spina bifida and also children who have epilepsy. I enjoyed two very special weeks with a lot of very special kids. As I see it, all the kids at camp were and are special; and by special I don't mean different. They are special because they have their own dreams and desires, their own hobbies, and favorite toys and colors and best friends just like everyone else. They are special because they are independent and strong and try their very hardest in everything they do. They are special because they keep trying even though they make

mistakes or can't quite reach something or don't walk or run as fast as others. Despite overwhelming obstacles these kids keep trying and that is what makes them special. They are self-confident, self-reliant and in a word, independent.

Camp Carefree is a place of self-discovery; a place where kids ride horses, interact with cows and goats, canoe, hike, fish and at the end of the day, hunker down around a campfire toasting marshmallows, and giving high-fives while reliving the memories of the day. One of the many highlights of Camp Carefree is the weekly dance. The kids absolutely love it and with a bit of coxing even the counselors get into the "dance-offs." My favorite activity is the fashion show held the first day of camp. At one time, I would have rather been a spectator to this event instead of a participant. But this summer, my job as a CIT was to lead by example, try new experiences and walk just a little on the "wild-side". I had a blast and can't wait to volunteer again next summer.

Camp Carefree is a very relaxed and "carefree" environment. There are no cliques or social hierarchy; everyone is there to have a good time. I'll be back again next summer because at Camp Carefree, everybody is somebody.

Spencer has hemophilia and he and his family are active members of Hemophilia of North Carolina. We thank Spencer for sharing this wonderful experience with us and helping to support the community by giving back.



Camp Carefree is located just north of Greensboro in Stokesdale, NC and is open to all children regardless of their treatment center. For information visit their website at www.campcarefree.org or call (336) 427-0966.



Look for Your Invitation to... Hemophilia of North Carolina's Holiday Celebration

Saturday, December 6th 3:00pm – 6:00pm

Village Inn Golf & Conference Center – Winston-Salem, NC

Come join us at the end of year Holiday Celebration on December 6th. There will be food & fun for all ages as we use this opportunity to look back over the past year and get together with old and new friends as the year comes to a close. The celebration will include a visit from Santa & Mr. Claus, buffet lunch/dinner and

plenty of time to meet & greet! Our celebration will be followed by a bus tour of the famous Festival of Lights at Tanglewood Park in Clemmons. The festival is visited annually by over 250,000 people and boasts over a million individual lights! Tanglewood's Festival of Lights has been selected as a Top 20 Event in the Southeast and a Top 100 Event in North America.

Our keynote speaker for the celebration will be Glenn Mones, National Hemophilia Foundation's Vice President for Public Policy.

Look for your invitation to HNC's Holiday Celebration in the mail soon! Registration will also be available online by October 15th. *Please RSVP for the event by November 22, 2008.*

On the HNC Board...

Hemophilia of North Carolina is excited to announce the appointment of **Steven Humes, MM, MPH**, Regional Coordinator for Region IV North Hemophilia Treatment Center Network, to its Board of Directors. Steve was the former Director of Research at the National Hemophilia Foundation and joined the Hemophilia Diagnostic and Treatment Center at UNC-CH in 2005 as the Regional Coordinator for Region IV-North. Steve received his Master's degree in Public Health from the Community Health Education Program at Hunter College, CUNY.

We also regretfully announce the resignation of **Warren Jewett** from the HNC Board of Directors for personal reasons. Warren played an integral role in the growth of HNC and contributed his talents and expertise to many projects. We are honored to have had Warren as part of the HNC Board of Directors and thank him for his endless contributions and dedication to the bleeding disorders community.

For additional information on board members or interest in pursuing a position on the board, please contact HNC at (800) 990-5557 or info@hemophilia-nc.org.



DID YOU KNOW?

We've been tracking information about our web site recently and found that the HNC site, www.hemophilia-nc.org, is getting an average of 23,000 hits per month during this past quarter! That's an increase of 50% in just six short months.

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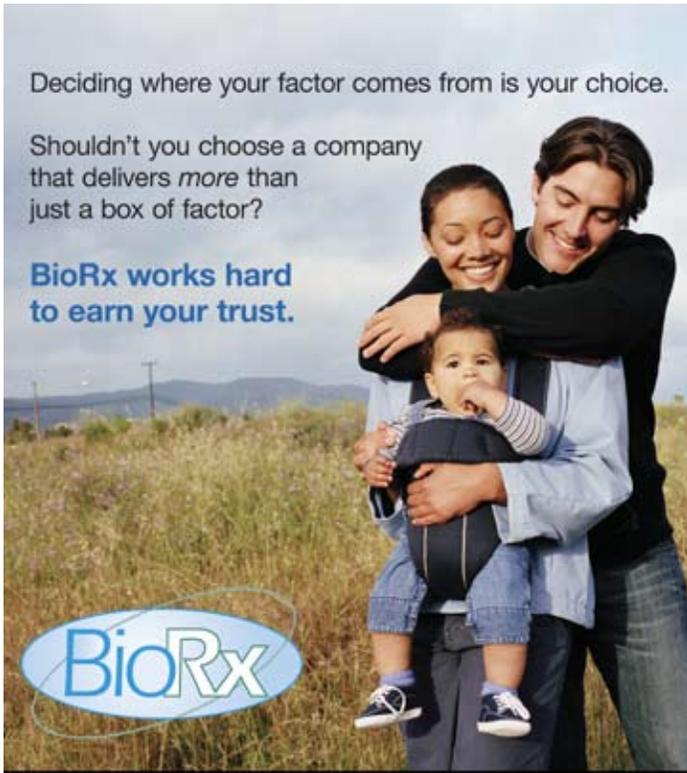
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New Book Features Character With Hemophilia

Mark Eastburn with his children and scenes from the story



When NHF member Mark Eastburn decided to write a book, he knew right away that one of his main characters would have a bleeding disorder. "I wanted to create a hero who my children will be able to look up to; someone with hemophilia who is still able to do amazing things," Mark reports. As father of a child with hemophilia and von Willebrand Disease (VWD), a daughter with von Willebrand Disease, and having VWD himself, bleeding disorders have been close to Mark for many years.

Mark Eastburn's novel, titled *Secrets of the Survivors*, has been receiving great reviews from readers of all ages. It is available through the website <http://www.aprenden.com> and major online bookstores such as amazon.com.



“Hearts for Hemophilia”

HNC'S 2ND ANNUAL CASINO NIGHT

**Saturday, January 10th, 2009
Museum of Natural Sciences, Raleigh, NC**

Please take note that we have changed the date of our Casino Night to January 10th due to a scheduling conflict at the Museum. Please save the new date!

For information on helping to plan the event, attend or sponsorships, please contact Sue Cowell at (800) 990-5557 or info@hemophilia-nc.org



Hemophilia of North Carolina is excited to announce that we have placed 5th (out of 11 places) in our division and will receive a \$3,000 Winner's Check, a Victory Party and a Limited Edition Camp SuperFly Gold medal for all who participated. We are also excited to announce that some of the Express Yourself entries will be displayed at the NHF conference in November. Congratulations and thank you to everyone who participated in this year's camp and be on the lookout for information about the Victory Party

– Go Monarchs!

NHF & CDC Research & Evaluation Study

Hemophilia of North Carolina is working with the National Hemophilia Foundation (NHF), the Centers for Disease Control and Prevention (CDC), and Macro International Inc., a research and evaluation company, to evaluate NHF's National Prevention Program. We are recruiting people to participate in a 25-minute telephone survey. You will be asked about hemophilia management, treatment products, and exercise. The survey also includes questions about where people with hemophilia get hemophilia information. As you know, people with hemophilia get information from many sources, including doctors, the Web, radio, and TV. This study looks at how people get information from recent programs that focus on hemophilia treatment.

This evaluation serves as a follow-up to a 1999 survey conducted by the same group to identify the needs and resource utilization among males living with hemophilia.

They are surveying 1,100 people nationwide. The survey will take approximately 25 minutes to go through a series of questions and provide your answers about how people feel about, and what they know, believe, and do about, hemophilia care and treatment. To

participate in this survey, you will need to sign a consent form (parent signs for minor child) allowing Hemophilia of North Carolina to enter your name and phone number into a secure database that will be used only for the purposes of this project. Once you agree to be contacted, a trained interviewer from Macro International Inc. will call you by phone. You may decide, at any time, not to participate in this study.

To qualify for the study, you (or your child) must meet the following specifications: 9 years old and younger or 13 years of age and older (10-12 year olds omitted), diagnosed with hemophilia before age 15 and have used clotting factor.

Your responses will be confidential. Macro International Inc. will not use the information to contact you for any other purposes, and they will destroy any and all records of your name and telephone number after the study is completed.

If you or someone you know may be interested in participating in this survey, please contact Sue Cowell, Executive Director for HNC, at 800.990.5557 or by email at info@hemophilia-nc.org.



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HNC Mes de la Herencia Hispana

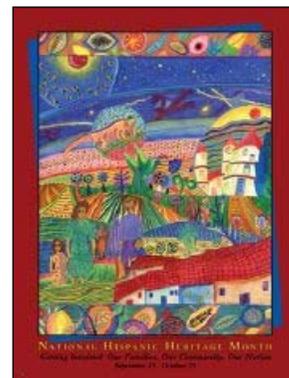
El sábado 06 de septiembre los integrantes de la comunidad latina de HNC se reunieron para disfrutar de una buena comida, diversión, y la oportunidad de aprender temas importantes relacionados con el tratamiento y apoyo hacia la hemofilia. Fue un privilegio contar con la participación del Dr. Harold H. Roberts, profesor de medicina en el Centro de Patología Sarah Graham Kenan de UNC-CH. El Dr. Roberts habló sobre la historia en el tratamiento de la hemofilia, y compartió su visión a futuro. Después de la presentación Guillermo Sánchez, del enlace hispano de HNC, habló de la importancia de crear una red de soporte para la comunidad latina. Por ello se nombró a esta red: "Unión Latina de Personas con Hemofilia" (The Latin Union for People with Hemophilia), y se discutieron algunos de los proyectos a futuro, los cuales están en planeación.

Después de la deliciosa comida, el grupo se entretuvo con el Mariachi Los Caporales y la actuación del Mago Adrian. Para terminar, Patricia Espinosa-Thomson, del Programa de

Educación para la Salud de BAXTER BioScience, nos dio una plática relacionada con la hemofilia.

Expresamos nuestras gracias a **Baxter** por su generosa ayuda para la realización de este programa.

Para mayor información acerca de la Unión Latina de Personas con Hemofilia, por favor contacte a Guillermo Sánchez al 704/605-4376 o al email: guillermosanchezab@yahoo.com.



HNC Celebrates Hispanic Heritage Month

On Saturday, September 6th members of the HNC Latino community gathered together for an afternoon of good food, great fun and a chance to learn some very valuable information about support and treatment. The group was treated to a presentation in Spanish by Harold R. Roberts, MD, a Sarah Graham Kenan Professor of Medicine and Pathology at the UNC-CH. Dr. Roberts discussed the history of hemophilia treatment along with sharing his vision for the future. After the presentation, HNC Hispanic Liaison, Guillermo Sanchez, spoke about the importance in creating a network of support and helped to guide the members in deciding a name for the group, "Union Latina de Personas con Hemofilia" (The Latin Union for People with He-

mophilia) and discussing future opportunities which are already in the planning!

After some delicious food, the group was entertained by Mariachi Los Caporales & Adrian the Magician. Dinner was followed with a presentation by Patricia Espinosa-Thomson, Spanish Health Educator with Baxter BioScience.

Our thanks to **Baxter** for their generous support of this program. For more information on the HNC Union Latina de Personas con Hemofilia, please contact Guillermo Sanchez at 704-605-4376 or by email at guillermosanchezab@yahoo.com.

2008 Friends of HNC

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

Mr. Richard Atwood

Mr. & Mrs. Jeffrey Brill

Mr. Spencer Brill

Mr. Dwayne Cannon

Mr. & Mrs. W. Allen Heafner

Mr. Eric Hill

Mr. Doug Kaiser

Mr. Lance Koegel

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Important Medicare Dates

The open enrollment period for the Medicare Part D Prescription Drug Plans (PDP) is November 15 through December 31, 2008. Medicare beneficiaries can join, switch, or drop a PDP during this time period, and changes will take effect January 1, 2009. The Medicare Prescription Drug Plans are provided by private companies that sell drug plans approved by Medicare. The “Medicare & You” handbook beneficiaries will receive this fall will include information about the Prescription Drug Plans in North Carolina. The NC Seniors’ Health Insurance Information Program (www.ncshiip.com) can provide enrollment assistance to Medicare beneficiaries of all ages by calling 800-443-9354. Information is also available by going to the Web site: www.medicare.gov and selecting “Compare Medicare Prescription Drug Plans” under “Search Tools.”

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American Society of Hematology Launches New Campaign to Educate Consumers on Vital Connection Between Blood and Personal Health

Program developed in response to results of national survey indicating most Americans have low awareness of common blood conditions

WASHINGTON (September 16, 2008): In conjunction with its 50th anniversary, the American Society of Hematology (ASH), the world's largest professional society of blood specialists, today launched a new public education campaign, Blood: The Vital Connection, with the goal of helping health-care consumers understand the important role of blood in overall health. As part of this effort, ASH has developed the **Blood: The Vital Connection** Web site, a credible online resource addressing disorders of the blood, including bleeding and clotting disorders, anemia, and cancer, as well as how specific populations of people, such as women, are affected by these conditions.

"Your blood has many different functions that are crucial to being healthy, including carrying oxygen and nutrients throughout your body, warding off infection, and protecting against excessive bleeding or clotting. Blood is the window to the body -- from one vial of blood your doctor will know if you are pregnant or if you have anemia or any other number of blood diseases," said Dr. Kenneth Kaushansky, ASH President. "We want people to make the connection between their blood and total wellness."

Blood: The Vital Connection provides hematologist-approved information about common blood conditions, risk factors, preventive measures, and treatment options. The informative Web site includes helpful tips that answer questions such as:

• **What is anemia and am I at risk?** Anemia is one of the most common blood disorders that affects more than 3 million Americans according to the National Heart, Lung, and Blood Institute (NHLBI). Blood: The Vital Connection provides information on sickle cell anemia, an inherited disease that disproportionately affects African Americans (one in 12 carry the sickle cell gene), and on anemia in the older population (almost 10 percent is currently anemic), amongst many other disorders.

• **How does flying or sitting for long periods affect my blood health?** Lack of physical movement increases your risk of deep-vein thrombosis, which occurs when a blood clot forms in the leg. This clot can detach and travel to the lungs, causing a pulmonary embolism. Visit Blood: The Vital Connection to learn prevention strategies for this potentially fatal condition.

• **Why should women in particular pay close attention to their blood health?** According to the Department of Health and Human Services (HHS), more than 2.5 million women in the U.S. have bleeding disorders, such as von Willebrand disease, but are unaware of it. In addition, women who are pregnant are at higher risk for having anemia and a blood clotting disorder. Blood: The Vital Connection arms women with the information they need about these conditions.

• **What should I know about blood cancers such as leukemia, lymphoma, and myeloma?** Blood: The Vital Connection provides information on risk factors and treatments for these blood cancers, as well as tips for navigating clinical trials.

• **What should I do if I think I may have a blood condition?** You should talk with your primary care physician. Blood: The Vital Connection provides a list of suggested questions to ask during your visit, as well as a feature that allows you to search for a hematologist in your area if your doctor thinks you should see a blood specialist.

Blood: The Vital Connection also provides information for consumers on participating in clinical trials and links to the latest research. Health-care providers who visit the site can access printable resources that help explain common blood conditions for easy distribution to patients. In addition, the site includes a career resources section for medical students who want to learn more about the field.

Survey Reveals Low Awareness of Hematology, Blood Conditions, and Health Risks ASH's new public education campaign was launched in part to respond to the results of a recent national survey that indicated a serious lack of awareness of common blood disorders among the majority of Americans. Most participants polled were unable to name common blood conditions such as anemia, blood clotting, hemophilia, and deep-vein thrombosis. Additionally, only one in five people correctly answered that a hematologist is the type of specialist who treats blood disorders; similarly, only one in five could define hematology.

About the Survey The omnibus phone survey was conducted Nov. 8-11, 2007. A random sampling of 1,013 adults, 18 years of age and older was surveyed, thus yielding an overall margin of error of +/- 2-3 percentage points at a 95 percent confidence level. Overall, respondents represent the four regions of the United States. Demographic factors such as age and gender were quota controlled and slight weights were applied to reflect the general population.

About the American Society of Hematology The American Society of Hematology (www.hematology.org) is the world's largest professional society concerned with the causes and treatment of blood disorders. Its mission is to further the understanding, diagnosis, treatment, and prevention of disorders affecting blood, bone marrow, and the immunologic, hemostatic, and vascular systems, by promoting research, clinical care, education, training, and advocacy in hematology.

Source: American Society of Hematology

New Study Will Monitor Postpartum Bleeding in VWD Patients

A new multi-site study will measure postpartum von Willebrand factor (VWF) levels in women with von Willebrand disease (VWD) to provide clinical data for physicians who, until now, have had to rely on anecdotal evidence. **Andra James, MD, Duke University Medical Center in Durham, NC**, is the principal investigator of the study. Other sites that will participate include the Mary M. Gooley Hemophilia Center in Rochester, NY, and the Robert Wood Johnson University Hospital in New Brunswick, NJ. Two additional locations will be added later. James and her colleagues will assess how VWF levels fluctuate during the postpartum period and whether decreases in these levels can be linked to hemorrhaging.

Virtually all women experience a rise in their VWF and factor VIII (FVIII) levels during the third trimester of pregnancy. However, within one month postpartum there can be a gradual decrease to baseline levels. According to investigators, this situation contrasts significantly among women with VWD who may experience precariously low drops in their VWF and FVIII levels—below the baseline—during the postpartum phase. While this condition seemingly exposes VWD women to a significantly greater risk for excessive bleeding,

the evidence until now has been mostly anecdotal.

The prospective cohort study is designed to compare changes in blood levels of VWF postpartum in an equal number of women with and without VWD. Tests to determine patients' VWF levels will be conducted at periodic intervals in the immediate postpartum period. Investigators will assess how quickly, to what levels, and for how long VWF levels drop in the days post delivery. The data will help establish optimal clinical protocols.

“While we know that decreasing VWF levels following childbirth can result in serious complications for women with VWD, there are very little clinical data available to guide physicians in treating these patients,” said Peter Kouides, MD, a principal investigator of the study. He is the Medical and Research Director of the Mary M. Gooley Hemophilia Center. “By studying the patterns in declining VWF levels, we hope to learn whether treatment following birth is needed and the optimum duration of therapy.”

The study is being funded through a \$1.2 million grant provided by CSL Behring.

Source: CSL Behring press release dated August 18, 2008

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NHFs MASAC Issues First Standards for Clotting Factor Providers

The National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Council (MASAC) issued its first "Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients with Bleeding Disorders" after the recommendations were approved by MASAC on April 17, 2008, and adopted by NHF's Board of Directors on June 15, 2008. The document established standards in the following areas: pharmacy staff knowledge of products and supplies; availability of a full range of products; prescription order processing; hours of operation and access to staff; delivery of orders; and recordkeeping, billing and product recall procedures.

"We've long promoted the importance of having safe, effective treatments," said Craig Kessler, MD, Chair of MASAC. "With this recommendation, we are recognizing that the manner in which factor is provided also has an impact on patient health."

The standards were the result of a two-year effort by a working committee of the Great Lakes Hemophilia Foundation in Milwaukee, with additional input from a wide range of consumer, professional and provider groups across the

country. "Having input from such a broad group, including consumers and healthcare providers, allowed us to create standards that genuinely address the needs of patients," Kessler said.

NHF will distribute the document to all interested parties – consumers, NHF chapter, hemophilia treatment center staff and other healthcare providers, homecare companies and specialty pharmacies.

"We've been very concerned that all of the change in the marketplace during the last few years could lead to poor service from some pharmacies that either currently provide factor or may do so in the future," said Val Bias, NHF CEO. "Of course, we encourage all providers to offer the highest level of service possible. These standards make clear what the minimum expectations are for anyone selling factor products."

Note: Copies of the standards are available on the NHF web site at www.hemophilia.org or through HNC at 800.990.5557.

Source: the HemoLink, NOHF newsletter – summer 2008

Wyeth's XYNTHA Approved by FDA for Treatment of Hemophilia A

Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), announced today that it has received approval from the U.S. Food and Drug Administration for XYNTHA™ (Antihemophilic Factor [Recombinant], Plasma/Albumin-Free), a recombinant factor VIII product, for patients with hemophilia A for both the control and prevention of bleeding episodes and surgical prophylaxis. XYNTHA (pronounced "ZIN-tha") is manufactured using a completely albumin-free process and state-of-the-art nanofiltration purification technology. In addition, XYNTHA is the only recombinant factor VIII product to utilize an entirely synthetic (non-human and non-animal based) purification process in its manufacture.

Until now, the purification process for all recombinant factor VIII products used monoclonal antibodies derived from mouse cell lines. In the manufacture of XYNTHA, the mouse monoclonal antibody is replaced with a synthetic peptide ligand, which was invented by Wyeth scientists.

"XYNTHA is important for hemophilia A patients because it establishes a new standard in recombinant factor VIII product purification technology," says Robert R. Ruffolo, Jr., Ph.D., President, Wyeth Research, and Senior Vice President, Wyeth. "This is another example of Wyeth's continued commitment to the advancement of science in the treatment of hemophilia."

The safety and efficacy of XYNTHA in the prevention and control of bleeding episodes and for surgical prophylaxis for patients with hemophilia A has been demonstrated in pivotal clinical trials. For more information, visit <http://www.wyeth.com/hcp/xynta>.

Grifols Announces Award

Grifols has announced the awarding of the Martin Villar Prizes for Research in Haemostasis. **Dr Andra James, MD, Duke University**, was awarded 3rd prize in this international competition for her publication "Bleeding events and other complications during pregnancy and childbirth in women with von Willebrand disease"

The awards are Grifols' way of paying tribute to Dr. José Martin Villar, a world-renowned haematologist and a pioneer in the treatment of haemophilia in Spain. His rigor, determination and leadership during the difficult decade of the 1980s were fundamental in improving the safety of factor VIII concentrates. Congratulations to Dr. James for her continuing role in patient care, research, and education.

MedPro Rx, Inc. Awards Four Scholarships To North Carolina Students Living With Bleeding Disorders

MedPro Rx, a provider of specialty pharmacy services to clients with chronic illnesses, has announced that the pharmacy awarded four scholarships to students in North Carolina who are living with bleeding disorders. Nationally, MedPro Rx sponsored 67 scholarships in 29 states for students living with bleeding disorders, with the combined value of the donation totaling \$60,000. Since starting its "Education is Power" scholarship program in 2006, MedPro Rx has distributed \$135,000 to students nationwide who have either hemophilia or von Willebrand Disease (vWD). The annual scholarships are open to United States residents who are living with a bleeding disorder, entering or attending a community college, junior college, four-year college, university or vocational school, and active in their community.

Phase I Clinical Research Study for Previously Treated Severe Hemophilia B Patients

Syntonix, a division of Biogen Idec, is conducting a phase I clinical research study to evaluate a single dose of a long acting recombinant FIX product in severe hemophilia B previously treated patients. A key requirement for this study is to have at least 150 prior FIX exposure days. Other requirements for participation in this study can be discussed with the contact person listed below. This phase I study is the first step in confirming that this is a long acting FIX product. **If you are interested in participating in this study, please contact Aimee_grimsley@med.unc.edu or at 919-966-4736.**

NC Hemophilia Assistance Plan Funding Terminated *We Still Need Your Help!*

Hemophilia of North Carolina learned recently that the budget for the NC Hemophilia Assistance Plan has been cut in its entirety and all centers lost their funding as of September 1, 2008. We just recently confirmed that it does impact patients at all the centers including UNC, WFU, ECU and Duke. The bill for this funding was ratified in 1981 with an appropriation of \$100,000 to assist with the treatment of hemophilia. Each year since that date, the funding has been available at approximately that same level and disbursed through the centers for assistance with many items including transportation, medical equipment and supplies, dental care and other necessities. We recently visited with our Legislators on June 10th as part of our Legislative Day and one of our talking points was the Hemophilia Assistance Plan. We asked that the funding remain intact and explained the importance of the plan. At that time, we were given every indication the funds were to be appropriated again this year and were in the continuation budget. It appears that the General Assembly directed the Division of Health and Human Services to reduce operating funds and contracts by \$2 million and the decision

on which programs to reduce fell within their department. We have been in touch with a number of Legislators and some of our members have made contact as well to ask support in reversing this decision. This is the time to get involved, whether this cut has a direct impact on you or not. We encourage you to **TAKE ACTION NOW and contact your Legislator** via phone, email or letter asking them to look into this matter. To locate your representative, visit www.ncleg.net and enter your zip code in the locator on the bottom right side or call the NC General Assembly at 919-733-7928.

The communications should be sent to any Legislator you may know, those that represent you in district and if you participated in HNC Legislative Day, the ones that you visited with. We encourage everyone to advocate for this funding including chapter members, industry representatives as well as the medical community. For more information, including details on the Hemophilia Assistance Plan and the critical role it plays in treatment for our members, contact HNC at 800-990-5557 or by email at info@hemophilia-nc.org.

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Lifetime Insurance Caps Bill Introduced In U.S. House of Representatives

On Thursday, July 17, 2008, Congresswoman Anna Eshoo (CA) along with Representatives Betty Sutton (OH), Jason Altmire (PA) and James Langevin (RI) introduced H.R. 6528, the Health Insurance Coverage Protection Act, which raises the minimum lifetime cap for private health insurance to \$10 million. This bill is identical to the Senate bill (S. 2706) that was introduced by Senator Byron Dorgan in March during NHF's Washington Days.

H.R. 6528:

- Sets the minimum level of a lifetime cap placed on a group health plan at \$5 million for the first two years and \$10 million in years three and four.
- Provides for an annual inflationary adjustment to a group insurance plan's lifetime cap based on the consumer price index in subsequent years.
- Exempts health plans offered to businesses with fewer than 20 employees, but would require that health plans meeting

the parameters of the bill be offered to a small business at the employer's request.

- Calls for an Institute of Medicine Study to determine the number of individuals who reach their lifetime caps.

Introduction of the House bill is a result of the cumulative efforts of the bleeding disorders community. Special recognition goes out to the members of the California chapters who contacted Congresswoman Eshoo and to the Northern Ohio Hemophilia Foundation, the Western Pennsylvania Chapter of NHF, and New England Hemophilia Association who visited with Representatives Sutton, Altmire and Langevin during NHF's Washington Days.

If you haven't already done so, please contact your U.S. senators and representative to urge them to co-sponsor these important bills, there is still time.

Source: National Hemophilia Foundation, www.hemophilia.org



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

For new members,
please complete the following application form.

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

Please mail completed applications to:
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.

Planning Groups Now Forming Please Call Now!

We have a busy year ahead and need all the volunteers and expertise we can get to help move these initiatives forward. We hope that you will take the time to call and talk with us about joining one of the planning groups that are now forming for the following:

“Hearts for Hemophilia” Casino Night - January 2009

5th Annual Charity Golf Classic - April 2009

HNC Annual Meeting - May 2009

Women’s Task Force - ongoing

2009 Hemophilia Walk - October 2009

For more information, please call Sue Cowell at 800-900-5557 or email at info@hemophilia-nc.org. Thank you for your support!

Membership Application

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Cell Phone: _____

Email: _____

Check One

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

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

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



Saturday, October 18th

9:00am Check In | 10:00am Walk Begins
Lake Crabtree County Park | Morrisville, NC
Walk Distance: 5K/3.1 mile walk

www.hemophilia.org/walk
800.990.5557

*Come join us as we raise funds to support NHF and Hemophilia of North Carolina,
while raising awareness about the bleeding and clotting disorders community.
Your support is greatly appreciated!*

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.



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