2008 Hemophilia Walk – A Great Success!

Our inaugural 2008 Hemophilia Walk in NC is now complete and what a great day it was. We had over 420 people participate in the Walk on Saturday, October 18th, 2008 and raised more than $63,000! Despite the looming threat of rain, the skies cleared for the Walk and it was a beautiful fall morning.

The Walk would not have been the success that it was without many people who worked tirelessly to promote the event, recruit volunteers, collect donations & assist in the activities of Walk Day! We have many people to thank and would like to acknowledge those groups and their contributions to the Walk.

Our thank you to the vendors & entertainers who woke up early in the morning and provided the crowd with delicious food & beverages along with some terrific entertainment to keep the crowd pumped up! We would also like to acknowledge the staff at Lake Crabtree County Park for their hospitality and assistance in allowing us to host the Walk at their facility. It was a beautiful walk route and a great venue.

Thank you to our media sponsors who helped to promote the Walk and to Julie Henry, NBC 17’s Health & Fitness Reporter, who did an outstanding job of emceeing the festivities.

Our sincere thanks to the sponsors who supported the Walk and many of whom had huge walk teams that provided so much support to this effort.

A very special thanks to the volunteers who came from all over to help make sure things ran smoothly. We had groups from high schools, universities and companies along with HNC members that came out and jumped right in to help.

Finally, a huge thank you to our walkers, Continued on page 8

A Visit by Santa & Mrs. Claus!

On December 6th our community members, along with friends & family, joined together to attend the Hemophilia of North Carolina’s 2008 Holiday Celebration at the Village Inn Golf & Conference Center in Clemmons. We had 143 people attend the event and filled the room to capacity!

We began with some time to relax, enjoy hors d’oeuvres and visit with friends. The young kids were busy making some fun crafts including reindeer food, holiday ornaments and reindeer heads from their hands and feet! The older kids had lots of fun playing the latest Wii games. While we took time to mingle and have fun, pictures of events from throughout

Continued on page 5
Hemophilia of North Carolina is a non-profit organization whose goal is to assist, involve and educate persons affected by bleeding disorders and to educate the medical community and the public about bleeding disorders.

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557

Executive Director, Sue Cowell
(919) 319-0014

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

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

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

About This Publication

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

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

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

Hemophilia Treatment Centers

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

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

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

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

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

Additional Medical Resources

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

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

Patent 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

A very Happy New Year to all! Like most of 2008, the holiday season was very busy preparing for our end of year events and getting ready to spend some time with family & friends. It is my hope that all of you shared your holidays with loved ones and enjoyed the spirit of the season.

In looking back over 2008, it is astonishing to see how many programs were put together and watch the growth of the organization in just one short year. 2009 is sure to be another year filled with more of the programs that members look forward to attending in addition to new and innovative ideas.

As always, we welcome your suggestions and support. Remember, together we can make a difference!

Sincerely,

Sue Cowell
HNC Executive Director

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Inclusive Health is our state’s new health plan for North Carolinians who do not have access to employer coverage and face high premiums because of their preexisting medical conditions. It is now enrolling individuals for coverage that will begin January 1, 2009. Anyone who enrolls by June 30, 2009 will be entitled to a reduced preexisting condition waiting period of 6 months rather than the standard 12 month waiting period. Applicants who currently have insurance coverage may qualify for a reduced or waived waiting period. Visit inclusivehealth.org or call 1-866-665-2117 for an application and complete details. Note: we encourage you to discuss any decisions related to this coverage with your HTC Social Worker as there are annual limitations on factor that should be considered.

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For more information, please contact your local Bayer HealthCare Account Executive, Spencer Miller, at (803) 319-7114, or by e-mail at spencer.miller@bayer.com.
2009 SUMMER CAMP INFORMATION – NORTH CAROLINA

We realize with holiday season just passing and the chill settling in, most people aren’t thinking about summer camp. Despite the temperatures, it really is time to start planning, marking your calendars and making your reservations.

Camp Carefree

Camp Carefree is located just north of Greensboro in Stokesdale, NC. Camp Carefree is open to all children regardless of their treatment center and they even welcome kids from neighboring states! The 2009 summer camp for children & teens – ages 6 to 16 – with hemophilia and other bleeding disorders is July 26th – August 1st. Also offered at Carefree are additional camps for well siblings who have a brother or sister with a chronic medical condition (June 21st – June 27th) and one for well children of ill/disabled parents (July 19th – July 25th).

This camp is completely funded by donations, there is no charge to attend this beautiful 22 acre facility. For more information and application forms contact Camp Carefree, Inc., (336) 427-0966 or on the web www.campcarefree.org

Camp Rainbow

Camp Rainbow is a summer camping experience for children with cancer or hemophilia treated by the Brody School of Medicine at East Carolina University. Camp Rainbow is a week long experience with an estimated 100 campers attending each year. The camp is staffed by physicians, nurses and other volunteers who provide necessary medical support and emotional encouragement. Camp Rainbow is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Our goals in providing this camping experience include: building self-confidence and independence, emotional and social development and well being, and learning and sharing support with others who are living with a chronic blood disorder. Camp activities include sailing, canoeing, swimming (lessons adapted for handicapped), arts and crafts, music, campfires, nature, and specialized support and educational sessions.

Summer camp for 2009 will be held June 14th – June 20th. For more information about Rainbow Services programs, camps volunteer opportunities and donation opportunities, please contact Jacquelyn P. Sauls, MS, CCLS – (252)744-4102 or saulsj@ecu.edu or Shannon W. Skinner, BS, CCLS – (252)744-1170 or skinners@ecu.edu.

Just for You

A Women’s Retreat

March 6-8, 2009
The Umstead Hotel and Spa
100 Woodland Pond – Cary, NC

Hemophilia of North Carolina is pleased to offer this special educational weekend retreat for women with bleeding disorders, women who are carriers and teenage girls (ages 13-17) of both groups. You are invited to join us for this retreat which will provide a comprehensive program on research, treatment, genetics, and empowerment and much more from leading experts in the field including Alice M. Ma, MD (UNC-CH), Andra H. James, MD, MPH (Duke University) and Tamison Jewett, MD (Wake Forest University).

Beyond the educational component, you will have the opportunity to meet others who also face similar challenges. Facilitators will lead discussions where groups will have a chance to share their stories and benefit from networking with others. There will also be fun, empowering components to help you be better equipped to positively impact your life.

This retreat is hosted by Hemophilia of North Carolina and provided at no cost to HNC member families through a generous grant from the CSL Behring Foundation. Invitations have been mailed and registration and information is also available on the web site at www.hemophilia-nc.org or by calling 1-800-990-5557.

Victory Junction Gang Camp – Summer Sessions

Victory Junction Gang Camp is located south of Greensboro in Randleman, NC. Victory Junction is a year-round camp that serves children, ages 6 to 16, with a variety of health issues. During the summer, the Camp offers week-long, disease-specific sessions with up to 128 kids per session. During the fall, winter and spring, family weekends are offered with 32 families per weekend. The 2009 summer camp for children & teens ages 7 to 15 with bleeding disorders is June 21st – June 26th. Sibling week will be held July 13th – July 17th.

Victory Junction is completely funded by donations. Summer applications begin December 15th and end on March 15th. For more information and application forms visit them at www.victoryjunction.org or call 877-854-2267.
A Visit by Santa & Mrs. Claus! continued

Fresh from the North Pole, Santa and Mrs. Claus stopped by for a visit! Each child took time to share their wish lists with Santa and everyone received gift to take home. Our special thanks to Santa and Mrs. Claus (alias: Terry & Becky Crotts) once again for making this a memorable moment for the children!

We concluded the event with a special bus tour through the Tanglewood Park Festival of Lights where there were thousands of lights and beautiful displays to put us all in the holiday spirit!

Hemophilia of North Carolina would like to graciously acknowledge our sponsors who made the HNC 2008 Holiday Celebration possible.
Remembering “Dr. Mac”

We were saddened by the news that Dr. Campbell McMillan passed away peacefully on October 13th. We wanted to take this opportunity to share the thoughts of Dr. Paul Monahan about his experience with Dr. McMillan, a friend and colleague who touched the hearts of so many. Thank you.

Dr. Alan Stiles, the Chairman of Pediatrics at UNC-Chapel Hill and a student of Dr. Mac’s, encapsulates the influence Dr. Mac had in the statement:

“Dr. Mac was the first of the Ped Heme/Onc faculty here at UNC and although a very successful investigator, teacher and clinician, was best known for his ‘heart.’ Beloved by his patients, both trainees and faculty learned about the human side of medicine from him.”

Although I am only the last of the hematologists on whom he left a direct imprint, I can try to get across to an extent his importance to hemophilia research. Keith Hoots was his fellow 1978-1980 and can attest to his unique character.

Dr. McMillan was a Pediatric Hematology/Oncology fellow with Dr. Louis Diamond at Boston Children’s Hospital during the decades when that program turned out most of the prominent individuals in our field. During this time, with Drs. Diamond and Douglas Sugeonor, he tested and published (in 1961) the effects of the first commercially available plasma fraction for the treatment of hemophilia, “fraction one” (enriched with fibrinogen and factor VIII). He was finally convinced to join the faculty at UNC Chapel Hill in 1963 as the first full time Pediatric Hematologist-Oncologist for the state’s medical school. He also set up the first research program in hemostasis on the Pediatric side, complemented perfectly by the extensive program initiated by Dr. Kenneth Brinkhous. Together, they performed research on hemophilia in the neonate, studying the blood clotting in newborn hemophilia dogs at the Chapel Hill Blood laboratory. Dr. Mac generally perfectly melded laboratory observations with clinical observations. Dr. McMillan also published (with Dr. Roberts) the first report of continuous infusion of clotting factor concentrates.

In the laboratory, he was also involved in early studies of the inhibitors to factor VIII and the quantitation of the effects of factor VIII inhibitors upon clotting function. On the clinical side, he organized a cooperative study (with ten institutions across the nation) that described the natural history of the development of inhibitors in hemophilia A, documenting incidence and characteristics of inhibitors in the early and later years of life. Naturally, Dr. McMillan was at the table with the group in Bethesda that agreed upon “A more uniform measurement of factor VIII inhibitors,” the assay now referred to as the Bethesda Assay. When recombinant factor VIII products became available and screening for inhibitor development became more rigorous, Dr. McMillan (along with Dr. Jeanne Lusher and others) reported the frequent occurrence of low titer, transient factor VIII inhibitors as a common and less clinically devastating a complication than the previously recognized high titer inhibitors. Also with Dr. Roberts, he published the first report of a family with an inherited combined deficiency of clotting factors, the combined deficiency of vitamin K dependent clotting factors II, VII, IX, and X. With the orthopedist Dr. Walter Greene, Dr. McMillan also published on the care of musculoskeletal complications of hemophilia. I am certainly omitting many achievements.

On the occasion of the National Hemophilia Foundation’s 50th anniversary celebration in 1998, Dr. Campbell W. McMillan received the organization’s Outstanding Achievement Career Award. “Although Dr. McMillan made lasting contributions to the field of hemophilia care, he is best known for the extraordinary care he gave to his patients,” the award citation said.

Although remarkably outgoing and giving, Dr. McMillan was inordinately humble. His Department Chairman of 20 years summarized Dr. McMillan’s many contributions, concluding his own remarks with the statement: “For twenty-eight years he served as the “conscience” of the Department. We could always be certain that he, in his humble way, would let us know if we were showing any tendency to make any move that was not in the best interests of children.” Rather than give in to doubt or a selfish notion, Dr. Mac’s instinct was always to be mindful of those around him, as reflected in his statement in the book The Gift of Experience: Conversations About Hemophilia:

“What offset the problems was the never-ending demonstration by my patients of their ability to respond to difficulties. This was a continuing blessing of the highest order and the greatest gift of all, not from me, but to me, from my patients.”

— Paul Monahan, MD
Important Safety Information
Helixate® FS is a recombinant factor VIII treatment indicated for the treatment of hemophilia A. The most frequently reported adverse events were local injection-site reactions, dizziness, and rash. Known intolerance or allergic reactions to constituents of the preparation is a contraindication to the use of Helixate® FS. Known hypersensitivity to mouse or hamster protein may be a contraindication to the use of Helixate® FS.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see brief summary of prescribing information on next page.

Helixate® FS is manufactured by Bayer HealthCare LLC for CSL Behring.

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GET YOUR GAME FACE ON
at www.HFSGameFaces.com!

New GameFaces™ from Helixate® FS—
Physical challenges that help kids with hemophilia A get active
- Log on to www.HFSGameFaces.com
- Register and choose your GameFaces™ character
- Complete outdoor and indoor physical challenges—even Wii™ games—on your own
- Come back to the site to log your physical activity progress
- When you complete a challenge, you will be entered in a sweepstakes to win a Wii™

Don’t miss your chance to win…
register now at www.HFSGameFaces.com!

Register for a chance to win a Nintendo® Wii™!
2008 Hemophilia Walk – A Great Success! continued

fundraisers and donors. **We could not have done it without you!** The goal of the Walk was to raise funds and awareness for those people affected by a bleeding or clotting disorder. Not only did you succeed in accomplishing both of these goals, the energy and enthusiasm from the Walk helped to form many new relationships and helped renew old ones that will last for years to come - a very sincere thank you for all of your support!

We are looking forward to the 2009 Hemophilia Walk that is tentatively scheduled for **Saturday, October 17th** so **SAVE THE DATE!** Also, we will begin planning for the 2009 Walk soon and if you are interested in being a part of the planning committee, please contact me!

Thank you again for your wonderful support!

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HNC and Members Recognized by NHF at 60th Annual Meeting

Hemophilia of North Carolina was awarded the prestigious **Award of Distinction in Programs** by the National Hemophilia Foundation at their 60th Annual Meeting. The Award of Distinction recognizes chapters and associations with outstanding programs in health education, outreach and communications. Longtime members, **Charles & Kathy Register**, were also honored with **Chapter Recognition Awards**. Charles & Kathy were founding members of Hemophilia of North Carolina in 1973. Over the past 35 years they have worked tirelessly on behalf of the bleeding disorders community in the state of North Carolina. Although their roles in the organization have changed over time, their dedication has not and we are thrilled that they received this well deserved award. **Congratulations!**
2008 Hemophilia Walk

Some members of the UNC Tarhealers – Winners of the Hospital Cup!

Guillermo & his friend Stormy

Gavin’s Gang – Winners of Best tee Shirt

Definitely – a walk to remember!

Some of the Kitty Kat Kathryn team on the move – the #1 family team that raised nearly $4,500 – Congratulations!

The kids visit with the Mad Scientist at the Talecris Booth

Nick – getting ready to make his donation!

Team Jewett

A Chilly Waddler duo from the MedPro Rx Team

Opening Activities

Patricia and friends sharing a dance at the Baxter Booth

Please visit our web site at www.hemophilia-nc.org for lots more pictures of the 2008 Hemophilia Walk!
2009 Scholarship Information

We are fortunate to have many opportunities for scholarships in the bleeding disorder community. To assist you in your search, we have compiled this information on some of the scholarships available and the companies that provide them. This list is not exhaustive and we recommend visiting the NHF and HFA websites for additional resources.

Beth Carew Memorial Scholarship
Amount: ten $2,000 college awards
Candidate: person or family member with hemophilia or other bleeding disorders, enrolled full-time in an accredited college
Contact: Colburn Keenan Foundation, Inc.
Phone: (800) 966-2431
Web site: www.colburnkeenan.org

Bill McAdam Scholarship Fund
Amount: one $2,000 award
Candidate: a person with hemophilia, VWD or other hereditary bleeding disorder or the person’s spouse, partner, child or sibling planning to attend an accredited college or university or certified training program.
Contact: Cathy McAdam Scholarship Fund
Phone: (313) 563-1412
E-mail: mcmadam@comcast.net

BioRx/Hemophilia of North Carolina Educational Scholarships
Amount: three $2,000 scholarships
Candidate: intended for caregivers of children affected with bleeding disorders, a person who has been diagnosed with hemophilia or a sibling of a person diagnosed with hemophilia. Preference will be given to a hemophilia community member, parent and family members seeking healthcare related education from an accredited college or university or certified training program.
Contact: BioRx
Phone: 866-442-4679
Web site: www.biortx.net
Email: cbarnes@biortx.net

Christopher Pitkin Memorial Scholarship
Amount: amounts of scholarships vary from $500 - $1,000
Candidate: all members of the hemophilia and bleeding disorders community, including spouses, siblings and children
Contact: Hemophilia Foundation of Southern California
Phone: (323) 525-0440
Web site: www.hemosocal.org

CoaguLife Education Scholarships
Amount: several scholarships up to $5,000 each
Candidate: person with hemophilia, von Willebrand disease or other inherited bleeding disorder
Contact: CoaguLife
Phone: (866) 858-9200
Web site: www.coagulife.com

Dave Madeiros Scholarship Program
Amount: several scholarships up to $1,000 for creative arts and $2,000 for continuing education
Candidate: individuals with a bleeding disorder and their immediate family
Contact: Factor Foundation of America
Phone: (866) 843-3362
Web site: www.factorfoundation.org

“Education is Power” Scholarship - MedPro Rx
Amount: a minimum of twenty-five scholarships, ranging from $500 to $2,500, totaling $60,000 in 2009
Candidate: individuals living with hemophilia and von Willebrand disease entering or attending a community college, junior college, four-year college, university, or vocational school.
Important note: Prior applicants and winners are encouraged to reapply each year
Contact: MedPro Rx, Inc.
Phone: (866) 528-4963
Web site: www.medprorx.com
E-mail: educationispower@medprorx.com

Edu-Grants (for K-12 learning assistance)
Amount: up to $500 financial award per child per year to help pay for tutors or learning assistance when students (K-12) miss a significant number of school days due to hemophilia
Candidate: people with hemophilia diagnosed with an inhibitor or individuals with factor VII deficiency
Contact: Novo Nordisk
Phone: (856) 573-9400
Web site: www.novoseven-us.com

Eric Delson Memorial Scholarship
Amount: one $1,500 award per year, renewable up to four years, for private high school. Three $2,500 award per year, renewable up to four years, for college or trade school.
Candidate: students clinically diagnosed with hemophilia or von Willebrand disease
Contact: Caremark
Phone: (866) 792-2731
Web site: www.caremark.com

Eric Dostie Memorial College Scholarship
Amount: ten $1,000 awards
Candidate: student with hemophilia or other related bleeding disorder, or a family member. Must be a US citizen and enrolled full-time in an accredited two or four year college program
Contact: NuFACTOR
Phone: (800) 323-6832 ext 1300
Web site: www.nufactor.com

Factor Foundation Scholarship Program
Amount: several scholarships awarded for continuing education and creative arts
Candidate: individual with a congenital bleeding disorder and their siblings or parents
Contact: Factor Foundation of America
Phone: (866) 843-3362
Web site: www.factorfoundation.org

HemAspheres University Scholarship Fund
Amount: three scholarships up to $5,000
Candidate: scholarship program is funded by the American Red Cross for persons affected by hemophilia pursuing college studies leading to a degree
Contact: Scholarship America
Phone: (507) 931-1682
Web site: www.redcross.org

Hemophilia Federation of America
Amount: several $1,500 awards
Candidate: person with hemophilia or VWD, including parents and siblings attending any accredited two- or four-year college, university or vocational/technical school in the US. Also include awards for completing a visual/performing art project
Contact: Hemophilia Federation of America
Phone: (800) 230-9797
Web site: www.hemophiliafed.org
Email: info@hemophiliafed.org

Hemophilia Health Services Memorial Scholarship Program
Amount: several $1,500 and more awards a full academic year.
Candidate: a US citizen with hemophilia, VWD or other bleeding disorder.
Must be a high school student about to attend college, a college student, a college senior planning to attend graduate school or graduate school student.
Contact: Hemophilia Health Services
Phone: (800) 289-6501 ext 5175
Web site: www.HemophiliaHealth.com
E-mail: key is HEMO

Hemophilia of North Carolina
PO Box 70, Cary, NC 27512-0070 • (800) 990-5557 • info@hemophilia-nc.org • www.hemophilia-nc.org
Chapter News & Information

Joshua Gomes Memorial Scholarship Fund
Amount: several $1,000 awards
Candidate: individuals living with HIV/AIDS accepted or enrolled in college in the US
Contact: Joshua Gomes Memorial Scholarship Fund
Phone: (303) 761-3055
Web site: www.joshuagomes.org

Kevin Child Scholarship
Amount: one $1,000 award
Candidate: individual diagnosed with hemophilia or von Willebrand disease attending college, university or vocational school in the US
Contact: National Hemophilia Foundation
Phone: (800) 42-HANDI ext. 5700 (ask for Renee)
Web site: www.hemophilia.org

Lawrence Madeiros Scholarship
Amount: several $1,000 or more awards
Candidate: student with an inherited bleeding disorder or other chronic disorder attending an accredited college or university
Contact: Positides - The Lawrence Madeiros Scholarship
Phone: (518) 661-6005
Web site: www.adirondackspintacular.com

Michael Bendix Sutton Foundation Scholarships
Amount: two $2,000 scholarships
Candidate: student with hemophilia pursuing pre-law study
Contact: Michael Bendix Sutton Foundation
c/o Marion B Sutton
300 Maritime Avenue
White Plains, NY 10601

Mike Hylton and Ron Niederman Memorial Scholarships
Amount: five $1,000 scholarships
Candidate: a person with hemophilia or von Willebrand disease and their immediate family members
Contact: Factor Support Network Pharmacy
Phone: (877) 376-4968
Web site: www.factorsupport.com
Email: scholarships@factorsupport.com

Millie Gonzalez Memorial Scholarship
Amount: two $1,000 awards
Candidate: women diagnosed with hemophilia or von Willebrand disease entering or attending college or vocational school
Contact: Factor Support Network Pharmacy
Phone: (877) 376-4968
Web site: www.factorsupport.com
Email: scholarships@factorsupport.com

National Cornerstone Healthcare Services
Amount: several $500 to $1,000 awards per a year
Candidate: a person diagnosed with a bleeding disorder, parent, spouse, partner, child or sibling of a person diagnosed with a bleeding disorder.
Contact: National Cornerstone Healthcare Services
Phone: (877) 616-6247
Web site: www.nc-hs.com

Project Red Flag Academic Scholarship for Women with Bleeding Disorders
Amount: two awards of $2,500
Candidate: applicants must be female residents of the US and have a bleeding disorder (includes von Willebrand disease, hemophilia carrier or other clotting factor deficiencies)
Contact: National Hemophilia Foundation
Phone: (800) 424-2634 ext. 3700 (ask for Renee)
Web site: www.projectredflag.org

Rachel Warner Scholarship
Amount: funds are varied and limited
Candidate: person with bleeding disorder
Contact: The Committee of Ten Thousand
c/o Rachel Warner Scholarship
Phone: (800) 488-2688
Web site: www.cott1.org
Email: cott-dc@earthlink.net

Salvatore E Quinci Foundation Scholarship
Amount: two $2,000 scholarships
Candidate: person diagnosed with hemophilia or other bleeding disorder accepted into an accredited university, college or vocational/technical school
Contact: S.E.Q Foundation, Inc
Phone: (781) 760-7138
Web site: www.sequindie.org

Seven SECURE Scholarship
Amount: several grants of up to $500 per person per year or up to $7,000 per person per year.
Candidate: patients must be factor VIII or IX deficient with inhibitors and a customer of Novo Nordisk, Inc., and enrolled in full time at a vocational school, college or graduate school.
Contact: Novo Nordisk
Phone: (877) Novo-777
Website: www.us.novoseven.com

Soozie Courter Sharing a Brighter Tomorrow Hemophilia Scholarship Program
Amount: two $7,500 graduate study awards, sixteen $5,000 college scholarships and two $2,500 vocational scholarships to applicants with hemophilia A or B.
Candidate: a student with hemophilia A or B who is a high school senior (or has graduate equivalency diploma), college student (undergraduate or graduate) or vocational school student.
Contact: Wyeth/Genetics Institute, Inc.
Phone: (888) 999-2349
Web site: www.hemophiliavillage.com

Professor Ulla Hedner Scholarships
Amount: from $2000 to $7000 per person per year
Candidate: having either hemophilia with an inhibitor or FVII deficiency. Must be a high school senior, college or vocational student under the age of 23
Contact: Novo Nordisk
Phone: (877) 668-6777
Web site: www.us.novoseven-us.com (click on sevenSECURE)

Rachel Warner Scholarship
Amount: funds are varied and limited
Candidate: person with bleeding disorder
Contact: The Committee of Ten Thousand
c/o Rachel Warner Scholarship
Phone: (800) 488-2688
Web site: www.cott1.org
Email: cott-dc@earthlink.net

Salvatore E Quinci Foundation Scholarship
Amount: two $2,000 scholarships
Candidate: person diagnosed with hemophilia or other bleeding disorder accepted into an accredited university, college or vocational/technical school
Contact: S.E.Q Foundation, Inc
Phone: (781) 760-7138
Web site: www.sequindie.org

Seven SECURE Scholarship
Amount: several grants of up to $500 per person per year or up to $7,000 per person per year.
Candidate: patients must be factor VIII or IX deficient with inhibitors and a customer of Novo Nordisk, Inc., and enrolled in full time at a vocational school, college or graduate school.
Contact: Novo Nordisk
Phone: (877) Novo-777
Website: www.us.novoseven.com

Soozie Courter Sharing a Brighter Tomorrow Hemophilia Scholarship Program
Amount: two $7,500 graduate study awards, sixteen $5,000 college scholarships and two $2,500 vocational scholarships to applicants with hemophilia A or B.
Candidate: a student with hemophilia A or B who is a high school senior (or has graduate equivalency diploma), college student (undergraduate or graduate) or vocational school student.
Contact: Wyeth/Genetics Institute, Inc.
Phone: (888) 999-2349
Web site: www.hemophiliavillage.com

Professor Ulla Hedner Scholarships
Amount: from $2000 to $7000 per person per year
Candidate: having either hemophilia with an inhibitor or FVII deficiency. Must be a high school senior, college or vocational student under the age of 23
Contact: Novo Nordisk
Phone: (877) 668-6777
Web site: www.us.novoseven-us.com (click on sevenSECURE)
2008 Friends of HNC
We would like to acknowledge the following individuals who generously donated to HNC during the fourth quarter of 2008. We extend a sincere thank you to our supporters...many of whom contributed several times during this period.

Donation Made In Honor of Heather & Dalton Dawes
Mr. & Mrs. Horace Uffelman

Donation Made In Honor of Jesse W. Cornaire
Ali K. Boutique

Additional Donors
Mr. & Mrs. Matt Barnes
Mr. & Mrs. W. Allen Heafner
Mr. Eric Hill
Mr. Jim Jarratt
Dr. & Mrs. Harold R. Roberts

2008 Hemophilia Walk Donors
Due to the overwhelming response in donations from individuals for the 2008 Hemophilia Walk, space prohibits us from listing the names of those 559 donations in the newsletter. We would like to graciously acknowledge their contributions and encourage everyone to visit the walk web site at www.hemophilia.org/walk to browse through the site and take a look at the generosity of these individuals and their families. Thank you again.

We would also like to acknowledge, Hemophilia First, LLC, a sponsor that was omitted in error from our 2008 Honor Roll of Corporate Sponsors. Thank you for being a FRIEND OF THE COMMUNITY (with a donation up to $499)

Thank You!

2008 HNC Volunteers of the Year

As most of you know, volunteers are the life blood of any non-profit organization and the most important resource we have. The ability of people to work willingly together for the betterment of this community is truly a win/win situation that provides a meaningful experience for the volunteers as well as for Hemophilia of North Carolina.

The image and description of a volunteer has changed over time. Volunteers come from all walks of life and contribute in so many different ways. In looking back over our programs and events of 2008, members of HNC and their families have contributed thousands of hours of their valuable time. Every minute they have contributed has helped to improve the lives of so many people in the community.

We would like to acknowledge everyone who has volunteered their time or talents over this past year. We applaud your efforts and thank you for generously giving of yourselves to help others.

This year, we would like to recognize the extraordinary efforts of one family who has embraced the community and given their time and talents in helping with many of the events this year including the golf tournament, hemophilia walk and holiday celebration. Their contribution has helped bring awareness to HNC and its members by reaching out to many people in the business community and inspiring dozens of people to also get involved in their efforts. Our congratulations to the Griffith Family (Tera, Russ & Gavin) and Terry & Becky Crotts on being our 2008 HNC Volunteers of the Year!
Wisconsin Researchers Use Genetically Engineered Bone Marrow to Treat Bleeding in Mice

A team of Wisconsin researchers recently increased factor VIII (FVIII) levels in mice with hemophilia A and inhibitors through a specific type of gene therapy involving bone marrow. The technique also involves platelets, which are produced inside the bone marrow. The lead investigator of the study was Qizhen Shi, MD, PhD, Department of Pediatrics, Medical College of Wisconsin in Milwaukee. Dr. Shi’s research is currently being funded through the National Hemophilia Foundation’s Career Development Award Program. She was initially granted the award in July 2007. Dr. Shi presented her research at NHF’s 60th Annual Meeting in Denver, Colorado, last month.

Shi and colleagues effectively removed portions of bone marrow from mice, genetically modified the stem cells in them and then returned the altered marrow to the mice. This approach triggered “normal” production levels of FVIII. The FVIII was then delivered into the bloodstream by the platelets. In lab tests, the majority of the hemophilia A mice with inhibitors showed healthy levels of FVIII and significantly less bleeding following delivery of the therapy. Although the reported results are promising, additional animal studies, followed by eventual human trials will need to be completed before this kind of therapy becomes an option for patients.

The study, “Syngeneic Transplantation of Hematopoietic Stem Cells That are Genetically Modified to Express Factor VIII in Platelets Restores Hemostasis to Hemophilia A Mice with Pre-existing FVIII Immunity,” was published in the October 2008 issue of Blood.

Source: Medical News Today, November 14, 2008
Duke Study Shows IUD Can Reduce the Length of Heavy Periods

Results from a Duke University study show that an intrauterine device (IUD) that releases levonorgestrel, a synthetic form of the hormone progestin, can help contain unusually heavy and prolonged menstrual bleeding (menorrhagia). While the device is more often used as an effective means of contraception, the study demonstrated a potential to reduce these symptoms in women with inherited bleeding disorders or who are on anticoagulant therapies (drugs that lower the risk of developing dangerous blood clots). The head researcher of the small study was Andrea S. Lukes, MD, MHSc, former Director of Gynecology for the Women’s Hemostasis and Thrombosis Clinic at Duke University in Durham, NC. Lukes now directs the Carolina Women’s Research and Wellness Center in Raleigh.

Among the seven women ranging in age from 28 to 48 years old who participated in the study, four had von Willebrand disease (VWD) and four were on anticoagulation therapy-- warfarin or aspirin. Overall, five of the women, or 71%, experienced much less monthly bleeding; the average number of days of bleeding dropped from nine per month to only three. These women also reported that the quality of their lives improved as the length of their menstrual cycles was shortened. The two other women, or 29% of the study participants, experienced no change in their bleeding symptoms. One woman in the study decided to have her IUD removed in order to become pregnant.

“In my opinion, the levonorgestrel-releasing intrauterine system (LNG-IUS) is a great choice for women with hemostatic disorders, for both contraception and for treatment of heavy periods,” said Lukes. “I consider it a safe and effective choice.”

Previous studies of IUIDs and menorrhagia have also indicated the device’s ability to drastically reduce bleeding. Note that this study only measured the results of seven women. Future studies will need to be conducted on a larger number of participants.

The study, “Use of the Levonorgestrel-Releasing Intruterine System in Women with Hemostatic Disorders,” was published in the September 2008 issue of *Fertility and Sterility.*

Source: Reuters, October 7, 2008
CSL Behring launches GamesFaces™ program

Interactive family-oriented online initiative designed to encourage physical activity provides physical challenges for patients with hemophilia A

CSL Behring announced today it launched the first challenge of GamesFaces™, a family-oriented online initiative for patients with hemophilia A, at the 60th Annual Meeting of the National Hemophilia Foundation (NHF). GameFaces is designed to encourage real-life physical activity through a series of three customized challenges based on the individual’s age, disease severity and current level of physical activity. Participants can now log on to the program website at www.HFSGameFaces.com, create their GameFaces character and begin the first challenge.

CSL Behring, the providers of the hemophilia treatment Hemihelix™ FS (Antihemophilic Factor, Recombinant), developed GameFaces to inspire hemophilia A patients to participate in physical activities and also to allow them to feel connected to other patients with this serious bleeding disorder. At the conclusion of each challenge period, those who have completed the challenge will be entered into a drawing to win a Nintendo® Wii™ game console. Nintendo Wii has been recognized as the next generation of video games and is known to inspire physical activity through games that require movement.

“We are pleased to officially unveil GameFaces to the hemophilia community at the NHF’s annual meeting, where the theme this year is ‘Reaching New Heights’, ” said Garrett E. Bergman, M.D., Senior Director, Medical Affairs, U.S. Commercial Operations at CSL Behring. “GamesFaces promotes the kind of daily physical activity that will empower hemophilia A patients, from those with a mild form of the condition to those with the most severe form, to reach new heights in developing a healthy and safe lifestyle.”

“We appreciate CSL Behring’s commitment to our children and their specific needs,” said Rhonda Boni-Burden, mother of Alex, a 14-year-old boy with severe hemophilia A. “A program like GameFaces enables our children to build their self-esteem and helps manage these bleeding disorders, which is important to our families’ quality of life.”

The program’s physical challenges include both outdoor and indoor activities, which patients can complete on their own or with family and friends. Challenges are designed to be completed over a one-month timeframe during the challenge interval. Participants can track their progress by logging on to the program’s website at www.HFSGameFaces.com. Children under 18 must have a parent’s permission to participate.

Bayer’s Summer Internship Program

The Bayer Hemophilia Leadership Development Program was developed with input from members of our hemophilia advisory boards who saw a need for an internship program to develop future leaders in the bleeding disorders community. Applications are due by Friday, February 13, 2009. Applicants should be college students (sophomore through senior year), with a strong tie to hemophilia, who demonstrate a commitment and interest in being a future leader in the hemophilia community.

During this eight-week, paid summer internship program, future leaders participate in a variety of hands-on modules designed to sharpen leadership skills in real-world scenarios to enrich the hemophilia community. Internship modules include:

• a visit to the Bayer HealthCare manufacturing facility in Berkeley, California

• work healthcare public policy professionals to see how effective advocacy relations impact legislative decisions

• an exploration of marketing and communications strategies

• leadership training classes to develop presentation skills, learn about effective project management, and discover successful time management techniques.

• a personal challenge project which allows interns to apply their new skills to design and create a project

The internship application (attached for your reference) and additional program details are available at www.livingbeyondhemophilia.com/internships. Information about the internship also is included in the January newsletters from the National Hemophilia Foundation and Hemophilia Federation of America.
Baxter Announces Dosing Of First Patient In Phase I Clinical Trial Of Recombinant Therapy For Von Willebrand Disease

First Recombinant To Be Tested in von Willebrand Disease (VWD) DEERFIELD, Ill., December 4, 2008 – Baxter Healthcare Corporation today announced the dosing of the first patient in a Phase I clinical trial of its recombinant von Willebrand Factor (rVWF), an investigational drug for the treatment of von Willebrand Disease (VWD), the most common type of inherited bleeding disorder. The multicenter, controlled, randomized, single-blind prospective trial will evaluate the pharmacokinetics, safety and tolerability of rVWF in Type 3 VWD patients. The study will be conducted in North America and Europe.

“All current therapies for von Willebrand Disease are derived from human plasma. A plasma- and albumin-free recombinant therapy would eliminate the potential risk of transmitting blood-borne pathogens since no blood components are added at any stage of manufacturing. Achieving this milestone is significant in supporting our commitment to improve care for the bleeding disorder community,” said Hartmut Ehrlich, MD, vice president of global research and development for Baxter’s BioScience business. Recombinant VWF is currently in development for the treatment of patients diagnosed with severe VWD and for other patients with VWD who are unresponsive or otherwise unable to receive desmopressin, a synthetic hormone that promotes the release of natural VWF. To learn about enrollment, patients and caregivers may go to www.clinicaltrials.gov, where details will soon be posted.
Your National Hemophilia Foundation is taking a vital step to ensure that everyone we serve has Access to Care Today until we Achieve a Cure Tomorrow (ACT).

This is an initiative with far-reaching and life-altering goals. It is a movement within the foundation to support a strong national organization, part of a coordinated and unified system within the bleeding disorders community that will result in access to care defined as:

- Adherence to state-of-the-art standards of care
- Access to hemophilia treatment centers (HTCs)
- Access to treatment products appropriate for the individual
- Adequate reimbursement for these life-saving therapies

Through the ACT initiative, NHF and local organizations will establish a strong, coordinated national network, which will focus on enhancing efforts in these Priority Areas: Government Awareness and Support, Education for All Life Stages, Access to Care at HTCs and Beyond & Research and Training. And to develop these areas we will build our national network including…Strong Local Organizations

With your help, we will work to strengthen our presence around the country -- in your community through our chapter network, which is where you work, live and receive your care. This means developing the capacity of our local chapters through a major investment in human resources and tools they need to more fully meet the needs of our families living with a bleeding disorder.

Act Now! We need everyone’s support to succeed. For information on ACT, visit the NHF web site at www.hemophilia.org or call (800) 42-HANDI.

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No matter where you are, we are there for you

- Factor Replacement Therapies for Hemophilia and von Willebrand Disease
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For more information, please contact:

**Kathy Robinette-Stoneberg**

National Director, Community Advocate

(866) 528-4963

Providing Hemophilia therapy to North Carolina & surrounding areas.
The HFA 2009 Annual Educational Symposium will be held March 13 & 14, at the Marriot East Indianapolis, Indiana. Call HFA at 1-800-230-9797 for more information or visit their web site at www.hemophiliafed.org.

HFA has completed their move to Washington, DC and are fully operational, focusing on their programming and public policy/advocacy initiatives. The new contact information is: Hemophilia Federation of America, 210 7th St SE, Ste B, Washington, DC 20003. The office phone is 202.675.6984 or toll free 800.230.9797 and fax is 202.675.6983.

NHF’s annual Washington Days empowers individuals in the bleeding disorders community to impact the legislative process. Join us to:

- Become more informed on critical issues that affect your continued access to high quality care
- Learn effective grassroots advocacy techniques
- Meet face-to-face with legislators and staff who shape national healthcare policy

Mark your calendars to walk the halls of Congress and make your voice heard!
For more information on attending with the North Carolina contingency, contact Sue Cowell at 80-900-5557 or by email at info@hemophilia-nc.org.

SAVE THE DATE!
February 25-26th, 2009

When Only the Best Will Do!

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

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

For further information contact:

Shirley Moorehead
866-243-4621

Setting the Standard of Care for the Bleeding Disorders Community

www.AHFinf.com
31 Moody Road, P.O. Box 985, Enfield, CT 06083 • 800-243-4621 • AHF@AHFinf.com
Save These Dates!

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 more programs and events to take place and will let you know when they become available.

Women’s Retreat – March 6th-8th
Camp Reunion Day – March 28th
Adult Retreat – April 18th-19th
5th Annual Charity Golf Classic – April 24th
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

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

Membership Application

Name:___________________________________________
Address:_________________________________________________________________________________
City:___________________________________________ State:_____________ Zip:__________________
Home Phone:____________________________________ Cell Phone:________________________________
Email:___________________________________________________________________________________

Check One

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

____ I am a family member of a person with a bleeding disorder
     Relationship ____________________
     Type of bleeding disorder _______________________

____ I am a medical professional

____ I am an interested person

____ I am a currently an active member – information update

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

- Individual Member $10
- Supporter $100
- Family Membership $25
- Patron $200
- Contributor $50
- Benefactor $500
Opportunities for Programs & Participation

Please tell us if you or a family member would be interested in assisting with any of the following programs or opportunities:

Call for more details and volunteer opportunities at (800) 990-5557
- Event Planning
- Women's Task Force
- Advocacy
- Regional Meeting Coordinators
- Educational Programming

We invite you to visit our website at www.hemophilia-nc.org for more information and pictures on all of the programs & events offered during the year.

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