

THE C NCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2009

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

Inside

Chapter News & Events
Resource Center
On the Health Front
Industry News
On the National & Legislative Front

Save The Date

Victory Junction Gang Camp
Family Sessions
Jan-Mar 2009

HNC Latin Union Meetings
February 21, 2009
March 21, 2009
Charlotte, NC

NHF Washington Days
February 25-26, 2009
Washington, DC

HNC Women's Retreat
March 6-8, 2009
Cary, NC

HFA 2009 Symposium
March 13-14, 2009
Indianapolis, IN

Coalition for Hemophilia B
3rd Annual Symposium
March 21, 2009
New York, NY

HNC Camp Reunion Day
March 28, 2009
Monroe, NC

HNC Adult Retreat
April 18-19, 2009
Wilmington, NC



*Hemophilia of
North Carolina*

PO Box 70
Cary, NC 27512-0070
(800) 990-5557
info@hemophilia-nc.org
www.hemophilia-nc.org

**MISSION
STATEMENT**

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

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557

Executive Director, Sue Cowell
(919) 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

**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/

**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.needpsi.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
Sue Cowell

HNC Executive Director

INCLUSIVE HEALTH

Insuring Individuals with Medical Conditions

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.*

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



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.



BAYER, the Bayer Cross, and Kogenate are registered trademarks of Bayer. BIO-SET is a registered trademark of Biodome SAS.

©2008 Bayer HealthCare LLC All rights reserved Printed in USA 8/08 KN10000308



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



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.

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 skinner@ecu.edu.

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

HNC 2008 Adult Retreat April 18-19, 2009 Wilmington, NC



Save the Date! Adults (age 21 and over) are invited to attend this weekend retreat where Inalex Communications will present their

popular workshop, "Getting your Head on Straight". The workshop will be presented by Dr. Ron Potter-Efron and explores how your thinking and emotions are affected by dealing with a bleeding disorder and how to deal with stress in a positive and optimistic manner. Meals, programs & entertainment will be available during the weekend at no cost to our members. Look for your invitation soon!



HNC Camp Reunion Day

All campers, future campers, ex-campers, parents & counselors invited!

HNC is hosting a Camp Reunion Day on **Saturday, March 28th, 2009 from 10:00am to 5:00pm at Xtreme Challenge in Monroe, NC.**

Come join in the fun with some of your fellow campers from past summers or meet new friends. The Xtreme Challenge facility offers ten acres of high and low ropes challenge courses, zip lines and a large fire circle where we'll enjoy some afternoon smores! There will be lots more activities including a scavenger hunt and camp theme games to remind you of those fun days of summer.

Activities will be planned for children ages 6-16. We encourage you to visit the Xtreme Challenge web site at www.xtreemechallenge.com for more information about the challenge courses and activities.

There is no fee to attend the event and lunch will be provided. Please RSVP by March 14, 2009 to hold your reservation. Registration is available online at www.hemophilia-nc.org or by calling 1-800-990-5557.

This opportunity was made available through Baxter's Camp Superfly III program and the 5th place win of HNC in our division. Thank you!

A Visit by Santa & Mrs. Claus! *continued*

the year scrolled on the overhead screen.

Before our main meal, we took time to recognize some recent awards given to HNC and members. A DVD of the Hemophilia Walk was then shared with the group and the success of this program for HNC and its members was acknowledged.

After a delicious lunch, our keynote speaker, Glenn Mones, NHF's VP of Public Policy, shared his thoughts on the recent election, what it means to the bleeding disorders community and what the future may bring. Although healthcare is sure to have more attention than in the past, Glenn cautioned the group that we can not just sit back and expect changes to happen by themselves. We need to take the initiative to meet with our legislators, get involved and tell them why these issues and legislation is important to us.

Hemophilia of North Carolina was then presented with a \$3,000 check from Baxter Healthcare for our Camp Superfly III standing of 5th place winner. In addition, children who participated in the Camp Superfly program this summer were invited up to receive their limited edition Gold Medals, just like the Olympics!



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.

Silver Sponsors






Bronze Sponsors





Remembering “Dr. Mac”



Dr. Campbell White McMillan

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 be more effusive; Harold Roberts, his co-investigator throughout Dr. McMillan’s career can be more eloquent; and Gilbert White, who saw adult hemophilia patients while Dr. McMillan was the Director of our HTC and saw the children, 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 Surgenor, 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

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™!

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.

© 2008 CSL Behring LLC, 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901, USA
www.CSLBehring-US.com Printed in USA IO#102-15061 10/2008



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!



A heritage of caring. For over 60 years Grifols has been dedicated to quality, safety, efficacy and purity in the products we manufacture.

Andrew, an actual patient with his son.

Alphanate®
Antihemophilic Factor (Human)

AlphaNine® SD
Coagulation Factor IX (Human)

Profilnine® SD
Factor IX Complex

As with all plasma-derived products, the risk of transmission of infectious agents, including viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, cannot be completely eliminated.

Working for health since 1940

GRIFOLS

Grifols Biologicals Inc. 5555 Valley Boulevard, Los Angeles, CA 90032
(888) GRIFOLS www.grifolsusa.com

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: mcmcadam@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.biorx.net

Email: cbarnes@biorx.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 \$2500, 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 access key is HEMO

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. 3700 (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: Positudes - The Lawrence Madeiros Scholarship

Phone: (518) 661-6005

Web site: www.adirondackspintacular.com

Michael Bendix Sutton Foundation

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 \$1000 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.seqfoundation.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.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)



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 trig-

gered "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

It's never been easier
to try ADVATE

FREEDOM OF CHOICE

trial program

Receive 6 FREE doses of ADVATE*

Visit www.advate.com or call 1-888-4ADVATE for more information.



[Antihemophilic Factor (Recombinant),
Plasma/Albumin-Free Method]

*For new ADVATE patients only, after consultation and approval by a doctor. Participants will receive 6 complimentary doses of ADVATE sent directly to their home.

Baxter and ADVATE are registered trademarks of Baxter International Inc.
© Copyright (August 2006), Baxter Healthcare Corporation. All rights reserved.

Baxter

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 for 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 IUDs 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 Intrauterine System in Women with Hemostatic Disorders," was published in the September 2008 issue of *Fertility and Sterility*.

Source: Reuters, October 7, 2008



Matrix Health

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

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



Turn to Matrix Health
Experience the Difference!

Contact your Regional Care Coordinators:

Matt Igelman
919-699-1972
migelman@matrixhealthgroup.com

Donna Compton
919-270-8382
dcompton@matrixhealthgroup.com

Visit Our Website at
www.matrixhealthgroup.com

CSL Behring launches GamesFaces™ program

*Interactive family-oriented online initiative designed to encourage physical activity provides physical challenges for patients with hemophilia A
Denver, CO — 19 November 2008*

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 Helixate® 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



When you need us,
Baxter will be there.

Through Therapies

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

Through Participation

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

Through Progress

Improving current therapies and developing new and better ways to manage hemophilia A—innovations inspired by listening to you.

For more information on Baxter programs and services, visit www.thereforyou.com.

There when you need us



Baxter, Advoy, Camp SuperFly, Factor Assist, and www.thereforyou.com are trademarks of Baxter International Inc. ©Copyright (January 2007), Baxter Healthcare Corporation. All rights reserved. HYL2652

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.

“Baxter is pleased to begin clinical testing of the first recombinant, plasma and albumin-free treatment for von Willebrand Disease, a clinically-challenging bleeding disorder with unmet needs in therapeutic options,” said Bruce Ewenstein, MD, PhD, vice president, clinical affairs, Baxter’s BioScience business.

“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.



ACCESS TO CARE TODAY ACHIEVE A CURE TOMORROW

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.

MedPro Rx, Inc.™

www.medprorx.com
(888) 571-3100

Specialized Pharmacy Services

No matter where you are, we are there for you



- Factor Replacement Therapies for Hemophilia and von Willebrand Disease
- 24/7 Access to Pharmacists for All Supply and Clinical Needs
- Exceptional Scholarship program:
www.medprorx.com/hemophilia_scholarship.php

education is power MedPro Rx, Inc.
SCHOLARSHIP PROGRAM

For more information, please contact:
Kathy Robinette-Stoneberg
National Director, Community Advocate
(866) 528-4963

Providing Hemophilia therapy to North Carolina & surrounding areas.

Hemophilia Federation of America

ON THE RIGHT TRACK

HFA 2009 Educational Symposium • Indianapolis, IN



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.



Hemophilia Federation of America

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.



WASHINGTON DAYS

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

SAVE THE DATE!
February 25-26th, 2009

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.

When Only the Best Will Do!

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

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

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



INCORPORATED
The Bleeding Disorders Homecare Company

www.AHFinfo.com

31 Moody Road, P.O. Box 985, Enfield, CT 06083 • 800-243-4621 • AHF@AHFinfo.com



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

For new members,
please complete the following application form.

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

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

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

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 |



*Hemophilia of
North Carolina*

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.hemophila-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.



HEMOPHILIA OF NORTH CAROLINA

PO Box 70, Cary, NC 27512-0070

(800) 990-5557 • info@hemophilia-nc.org

www.hemophilia-nc.org

NONPROFIT ORG
U.S. POSTAGE
PAID
CARY NC 27511
PERMIT NO. 830

ADDRESS SERVICE REQUESTED