

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2010



A Great Day at the second annual Hemophilia Walk!

We had over 650 walkers, volunteers, vendors and sponsors participate in the Walk on Saturday, October 17th at Lake Crabtree County Park in Morrisville and raised over \$86,000!

The Walk would not have been the success that it was without many of you who worked tirelessly to promote the event, recruit volunteers, collect donations and 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.



Factor 1 in a Million team members getting ready for their photo shoot!

Our thank you to the vendors and entertainers who woke up early in the morning and provided the crowd with delicious food and 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 as emcee for the festivities. The Walk was highlighted on NBC 17 Saturday evening and is also posted on their web site.

Our sincere thanks to the sponsors who supported the Walk and many of who had huge

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Tri-State Teens Come Together for Weekend

Teens arrived from up and down the east coast, including NC, SC and VA, to get together for the first NC Teen Weekend held in Charlotte from September 18-20th. It was a great group of 23 teens along with 4 chaperons and our lead facilitator, Patrick "Big Dog" Torrey.

Throughout the weekend we were encouraged to build confidence by challenging the limits of our comfort zones, learning to trust and encouraging leadership skills. This was accomplished by building bridges, eating skittles, tossing pennies, passing whirly rings, and setting mousetraps. You



Making time for a group picture at the Teen Weekend!

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Save The Date

HNC Latin Union Group
January 16, 2010
Charlotte, NC

"Hearts for Hemophilia"
Casino Night
January 23, 2010
Raleigh, NC

Blood Brotherhood – Men's Retreat
January 30-31, 2010
Charlotte, NC

Victory Junction Gang Camp
General Family Sessions
February 5-7 & 26-28, 2010
Randleman, NC

Teen & Parent CEO Program
February 20-21, 2010
Charlotte, NC

NHF Washington Days
February 24-25, 2010
Washington DC

HNC 6th Annual Charity
Golf Tournament
The Preserve at Jordan Lake
April 9, 2010
Chapel Hill, NC

World Hemophilia Day
April 17, 2010

HFA Symposium
April 23-24, 2010
Kansas City, MO



Hemophilia of
North Carolina

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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 27157-1081
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

LA Kelley Communications
1-800-249-7977
www.kelleycom.com

Patient Notification System
The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.
1-888-UPDATE U
www.patientnotificationssystem.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

It's amazing to me how fast time goes by and that we're turning the corner into 2010 already. Looking back at 2009, I reflect on how successful the year was and how much we were able to accomplish in twelve short months to support our goal of assisting, involving and educating members of HNC and the general public. Some of the highlights were definitely the number of programs and events we were able to host with the help of many volunteers who dedicated an enormous amount of their time and talent to HNC. We were able to provide and help support 29 programs that ranged from small dinners to large fundraising events. Through this support, we reached out to over 4000 members of the community and the general public. Although this number is certainly quantifiable, the impact it has had far exceeds any type of measurement. At these outreach opportunities, we were able to share information about what a bleeding disorder is and how it impacts the lives of individuals and families in the community. We also continued to touch the lives of many through our newsletter, which now reaches over 700 people each quarter, and the hundreds of people who visit our web site for the latest information and updates. This is evident in the growth of HNC and the 100 plus members who have joined the organization this year. This number is also a bit deceptive in that we count only one person as a "member" in the database but often that one "membership" includes many other individuals who are family members and friends. Through the generous contributions of individuals and sponsors to HNC, our financial assistance program provided a record amount of support to families during these very difficult economic times and enabled people to keep their homes, provide food for their family, stay connected in emergencies, have reliable transportation and much more so they could get through another month. We thank you for making this year of accomplishments possible and look forward to a very busy 2010.

Best wishes on a happy holiday season.

Sue
Sue Cowell

HNC Executive Director

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7/2007



The Blood Brotherhood Program is an ongoing program that provides opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. We are very pleased to announce that a grant opportunity from the Hemophilia Federation of America (HFA), through cooperative efforts with the CDC, has been made available to HNC to continue this program in our state. We have some great programs planned for 2010 to include a variety of topics along with webinars that are provided by HFA. Our first event is a **Men's Retreat** scheduled for the weekend of **January 30-31** in Charlotte. Look for more information and registration details very soon. *Other dates to save for the year are April 17-18, July 17-18 and September 25-26 for additional programs.* For more information about joining the Blood Brotherhood program, please contact HNC at (800) 990-5557 or by email at info@hemophilia-nc.org.

2009 Friends of HNC

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

Donors

Mr. & Mrs. Jeffrey Brill

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Mr. & Mrs. W. Allen Heafner

Hemophilia Federation of America

Rickie Lagana

Ms. Betty McMillan

National Hemophilia Foundation

Mr. Nelson Stewart

Mt. Zion United Church of Christ

Donation Made In Honor of Heather & Dalton Dawes

Ms. Sieglinde Uffelman

And the many generous donations we received for the 2009 Hemophilia Walk which are graciously acknowledged on the walk website at www.hemophilia.org/walk



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HNC Women's Group

As we enter 2010, HNC is working on programs for the Women's Group including participating in a Women's Leadership Conference being hosted by the Hemophilia Association of the Capital Area, a Women's Retreat and regional events to host the women of HNC. For information on these programs or getting involved with this group, please contact HNC at (800) 990-5557 or by email at info@hemophilia-nc.org.

Hemophilia Walk 2009 *continued*

walk teams that provided so much support to this effort. We gratefully acknowledge their generous support.

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, fundraisers and donors. We could not have done it without you! The goal of the Walk was



Carolina Hurricanes mascot, Stormy, gets the crowd ready to walk

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! A very special kudos to our Walk Chair Team this year, Kitty Kat Kathryn, with captains Eric & Melissa Morrison heading up a fantastic team! Many thanks to Eric, Melissa, Kathryn and their whole energetic family



The Talecris Biotherapeutics team that numbered 100+ walkers!

who raised over \$4,800 through some very creative efforts!

There is a wonderful photo gallery of pictures from the Walk that is available for viewing on our web site at www.hemophilia-nc.org along with more details about the success of the walk.

We are looking forward to next year's Hemophilia Walk, scheduled for **Saturday, October 16th, 2010** – so **SAVE THE DATE!** It looks like we will be back at the beautiful Lake Crabtree County Park but in a new location at the park, which will accommodate our ever-growing group of walkers and also provide some remote parking with transportation to the activities site. Also, we will begin planning for the 2010 Walk soon and if you are interested in being a part of the planning committee, please contact Sue Cowell at (800) 990-5557 or by email at info@hemophilia-nc.org.

Thank you again for your wonderful support!

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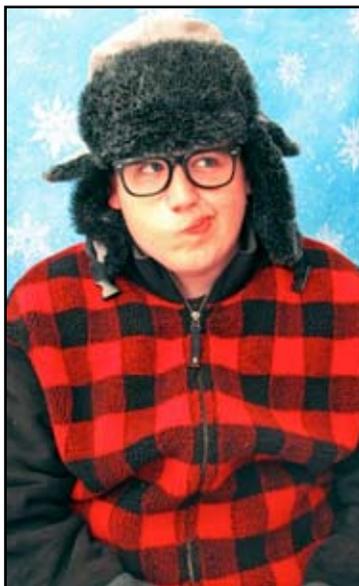
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HNC Member Highlight — Caleb's Hopes to Head to Scotland

Fifteen year old Caleb Taylor is getting set to embark on the adventure of a lifetime. Caleb attends a unique audition-only performing arts public high school in Greensboro, NC. He's a theatre student who has already had lots of opportunities to work behind the scenes and in the spotlight as part of a thriving arts community.

He recently appeared in *Almost, Maine*—both as a main stage production and in competition (where the play advanced to the State level). Caleb self-infuses three times a week and manages to maintain a busy schedule of academics and rehearsals.



Caleb Taylor in ALMOST, MAINE

And now Caleb is getting ready to continue his busy regime overseas! Out of over two thousand schools nominated, his drama department (Weaver Academy) is one of only fifty-two schools from across the country (and Canada) selected by a prestigious panel of college and theatre professionals to participate in the 2010 American High School Theatre Festival for two weeks at The

Fringe Festival in Edinburgh, Scotland this coming August! Students from our nation's top theatre programs will have an opportunity to further their education and showcase their skills within an international forum as they participate in workshops and master classes at the Globe Theater in London, explore theatre history, work alongside theater professionals



Caleb Taylor in GREASE

from around the world and perform their prepared work at The Fringe Festival. Representing North Carolina at the largest theatre festival in the world is a once-in-a-lifetime opportunity. Weaver's fundraising campaign, Fund the Fringe – Shape the Future, is well underway to raise the \$96,000 needed to cover the trip and the website, fundthefringeforweaver.com, is coming soon.

Caleb isn't allowing his special needs to keep him from this amazing opportunity; he is working hard to earn his portion of the trip too—monthly fund raisers and sponsorship letters are just the beginning of the task ahead! Would you consider sending a gift to help defray the cost of his trip? Gifts can be sent to Weaver Academy for the Performing & Visual Arts, attention theatre department, 300 S. Spring Street, Greensboro, NC, 27401. Remember to designate CALEB TAYLOR in the memo on your check.

Teen & Parent CEO Program

February 20-21, 2010

Great Wolf Lodge – Charlotte/Concord, NC

Teens ages 14-18 and their parents are invited to this terrific program that was created by the Indiana Hemophilia & Thrombosis Center in partnership with Baxter for members of the bleeding & clotting disorders community. Teens are encouraged to bring a friend along. This program is open to teens with bleeding disorders (does not apply to friends) or teens of parents with a bleeding disorder. CEO is a full-day experience designed to help young adults 14-18 years of age develop skills in career planning and financial independence. Parents will have a separate track to assist in talking with their child after the event

Great Wolf Lodge: North America's Largest Family of Indoor



Waterpark resorts, and offer an amazing guest experience in a one-of-a-kind, rustically elegant setting. They feature a gigantic indoor waterpark, where it's always 84 degrees. Besides the waterparks, there are themed restaurants, interactive arcades, full service spas (and even a version for kids!), fitness centers, and so much more.

Information will be available on our web site at www.hemophilia-nc.org and by mail very soon!

Tri-State Teens Come Together for Weekend *continued*

would be surprised at how many things you could do with mousetraps! These were just the indoor activities and we really challenged ourselves at the US National Whitewater Center (USNWC) on Saturday where the group strapped on the harnesses and teetered on wires 39 feet in the air, went down Class IV rapids in our rafts and helped each other over a 10 foot wall without the use of ladders, grips or any other devices.

Climbing the wall was a great test of team building as each person was helped by the group and trusted in their ability to 'whoosh' when they spotted the climber and 'grab the meat' to help them get over the top. Each person then had a chance to test their balance and conquer their fear of heights on the low and high ropes challenge. They had to work together as a team to cross a wire that was four stories in the air to get to the next platform and then belay down to the ground. The rafting was outstanding under the leadership of the center guides. We had four boats of 7 people that built up from Class II to Class IV whitewater channels for a wild trip! Many enjoyed a dip in the water when their boats hit the big rapids and a couple had to practice their



No fear!

spider man crawl from under the boat – good thing we were all paying attention in the training! We all had lots of laughs sharing our war stories from the trip down the river.



Team bridge building

A big kudos to Jennifer Meldau, MSRN, CPNP, Hemophilia Treatment Center Coordinator at Children's Cancer and Blood Disorders Clinic Palmetto

Health Richland, in SC, who joined us for our day at the USNWC and really had to leave her comfort zone to climb the rope ladder up 39 feet to treat a nose bleed! We really appreciate Jennifer's help in keeping everyone safe and looking out for us during our day at the Center while joining in all the activities.

Our many thanks to Big Dog for facilitating an excellent program! The Leading Edge program was certainly effective in helping to learn to take positive risks, build self-confidence, expand our capabilities and most of all great FUN for all! We are very grateful to Big Dog for taking the time to spend the weekend with group and share his outstanding leadership as our facilitator. The

Leading Edge program was made possible by a grant from Wyeth.

We would like to acknowledge all of the hard work that Joby Robinson, Ph.D., Coordinator with Palmetto Richland Advocacy Program at Palmetto Health Richland, SC, put into organizing and coordinating the group from SC. She donned the driver's hat and safely transported the group to and from Charlotte along with helping out with all the programs through the weekend.

Our program would not have been successful without the efforts of our chaperons and facilitator. Many thanks to our other helpers, Joe Fitzpatrick, Matthew Tucker and Charlene Cowell, for their wonderful assistance throughout the weekend.

We would like to acknowledge the support of Baxter, Bayer and MedPro Rx, Inc. for their support in helping to fund this outstanding weekend!

We have our sites set on the next event and eight teens from the group have graciously volunteered to help coordinate our next outing. Some great ideas were shared and the only stipulation has to be that there is a pool so Sue can get even with those who took part in throwing her in the pool on Friday night!

Black & White Ball Helps Support HNC

On November 14, 2009 the Mt. Zion United Church of Christ in Henderson, NC hosted its annual Black & White Ball at the Vance-Granville Community College. The venue was decorated beautifully and everyone looked eloquent in their gowns, dresses and suits to fit the theme of the evening! All attendees enjoyed a delicious meal and had our fill of laughter from entertainer, Elder Alcindor Hankins a.k.a. Gospel Comedian, LaSalle La-Salle of Laugh & Learn Ministry. Proceeds from the event benefited Hemophilia of North Carolina who was presented with a \$250.00 check by Pastor Calvin Brooks. Our many thanks to Pastor Brooks, the Bobbitt families and other member families who attended and helped facilitate the event and the congregation of Mt. Zion United Church of Christ who generously donated and organized the successful event.



A Wealth of Information Provided at the HNC Insurance & Health Care Symposium

Would you know what to do about your insurance if you lost your job, quit your job, have a child, went through a divorce, capped out or have a child age off of your insurance policy? All these scenarios and much more were the topic of the recent HNC Insurance & Health Care Symposium hosted at the Friday Center on November 14th.

Patient Services Inc (PSI) President & Founder, Dana Kuhn, PhD, presented information about the organization and how they assist the bleeding disorders community. He and fellow presenter, James



Dana Kuhn, PhD from PSI presents to the group

Romano, discussed many of the life changes that can affect insurance coverage and what to do if faced with these situations. Dana shared his experiences of working with members of the bleeding disorders community, many from NC, and his passion to assist those in need. His program covered the

multiple layers of insurance and educated us on being prepared. James further discussed the health care reform bills that are pending and the impact it could have on the community.

Elizabeth Phillips from the Orange County Department of Social Services did an outstanding job of presenting information on programs and services available in the state. She provided information on this very complicated subject in simple terms and gave us a much better understanding of the process by which people can apply for services in programs such as Work First, Medicaid,

NC Health Choice for Children and others.

After a delicious lunch at the Friday Center, Susan Cutter, MSW, LCSW, Assistant Director at Penn Comprehensive Hemophilia and Thrombosis Center, provided information on the financial impact of managing the costs of hemophilia. Her presentation included understanding your rights as a consumer, access to hemophilia treatment centers, keeping track of expenses, utilizing resources and being prepared for all stages of life.

The Consumer Panel that followed included members of HNC who shared their personal experiences and challenges with insurance coverage. This provided a great dialogue for the audience to share thoughts and suggestions with some of the members.

The recent changes in health care were discussed at length and Ryan Faden, CSL Behring Manager of State Government Affairs, provided up to date information on the ongoing reform including specifics in all the current bills that could affect the bleeding disorders community. There are a number of items of interest including changes to the high-risk pool, lifetime caps, the public option, Medicaid changes and follow-on biologics. He shared important information on staying involved in the process and how to advocate for changes that will benefit the community.

Hemophilia of North Carolina gratefully acknowledges the sponsors who made our Insurance and Health Care Symposium possible:

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Congratulations to HNC Members on Winning 2009 HFA Grants

Dale Michael Brisson – Artistic Encouragement Grant

Dale is the third of five boys, the only one with hemophilia, but this didn't stop him from leading an interesting life. Dale has worked as a live show announcer, radio personality, night club emcee, air show narrator, voiceover artist, television talk show host and published writer. His award-winning short stories, articles and poems have been published worldwide. But, ask Dale what his greatest accomplishment is? "That's easy," he beams. "My children, Michael, Spencer and Michelle."

Shawna Garrett – Artistic Encouragement Grant

Shawna is a young woman with von Willebrand disease. She intends to use the grant to assist her in her research regarding chronic pelvic pain conditions and overlapping bleeding disorders. Her ultimate goal is to write a book. She hopes to empower women with this information so they can be active in their own healthcare and obtain accurate diagnoses as early as possible in their lives.

Carolina Hurricanes Host HNC Families

Eric Staal and his wife Tanya created Eric's Entourage to invite non-profit children's organizations to come experience a hockey game VIP style in their all-inclusive suite. They hosted three lucky families from HNC on Friday, September 25th for a pre-season game between the Thrashers and the Hurricanes! One son called his mom four times from the game, he was so excited! Another member called the experience AWESOME! Our many thanks to Eric & Tanya Staal and the Carolina Hurricanes Hockey Club for making this opportunity available.



2010 Educational Scholarship Information

Information on the 2010 Educational Scholarships for the bleeding disorder community is updated on the HNC web site at www.hemophilia-nc.org. There are many opportunities available with details on the scholarships, contact information and web sites. For additional information on scholarships, visit the NHF website at www.hemophilia.org, the HFA site at www.hemophiliafed.org and the LA Kelley site at kelleycom.com.



2009 Volunteers of the Year

As you know, each year for the past three years we select a person or persons who have dedicated their time and talents to helping Hemophilia of North Carolina achieve its goal in promoting opportunities for improving the quality of life for persons affected by a bleeding disorder.

As we move into the third year of bestowing this honor, it becomes more and more difficult to make this selection. We are very fortunate to have so many wonderful people who volunteer their time to help with many of our programs and services. As we expanded the organization, so have we expanded our volunteer base who help in many areas including fundraising, grant writing, event planning, programming, web site development and much, much more.

This year, the honor of volunteer of the year goes to two people who have given so much of their time and have a passion in helping those in our community. They have braved the spring heat wave to distribute bags and register people at the golf tournament, tried their hand at gift wrapping at Barnes & Nobles during the holiday season, endured endless hours (and physical pain) of gift bag stuffing, made sure all our walkers were well attended to, advocate for the community at every opportunity and work tirelessly to support the men in the community through the Blood Brotherhood program and a chapter liaison to HFA.

It is our pleasure and honor to award the 2009 Volunteer of the Year awards to Matt Igelman and Tat'yana Shchetinina.



Tat'yana and Matt with HNC President Richard Atwood

Matt has been involved in HNC for many years since he was a young man. His mom, Judy Igelman, served on the Board of Directors and continues to help us today with her guidance and expertise. With credit to Judy, she raised Matt to be independent, passionate and above all remember those that helped him in the community by giving back to those in need. With the assistance of Tat'yana, they have made such a difference in the lives of those we serve and give back at every opportunity by helping to support HNC.

Congratulations to Matt & Tat'yana on this award and our many thanks to all those who have dedicated their time and service to HNC over the past 12 months.

WANTED: ADVOCATE SEEKS PARTNER

A Tale of Two Preschools

By Ziva Mann

Periodically, I put on my nicest shirt, walk into a roomful of teachers — and wish I could hide under the table. But I can't advocate for my sons from under the table. So I sit, sheaf of papers in hand, a list of our legal rights rippling through my brain, and hope that someone here will smile. Listen. And above all, work with me. Because we may have rights, but it takes teamwork — and a caring partner — to achieve those rights.

When Shai was two, I met Judi, director of a local preschool. I poured out our story: Shai's hemophilia, the inhibitor, his ballooning list of serious allergies, my fears and hopes. She listened carefully and, astonishingly, smiled. "Every child has needs," said Judi, simply. "Let's figure out how to meet Shai's needs." And she did, while I watched and learned.

Under Judi's eye, I filled out Shai's first individual health plan (IHP), condensing the overwhelming medical mess into a single, clear page. And I learned to build a positive working relationship with the teachers. Until Judi, I'd thought that advocacy was a battle: me against them. But she believed that advocacy means creating a partnership of shared goals, shared effort, and frequent, honest communication. We became friends, and Shai was happy at preschool. Judi's good will traveled with us to kindergarten. "They are good partners," she promised the new school. So that August, I walked into a room packed with smiling, soon-to-be partners — and Shai bounced into kindergarten.

Seeking a Partner, But Finding One Size Fits All

A year later, Judi had moved out of town, and now my younger son Akiva was ready to start at a different preschool. That September, I strolled confidently into a meeting with preschool staff. I described Akiva's unusual, aggressive allergies. I explained that he needed more accommodations than the average allergic child, more even than most children with multiple allergies. I pulled out Akiva's IHP, which I'd prepared with help from his physician, and asked if we could think together about allergy management. The preschool director held up a hand. "I have a system for allergies," she said, and left.

My smile froze: there was no Judi here. Instead, there was a system, built to handle medical oddities like us. A one-size-fits-all system for allergies.

The teachers and I tried teamwork: quick conversations in hallways, phone calls, emails. But agreements were broken or forgotten, and Akiva got sick from his allergens. Holding him as he wept and coughed, I realized that their system didn't fit us. And I couldn't change it.

Doggedly, I asked for another meeting. There were no smiles as I described Akiva's latest allergic reaction, and how close we'd come to calling 911. "We need to figure out how to meet Akiva's needs," I

urged. "Could I see your allergy management plan?"

I stared at their plan, horrified at the gaping holes: an incomplete list of Akiva's allergies, and inadequate accommodations to help avoid an allergic reaction; no mention of cleaning up allergen-laden foods or communicating with us in the event of a reaction. I compared the school's plan to our detailed, doctor-approved IHP, and shuddered. But the director believed her plan — the system — was fine, and the teachers followed her lead. "We don't understand why we're here," a teacher admitted. "Will Akiva be at school tomorrow?" Slowly, painfully, I shook my head.

And swung into action. I called the state board of education and a free legal hotline to ask about the preschool's legal responsibilities. I studied resources like Wrightslaw,¹ pestered an advocate specializing in disability and education, and contacted the national food allergy association (FAAN).² "Schools can assume that they know enough about allergies," a FAAN senior staffer warned me, "and don't slow down to learn more."

Akiva's preschool didn't just fail to slow down — they badly underestimated his needs. Later, we learned that this preschool director had believed that Akiva couldn't be as allergic as I'd claimed; that may explain why she chose their system over Akiva's IHP. I knew our rights: we could sue for discrimination or breach of contract, or file a formal complaint. But a lawsuit wouldn't get Akiva back into preschool — only a partnership would. And I didn't have one.

Seeking a Happy Ending, and Finding an Advocate

For weeks, I'd shake my head when I spoke to Akiva's preschool director. No, I wouldn't sign a waiver promising not to sue if Akiva got sick. No, I wouldn't change my mind about the accommodations he needed. And no, Akiva couldn't come back.

At home, Akiva wandered around wearing his backpack. "Am I going to peeschool today?"

"No, not today," I said, and he crumpled.

Shai was indignant. "They should listen to you," he insisted, "and be doing teams with you."

I heard Judi's echo in Shai's words, and hugged my little hemophilia advocate. Then I found my nicest shirt, my sheaf of papers, and walked into yet another room, in another preschool. "Let me tell you about my son, Akiva," I told the staff in that room. And oh, but they listened.

1. Wrightslaw (<http://wrightslaw.com>) is a resource for families, teachers and advocates working with children with disabilities.

2. FAAN: Food Allergy and Anaphylaxis Network (www.foodallergy.org) is a national organization for families and individuals with food allergies.

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Advocating for your child is a challenge for which few of us are trained, but the skills are simple:

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Your Child 101. Develop an IHP or a similar document to help the school understand your child's needs. Ask your HTC to review the IHP with you, to make sure it's accurate. Invite the school to "slow down" with you; every child is different, even with the same diagnosis.

Find a partner. A school nurse, teacher, or other partner who understands your child's needs, can work with you to use the school's resources to meet those needs. Ask yourself: Is my child's teacher or school a good match for our family?

Nurture partner relationships. Show your appreciation! We bring homemade cookies, and the boys make thank-you cards.

Know your resources. Free legal hotlines, advocates specializing in children with medical needs and in schools, your state board of education, and more.

Remember: You have an audience. Your children don't need you to be the perfect advocate, but they do need to see you try. If something isn't working, dust yourself off and try again.

Source: PEN Newsletter, November 2009 – LA Kelley Communications



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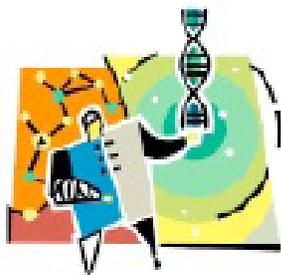
The HFA offers the Dads in Action Program as an educational and social support system designed to provide Dads with a sense of belonging as well as keys to strengthen the family unit. The program focuses on building strong family ties within the context of having a bleeding disorder. Program participants include both fathers of children with hemophilia and fathers with hemophilia.

The Dads in Action program is offered in a blended format of nationally coordinated webinars and face-to-face trainings. The face-to-face events (both local and national) offer Dads the opportunity to not only apply what they have learned through the webinar series, but also to engage their families in a coordinated Dads/Family program. As part of the program, Dads are challenged to set goals and share accomplishments with other Dads to encourage peer-learning.

If you would like more information on the Dads in Action program or to get a Dads group started in NC, please contact: programs@hemophiliafed.org or visit the HFA website at www.hemophiliafed.org.

HNC Reunión del Grupo Latino de Hemofilia

The HNC Latin Union Group was in full force this fall with several programs including the Hispanic Heritage Month Celebration at Clanton Park in Charlotte on September 26th where Dr. Jessica Bell from Presbyterian Blume Pediatric Hematology/Oncology Clinic presented a program on healthy joints. This program was generously sponsored by Baxter. The group also expanded into the Raleigh area on October 3rd at was treated to a great program presented by Elviana Tur, BSN, RN, Nurse Coordinator from the University of Kentucky HTC. This program was generously sponsored by Bayer. For 2010, Guillermo Sanchez, HNC program coordinator for the Latin Union Group, has some great events planned including a program on resources available for the community on January 16th in Charlotte, more programs in the Raleigh area, a Mother's Day Celebration in May, a fundraising event at the 2010 Festival Latino Americano in Charlotte in October and Festejo de Navidad in December.



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Santa Arrives at the Beach!

On December 5th, nearly 100 members of HNC enjoyed the 2009 Holiday Celebration at Wrightsville Beach. Although it wasn't the sunniest of days, everyone enjoyed the festivities and after-party tour through the Enchanted Airlie Gardens.

The children had fun with craft making and Wii game along with other games. Paper plate snowmen and holiday cookie bags were some of the crafts available to the group along with a game to see which team could fill their candy bucket up the fastest! Presentations were made to our Volunteers of the Year, Matt Igelman and Tat'yana Shchetinina along with a recap of the Chapter Recognition Award received by member, Guillermo Sanchez, at the NHF Annual Meeting for his work with the Latin Union Group of HNC.

After a delicious lunch of southern fare, Sue Cowell, Executive Director of HNC, presented a Reflection of 2009 and the accomplishments of HNC over the past twelve months. She shared how everyone in the community has made a difference in so many people's lives and helped to further the goal of HNC in improving the quality of lives for those affected by a bleeding disorder.



Taking time from his busy holiday season, Santa stopped by for a visit! Each child took time to share his or her wish lists with Santa and everyone received a gift to take home. Our special thanks to Santa (alias: Terry Crotts) for always making this a memorable moment for the children!

After the celebration, families were able to tour the Enchanted Airlie Gardens that was filled with holiday lights and great train displays! Fellow members Phil, Laurie and Ruth Bernard were on hand at the gardens to work the amazing train display and share some very interesting information on the history of the trains.

Hemophilia of North Carolina would like to graciously acknowledge our sponsors who made the HNC 2009 Holiday Celebration possible.

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We can not stress enough how important it is for anyone affected by a bleeding disorder to be prepared for an emergency. One way to do that is to make sure that you or your child are enrolled in the MedicAlert system. MedicAlert Foundation provides per-

sonalized medical identification bracelets and necklaces with a 24-hour emergency response and medical information service. You can order directly through MedicAlert via their website at www.medicalert.org or call them at (888) 633-4298. If you need assistance with the cost, HNC does provide these services through our Financial Assistance Program. For more information on this program, contact HNC at (800) 990-5557 or by email at info@hemophilia-nc.org.

UPDATE: Important Advisory for TRICARE Members

In November, NHF and HFA responded to community concerns about important pharmacy changes for individuals covered by TRICARE, the health care program of the United States Department of Defense (DOD) Military Health System. As a reminder, a letter was sent by Express Scripts, TRICARE's pharmacy benefit manager, in October notifying some beneficiaries that effective November 4, 2009 they would no longer be able to receive their specialty medications (including clotting factor) from certain providers. The letter listed three alternative providers that individuals could contact for services along with a toll-free number to contact Express

Scripts. However, the guidance was unclear and resulted in confusion for some TRICARE members.

NHF and HFA have discussed their concerns with Express Scripts and are pleased to provide you with a letter to clarify changes to the network. To view a copy of the letter, a list of participating hemophilia specialty pharmacies and/or view a copy of the TRICARE Pharmacy handbook, visit the HNC website at www.hemophilia-nc.org or call the HNC office at (800) 990-5557.

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FDA Approves New Indication for Tranexamic Acid

The U.S. Food and Drug Administration (FDA) has approved the first nonhormonal product to treat heavy menstrual bleeding in women (menorrhagia). Lysteda (tranexamic acid), manufactured by Newport, KY-based Xanodyne Pharmaceuticals, is an antifibrinolytic agent that prevents the breakdown of blood clots.

A synthetic derivative of the amino acid lysine, tranexamic acid (TA) has been available for more than 20 years. It was first approved by the FDA in 1986 as an injection (under the brand name Cyklokapron) to reduce or prevent bleeding during and following tooth extraction in patients with hemophilia. This newly approved indication in tablet form will help address the relatively high national prevalence of menorrhagia. According to the FDA release, heavy menstrual bleeding is reported each year by about 3 million U.S. women of reproductive age.

“Menorrhagia can be incapacitating for some women,” said Kath-

leen Uhl, MD, FDA’s associate commissioner of women’s health. “Heavy menstrual periods can cause pain, mood swings, and disruptions to work and family life.”

Side effects of Lysteda include headache, sinus and nasal pain, back and abdominal pain, muscle cramps, anemia and fatigue. The FDA also noted potentially severe side effects associated with Lysteda, particularly in women who are simultaneously taking hormonal contraceptives. According to Scott Monroe, MD, director of the Division of Reproductive and Urologic Products in the FDA’s Center for Drug Evaluation and Research, using the two drugs may increase the risk of blood clots, stroke or heart attack. Monroe cautioned that women using hormonal contraception should take Lysteda only if there is a “strong medical need,” and if the benefit of treatment will outweigh the potential increased risk.

Source: FDA news release dated November 13, 2009

Research Update: Investigators Look at Confusing Case of VWD Misdiagnosis

Researchers from the Medical College of Wisconsin recently looked at a puzzling case of laboratory testing for von Willebrand disease (VWD). The lead investigator of the study was Veronica Flood, MD, pediatric oncologist and assistant professor, Division of Hematology/Oncology, Department of Pediatrics, Medical College of Wisconsin, Milwaukee.

VWD and its subtypes are characterized by either quantitative or qualitative defects in von Willebrand factor (VWF) and associated with bleeding symptoms that, depending on the type, can be mild, moderate or severe. While VWD types I and III signify partial or complete lack of VWF, type II and its variation subtypes (2A, 2B, 2M, 2N) typically signify a dysfunction associated with VWF. Accurate diagnosis of these subtypes is generally considered far more complicated than hemophilia.

In many instances, a battery of tests that measure VWF quantity and function are required to pinpoint a VWD diagnosis. Flood’s study focused on one specific case of type 2MVWD and the limitations in a particular lab test, the VWF ristocetin cofactor activity (VWF:RCo), when determining a diagnosis. VWF:RCo is a relatively simple lab test in which blood cells are separated from a patient’s plasma (liquid component of blood). Ristocetin, an antibiotic that prompts the binding of VWF and platelets together, is then added to the plasma. In reaction, blood with viable VWF will clot and blood

with deficient VWF will not clot.

While the patient featured in this study showed a significant decrease in VWF:RCo, the other assay tests of VWF function were normal. In addition, the patient exhibited no bleeding symptoms. Flood and colleagues discovered that while VWF:RCo tests performed outside the body registered poor VWF function, the activity of VWF inside the patient’s body did not appear to be affected. Because of this discrepancy and the lack of bleeding symptoms, investigators called the initial diagnosis of type 2MVWD into question, pointing to the likelihood of an inaccurate diagnosis.

Flood and her colleagues concluded that a correct diagnosis of VWD, regardless of type, needs to be based on not just one test but rather on a comprehensive series of tests and the patient’s symptoms.

Flood’s research was supported, in part, by a Career Development Award from the National Hemophilia Foundation. Her work was also supported by a grant from the National Institutes of Health and a Mentored Research Award from the Hemophilia and Thrombosis Research Society.

Source: Flood V, Friedman K, Gill J, et al. Limitations of the Ristocetin Cofactor Assay in Measurement of VWF Function. *Journal of Thrombosis and Haemostasis*. 2009; Volume 7 (Issue 11): Pages 1832 – 1839.

Duke Study Links Genetic Determinant with HCV Therapy Success

A report published online in the August 6, 2009, issue of the journal *Nature* suggests that the reason for the disparity in responses to the standard hepatitis C (HCV) treatment, a combination therapy of interferon and ribavirin, may lie in a specific variation in a patient's genetics. The study was led by David B. Goldstein, PhD, Professor of Molecular Genetics & Microbiology, Institute for Genome Sciences & Policy, Center for Human Genome Variation, Duke University in Durham, NC.

Although the interferon/ribavirin combination effectively treats many chronic HCV patients, nearly 50% do not respond to it. Further, patients who do respond to it often experience debilitating side effects that can last the duration of the treatment—either 24 or 48 weeks. Interferon side effects include severe flu-like symptoms, depression, fatigue and insomnia. Ribavirin can cause anemia, skin rash and itching, fatigue and birth defects. It would be beneficial to be able to predict in which patients the therapy will work.

Goldstein and his team used a genetic test known as a genome-wide association study, to screen the three billion sites of the human genome from 1,671 patients with HCV genotype 1. They found that a specific site, the one near the gene (IL28B) responsible for a protein called “interferon-lambda-3,” contains genetic coding that could play a decisive role in HCV therapy response. Interferons are natu-

ral proteins manufactured by human cells to fight viral infections.

Investigators believe that the combination of DNA units a person inherits at IL28B determines the level of interferon production and subsequent ability to battle infections such as HCV. Since a person inherits two copies of the genome at IL28B (one from each parent), either a “T” or a “C” unit, three possibilities occur: CC, TT or CT. Individuals with the CC version respond much better to interferon/ribavirin. In this study, their sustained viral response rate (ability to clear the virus) was 80% compared to 30% in the subjects with the other versions. While C versions are more prevalent in East Asians and Europeans, they are far less common in people of African ancestry. C versions are most common among East Asians.

A comparison of the HCV therapy success rates in each of the three groups highlights the disparity. Approximately 75% of East Asians respond favorably to combination therapy, compared to 55% of Americans of European ancestry. In stark contrast, only an approximate 25% of African-Americans experience a successful round of HCV therapy.

The report, “Genetic Variation in IL28B Predicts Hepatitis C Treatment-induced Viral Clearance,” was published August 16, 2009, on the *Nature* Web site.

Source: *The New York Times*, August 17, 2009



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NHF 61st Annual Meeting & Chapter Recognition Award Winner Guillermo Sanchez!



Twelve HNC members attended the NHF 61st Annual Meeting that took place in San Francisco, CA from October 29-31, 2009. The conference was filled with excellent programs for designated tracks including chapter development, social workers, physicians, physical therapists, nurses, new families and consumers. The presentations

were very informative and conducted by experts in their fields including Andra James, MD, MPH from Duke University who hosted a variety of sessions on women and bleeding disorders, carriers and a NATT (National Alliance for Thrombosis & Thrombophilia) update to the National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC).

One of the proudest moments for HNC came at the Awards Luncheon that took place on Saturday. Fellow member, Guillermo Sanchez, was recognized for his contribution to the chapter with a Chapter Recognition Award.

One year ago, Hemophilia of North Carolina launched the Latin Union Group under the direction of Guillermo and his wife, Abi. This program was a result of meeting with the Hemophilia Treat-



ment Centers who felt that the Latino patient population was steadily increasing and that a support network for the families would be very beneficial. Guillermo and Abi were active community members

and graciously offered their time and talent to help with this effort.

Guillermo organized the first meeting, which was a wonderful success. The group determined their name, times and days of future meetings, preferred locations and topics that would be of interest to the community. In the short year that Guillermo has led the Latin Union Group, he has arranged monthly meetings for 20-25 people with a host of speakers including very notable local physicians and treatment center staff, representatives from local health departments and other experts in their fields. Topics have included nutrition, genetics, treatment & care, World Hemophilia Day, advocacy, healthy living and navigating emergency care.

Aside from providing the educational programs, Guillermo also prepares material for the chapter in Spanish including translating our brochure, writing articles for the newsletter, gives presentations and develops outreach materials for the families. He is currently working with the Hemophilia Treatment Centers and Hematology Clinics in Charlotte to expand the base of members in the Latin Union Group and provide assistance to the patients.

Guillermo brings to the position a wealth of experience. He was born in San Luis Potosi, Mexico, and has severe hemophilia. He moved to the US in 2003 with Abi. He holds a master's degree in psychology and has experience working with domestic violence, mistreatment, and sexual abuse. Guillermo's mother founded and is the current director of the hemophilia service organization in San Luis Potosi. He has a very personal understanding of the important role that Hemophilia of North Carolina can play in helping consumers advocate for better treatment and community services.

Guillermo is active in many other programs in the chapter including Blood Brotherhood, Legislative Day and outreach efforts. He has a strong desire to assist the Latino population in North Carolina and help Hemophilia of North Carolina accomplish its mission. We are very fortunate to have Guillermo and Abi as members of the chapter and are proud of what he has accomplished with the Latin Union Group in one short year. We are confident that this program will continue to grow and flourish under his guidance.

Our heartfelt congratulations go out to Guillermo and Abi for their wonderful contribution to the chapter and on a well-deserved award!

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Ryan White Program Reauthorized

On October 30, 2009, President Obama signed into law the Ryan White HIV/AIDS Treatment Extension Act of 2009 (P.L. 111-87), which reauthorized the Ryan White HIV/AIDS Program through September 30, 2013.

The federal Ryan White HIV/AIDS Program, named after an Indiana teenager with hemophilia who contracted HIV from contaminated blood products in the 1980s and who died in 1990, works with cities, states and local community-based organizations to provide HIV-related health services. The majority of Ryan White HIV/AIDS Program funds support primary medical care and essential support services, but there is also funding for technical assistance, clinical training and research on innovative models of care. The program serves approximately half a million people each year.

The law also includes provisions to:

- Increase authorizations for all parts of the program by 5% each year for the next four years, resulting in a rise from \$2.5 billion in funding in 2010 to nearly \$3 billion by 2013;
- Extend protections for states that are still transitioning their surveillance data systems to be names-based;
- Strengthen and continue the Minority AIDS Initiative to address the disproportionate impact of HIV/AIDS on racial and ethnic minorities; and
- Set a goal of 5 million HIV/AIDS tests through the Centers for Disease Control and Prevention and other federally supported HIV/AIDS programs.

HIV Travel Ban Lifted

On November 2, 2009, the Obama administration finalized a proposed regulation to overturn the regulations that for the past 22 years have prevented individuals with HIV from receiving visas to travel or immigrate to the U.S. NHF and the World Federation of Hemophilia (WFH) have long advocated for the removal of this discriminatory ban with congressional leaders and the Departments of Health and Human Services and Homeland Security. The implementation of this final rule is an important step forward for the international bleeding disorders community.

“If we want to be a global leader in combating HIV/AIDS, we need to act like it,” said President Obama. U.S. legislators, international health officials and consumer health advocates have expressed satisfaction and relief about the ruling.

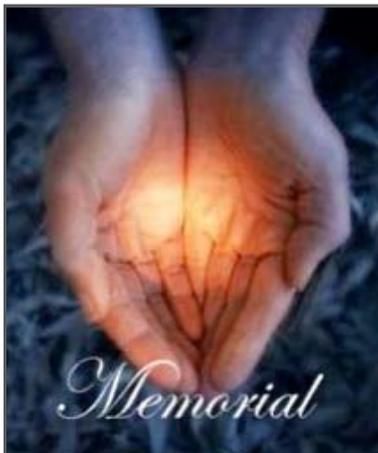
Effective on January 4, 2010, HIV will be removed from the list of

diseases that block admission to the U.S. Further, testing for HIV will no longer be required as part of the visa application.

“We think this is going to give a very positive image of where the United States is going in terms of eliminating stigma and discrimination in relation to HIV,” said Dr. Socorro Gross, assistant director of the Pan American Health Organization.

“We’re thrilled that the ban has been lifted based on science, reason, and human rights,” said Kevin Robert Frost, CEO of amfAR, The Foundation for AIDS Research. “Our hope is that this decision reflects a commitment to adopting more evidence-based policies when confronting the AIDS epidemic and developing a comprehensive national AIDS strategy.”

Source: The New York Times, October 31, 2009 POZ (online) new release dated October 30, 2009



Announcing The Formation Of The Hemophilia HIV/Aids National Memorial

A national memorial fund has been established to honor those who have lost their lives to Hepatitis C and HIV/AIDS as a result of tainted blood products in the 1980's. The memorial's mission is to create a public statement showing the enormity of this medical tragedy, in order to preserve history, to effect change, and protect the future of the blood supply. Donations are being accepted for the construction of the memorial. For more information or to make a donation, contact Mary Lou Murphy at (781) 444-8672.

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:
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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.

2010 Calendar of Events

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

- “Hearts for Hemophilia” Casino Night - January 23rd*
- Blood Brotherhood - Men’s Retreat - January 30-31st*
- Teen & Parent CEO Program - February 20-21st*
- NHF Washington Days - February 24-25th*
- HNC Charity Golf Tournament - April 9th*
- HNC Volunteer Dinner - May 21st*
- HNC Annual Meeting - May 22nd*
- NC Legislative Day - June 8th*
- HNC Family Retreat - September 4-6th*
- 2010 Hemophilia Walk - October 16th*
- HNC Holiday Celebration - December 4th*

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: _____

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Email: _____

Check One

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

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

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SAVE THE DATE
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It's not too early to sign up!

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