

THE CONCENTRATE



THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2010

Planning for the best...Prepared for the Worst

HNC 2010 Annual Meeting

HNC hosted our 2010 Annual Meeting on Saturday, May 22nd where over 170 people learned how to expect the best but prepare for the worst. Registration opened at 9:00am with a distribution of an emergency Go-Bag for each family that was filled with information provided by NHF on how to prepare their kits. Our vendor exhibit hall was also opened for the day and we graciously thank our sponsors for their participation and support of this event.

The day began with a presentation by Kelly Fitzgerald, Associate Director of Government

Relations, Patient Services Inc., who shared information on insurance and preparing for changes that often take place in our lives regarding coverage. She gave an in depth look at all facets of gaining and retaining insurance coverage for yourself and your family. The next panel was made up of Jennifer Crawford, Director of Education for NHF, Tami-Wood Lively, JD, MHA of ATHN and Pam Brynarsky from the American Red Cross. This panel provided extensive information on emergency preparedness, programs and resources that are available and how to make sure you stay connected in the event of an emergency.

We had an opportunity to break-out into sessions for women, men, parents and a Walk team captain strategy meeting. Three women from the HNC Women's Advocacy Group, Maria Schnaith-Ivan, Sue Fletcher and Sharon Ingram, had chance to

Continued on page 3



Morgan Major sharing her skills with the kids.

A Powerful Group of Advocates Come Out for the 2010 HNC Legislative Day

An enthusiastic and energetic group of members from Hemophilia of North Carolina gathered on June 8th to attend the 2010 HNC Legislative Day. The day started with breakfast and a morning meeting at the Hilton Garden Inn in Morrisville to talk over the events for the day, break into groups for the meetings and share an in depth discussion on the issues facing the bleeding disorders community during this very critical time with health care. We then hit the Raleigh 'hill' for a full day of meetings.

Continued on page 17



Matt, Tiffany & Brandon Visit with Senator Stan Bingham

Inside

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

Save The Date

HNC Blood Brotherhood Programs
July 17-18, 2010
September 25-26, 2010

Hemophilia Walk
"Kick Off Karnival"
August 7, 2010
Cary, NC

HNC Teen Retreat
August 8-10, 2010
Blowing Rock, NC

HNC Latin Union Group
August 14, 2010
Location TBD

HNC Family Retreat
September 4-6, 2010
Pine Knoll Shores, NC

Gettin' in the Game
Junior National Championships
September 25, 2010
Durham Bulls Athletic Park
Durham, NC

HNC Latin Union
2010 Festival Latino Americano
Fundraiser
October 10, 2010
Charlotte, NC

Hemophilia Walk 2010
October 16, 2010
Lake Crabtree County Park
Morrisville, NC



*Hemophilia of
North Carolina*

260 Town Hall Dr., Suite A
Morrisville, NC 27560
(800) 990-5557
info@hemophilia-nc.org
www.hemophilia-nc.org

**MISSION
STATEMENT**

Hemophilia of North Carolina is a non-profit organization dedicated to improving the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research and supportive programs and services.

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.hemophilafed.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**
600 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
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

ClinicalTrials.gov
A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

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

Patient Services Incorporated (PSI)
Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-800-366-7741
www.uneedpsi.org

World Federation of Hemophilia
514-875-7944
www.wfh.org

**VISION
STATEMENT**

Hemophilia North Carolina's vision is for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations, until a cure is found.

From the Executive Director

It has certainly been a busy quarter with our office move, HNC Annual Meeting, Legislative Day and many other events and activities taking place. One of my favorite events of the year is the Volunteer & Special Guest Dinner that we host the night before the annual meeting and have an opportunity to recognize everyone who contributed so generously of their time, talent and resources throughout the year. It is through these contributions that we are able to accomplish so much in meeting the needs of the community. Volunteerism ranges from help with our communications to running fundraisers in their neighborhood, being a walk team captain, writing a grant, organizing a program, serving on the board, sharing their experiences and expertise with fellow members and much

more. There are too many examples to list in this article but we all recognize that we could not sustain our programs and services without this support. People volunteer for a variety of reasons with one common goal – *to make a difference and help others!* Thank you to each and every one who has truly made a difference in the lives of so many and our hope is that the experience was as fulfilling for you as it has been for those you've helped.

Sincerely,

Sue

Susan Cowell

HNC Executive Director

HNC 2010 Annual Meeting *continued*

share their experiences and their mission as part of the group with the women who attended. This was followed by a discussion group led by Kristin Prior, who presents to groups nationally as part of the speakers circuit from CSL Behring. The men were able to listen

to a valuable presentation on aging by Raj Kasthuri, MD of UNC Chapel Hill. This is a very timely topic that has received a lot of attention nationally and will become a focus of HNC in the future. Parents and children ages 8-17 joined together for a self-infusion session facilitated by Anita Smith, RN of Wake Forest University Baptist Medical Center. Everyone had a chance to use the Bay Cuff self-infusion training system provided by Bayer Healthcare to learn more about the process. Walk team captains gathered with Sue Cowell to share some very creative ideas for activities, fundraising, recruitment and awareness of the 2010 Hemophilia Walk scheduled for October 16th this year. Our 2010 Walk Chairs, Tiffany & Brandon Hargett, have already secured a donation of a helicopter ride for two that will be raffled off to raise funds for their team – Zackary and the Factor 8's – how creative!

After lunch HNC President Richard Atwood, Treasurer Kathy Register and Executive Director, Sue Cowell presented the business meeting. A review of what HNC has accomplished over the past year and a look to the future was presented along with the election of the 2010-2011 Board of Directors. All current board members will be returning and two additional nominees were elected to serve. Stephen (Steve) Farrar of Charlotte, NC will join the board for a two-year term and has been past president and longtime member of HNC. Shawna Garrett of Charlotte, NC, an attorney and advocate for the bleeding disorders community is also joining HNC on the board for a two-year term. HNC VP of Advocacy, Leonard Poe, then discussed what is happening with issues impacting our community and suggested that everyone join us for the 2010 Legislative Day in Raleigh on June 8th. Decisions are being made daily on the changes in health care and it is important that we bring awareness to our needs. Leonard spoke about his upcoming trip to the Dominican Republic to assist with summer camp for children affected by a bleeding disorder. He has been working closely

Continued on page 4

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HNC 2010 Annual Meeting *continued*

with Laurie Kelley and her organization to help with this camp for 50 children. Throughout the meeting, Leonard collected baseball gloves, bats, balls and a number of other items donated by individuals and industry to help support the effort. Gina Raymond-Duncan of CSL Behring also presented Leonard with a \$500 check to help support the summer camp and purchase necessary items for its success.

Keynote speaker Tres Major, President of the Louisiana Hemophilia Foundation, spoke of the devastating affects from Hurricane Katrina with a very vivid slide show of the impact it had in their area and how it affected the bleeding disorders community. He talked about the lessons learned from this tragedy and how the Chapter rallied their troops to help members, learned valuable lessons and helped develop emergency preparedness policies that are helping throughout the United States. It was very inspiring to see the community pull together to help each other through this disaster.

Our afternoon included an update on research and new products in the pipeline from Alice D. Ma, MD of UNC Chapel Hill and continued with a panel on preparing for visits to the emergency room and working with first responders. Anne Lowish, RN of MedPro Rx presented information on how to proactively work with hospitals and personnel in your area in the event an emergency takes place. Tiffany Holland, HNC member, spoke about her experience during an emergency with her son where he was stuck way too many times without success and the complications this caused. Tiffany used this experience to help develop a hemophilia protocol with hospital personnel that is now in use at all Carolina Medical Center emergency rooms in her area. This is a wonderful example of advocating for yourself and our hats off to Tiffany on making a difference not only for herself but the entire bleeding disorders community who will benefit from her effort.

The children also had a full day activities and two groups (ages 3-7 and 8-17) had a number of presentations and programs. Both groups participated in a martial arts demonstration led by Tres Major and his wife, Morgan. Both are certified martial arts instructors and had a great time teaching the kids some new moves (that hopefully they aren't using on their parents or siblings). The American Red Cross presented information to the older group on how to prepare for emergencies while HNC members, Judy Igelman and Charlene Cowell worked with the younger group on identifying items that would be included in emergency kits. The afternoon programs for the younger group included a Dino Time and Keep it Moving session presented by Discovery Place and HNC member, Ann Skinner, hosted a wonderful craft activity of creating flowerpots. The older kids played a game of Bugger Wars (and yes



Alice D. Ma, MD-UNC Chapel Hill, speaks to the group.

it involved picking buggers out of a nose – green bean bags that is – and trying to stick them on the opposing teams vest) and also the Games2U Video Van that had the latest games available to entertain everyone. Our thanks to all the wonderful volunteers that helped with the children's programs.

Sue Cowell, HNC Executive Director, then closed out the meeting with a presentation about the 2010 Hemophilia Walk including information about the national initiative, sponsorships, team captain instructions, fundraising and an update on the great activities planned this year. We hope everyone comes out to join us for our 3rd annual Hemophilia Walk and a great day of fun for a terrific cause.

After the meeting, tickets were distributed for Carowinds amusement park so members and their families could enjoy a great evening on the rides!

2010 HNC Annual Meeting Sponsors

We gratefully acknowledge the pledge of support from the following companies for the 2010 HNC Annual Meeting.

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HNC Charity Golf Tournament a Great Success!

After a stormy night before the tournament the skies opened up to a beautiful day at the 6th Annual HNC Charity Golf Tournament that took place at The Preserve at Jordan Lake in Chapel Hill on April



9th. Twenty-four teams headed to the greens for a terrific day on the course and a very successful tournament for HNC.

As with all the events, it would not have run smoothly without the great assistance of our volunteers – the Ingram Family, the Caldwell-Moody Family, Scott Lane,

Richard & Shawna Wainwright, John Scott, Tim Duncan, Richard Atwood, Terry Lamb, Chris & Bennett Barnes. We thank them for their time and talent in helping to host the tournament.

A full field of golfers teed off at 12:00 noon with mulligan packages and their Putting Contest tickets in hand. Our congratulations to Dan McKinley of the CSL Behring team for his hole in one that won him a set of Callaway Irons!

A delicious lunch was catered and donated by Sweet Tomatoes who brought along a team of staff to help with the serving! The Women of the Moose at the Lexington Moose Lodge donated the non-alcoholic beverages that kept the golfers hydrated during the day again this year and we are very grateful for their continued generosity and support of HNC. After coming in off the greens, the golfers were treated to a great dinner and appetizers. Our thanks to Em R Wings of Apex who generously donated the chicken wings for the event.

After dinner, prizes were awarded for teams that placed 1st, 2nd & 3rd along with the Most Honest team.

1st Place – Mike Perry, Pete Huffey, Bobby Haynes & Keith Radcliffe

2nd Place – David Draper, Mike Meyer, Jay Kessing & Bobby Eve

3rd Place – Clay Molitor, Chris Wood, Danny Graham & Jason Kron

Most Honest Team – Jim O’Malley, Eric Petty, Rick DeMartino & Edward Perry

Closest to the Pin – Bobby Haynes

Longest Drive – Bryan Pursell

Longest Putt – Dan McKinley

Putting Contest Winner – Joe Kelly



During the tournament, there were very special entrepreneurs, Nick & Colin Carbone, who set up a lemonade stand on one of the holes again this year with help from their parents in honor of their friend Bennett who has hemophilia. After the tournament, Nick & Colin presented HNC with a donation of \$61.65 from the proceeds of the stand – thank you Nick and Colin for your generous support!



Nick & Colin at their lemonade stand for hemophilia!

This year we also offered Hearts for Hope, a program to honor loved ones with hearts that were displayed in the clubhouse and on the greens. Our many thanks to all those who contributed to this program in honor, memory and celebration of someone special in their lives. Seventeen hearts were on display with heartwarming messages.

The night concluded with our live auction, raffle and thank you from our President, Richard Atwood, to the players, sponsors, committee members and volunteers. HNC would like to thank all of our sponsors, gift bag donors, raffle & auction donors, players, volunteers & committee members – Matt Barnes, Todd Holder, LaQuenta-Caldwell Moody, Jim O’Malley and Sue Cowell.

We gratefully acknowledge our sponsors and players for their generous support. Thank you!

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Blood Brotherhood & World Hemophilia Day



programs presented on Keeping Active and Non Medical Treatment Options. Guest speakers included Dr. Michael Armstrong of Duke University who discussed non-medical treatment options for pain management and Angela Forsyth, PT, DPT of the University of Pennsylvania, a nationally renowned speaker, presented a very interactive session including: benefits of cardiovascular exercise, strength and resistance training, and general wellness techniques. Programs were also presented on Tai Chi by Norma Ferrell who works with the Arthritis Foundation to develop programs to improve mobility, breathing

The Blood Brothers of HNC and their partners celebrated World Hemophilia Day on April 17th, 2010. We had a full agenda of terrific speakers and and relaxation and Ryan Eves, YMCA Program Coordinator, discussed the benefits offered through their services. Partners enjoyed a great discussion group lead by Lisa Cook of NAMI and treated to an aromatherapy session while learning the benefits of stress relief. The evening was topped off with a wonderful baseball game at the Durham Bulls Athletic Park where our group and World Hemophilia Day was recognized on the reader board! Our next program will be held *July 17th at the Chetola*



Mountain Resort in Blowing Rock and includes a nutrition session, cooking class and a fly fishing clinic. Please visit the HNC website at www.hemophilia-nc.org for more details and the registration form. For more information about joining the Blood Brotherhood program, please contact HNC at (800) 990-5557 or by email at info@hemophilia-nc.org.



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HNC Latin Union Group Hosts Mother's Day Celebration at the NC Zoo

Over 50 members of HNC gathered together at the NC Zoo on May 8th to celebrate Mother's Day and honor those who give so much to the community for their families. The program included a very heartfelt presentation by William Cruz and his family. William's mother spoke of her journey from Honduras to the US in search of care for her son. Our thanks to Maria Schnaith-Ivan for translating

the presentation into English and helping us to learn more about the challenge this family, and many others, face in getting the proper treatment and care for bleeding disorders outside of the US. We all enjoyed a delicious lunch and a great visit through the zoo. Many thanks for Guillermo Sanchez and his wife, Abi, who do a terrific job in organizing these events for the Latin Union Program.

HNC Volunteer & Special Guest Dinner

The night before the HNC Annual Meeting, over sixty people who have generously donated their time, talent and resources during the past year gathered for the 2010 HNC Volunteer & Special Guest Dinner. The guest speaker for the evening was Warren R. Jewett, Sc.D., who is a longtime member of HNC. He shared wonderful stories about his life experiences, the virtues of volunteerism and the impact volunteers have had on his journey of nearly eighty decades through treatment and care for hemophilia. Warren graciously

acknowledged the support of family, teachers and mentors for his long and productive life. We were very pleased that Warren's daughter, Tamison Jewett, MD, who has also given generously of her time and talent to HNC, was able to join him for this event. Unbeknownst to Warren, we also celebrated his upcoming 80th birthday with a cake and chorus of Happy Birthday! We wish you many more years of celebration.



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Women's Advocacy Group Busy At Feed the Need



Women's Advocacy Group member, Maria Schnaith-Ivan, coordinated an opportunity to present information about bleeding disorders at an event in her area. The Feed the Need event on April 24th was held at Trinity High School's gym. Former NFL player Derwin Gray was a guest speaker. The day included free health screenings and other activities available to meet the needs of the community, including a collection of non-perishable food items and clothing at the event. Maria and HNC Executive Director Sue Cowell, were thrilled to have met two affected families at the event who are now members of HNC!



Congratulations to Guillermo & Abi!

Baby Cecilia joined the HNC family on May 18th, 2010. We are happy to report that Mom, Dad and baby are all doing well and she is a beautiful, healthy, and happy girl!

A Very Happy Birthday and Thank You to Aiden

On June 10th Aiden Zimmerman turned 5 years old – Happy Birthday! He wanted to have a birthday party but his parents, Andrea & Carey, acknowledged that some mommies and daddies don't have jobs right now so they would ask everyone to come and celebrate but not bring a gift. Aiden then asked if his friends at his birthday party could give a gift to his new friends (the kids he met in Charlotte at the HNC Annual Meeting). His parents embraced this idea and were very happy to see Aiden wanting to share and being okay with giving up a few toys :).



Many of Aiden's friends and family generously donated to HNC in lieu of a gift and we are so grateful for their support and very proud of Aiden for making such a difference!

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HNC Teen Retreat – “Big Dog” is Back!

August 8-10, 2010

Blowing Rock Conference Center

SAVE THE DATE

“Big Dog” is coming back to NC! Calling all teens, get yourself ready for a retreat filled with adventure and perhaps a few surprises from our favorite facilitator, Patrick “Big Dog” Torrey who will be joining us again this summer and bringing his bag filled with who knows what (last time it was mouse traps)!

The retreat will be hosted at the wonderful Blowing Rock Conference center beginning at dinner time on Sunday, August 8th and finishing up after lunch on Tuesday, August 10th. This event is open to anyone age 13-18 who has either a bleeding disorder or a sibling or parent with a bleeding disorder. Feel free to bring a friend along too!

Big Dog is one of the best in the nation at using our natural attraction to adventure and excitement and translating it into

positive, transferable life skills. He is internationally recognized and known for his powerfully engaging program, Leading Edge, which will inspire you to believe in your own ability to function at your optimal level and challenge you to grow, all while having a great time! We are thrilled that Big Dog will be joining us again and building on this program that we offered to our teen group in September.

We’ll be busy with some really fun activities including a Challenge Tower rock climb, ropes course, kayaking, tubing and more! HNC is offering this program to our teen members free of charge. This includes lodging, all meals and activities throughout the retreat. Look for more information by mail and on our web site. To sign up, please complete the registration form and permission form no later than July 22nd, 2010.



We’d like to congratulate all of the spring walks that have taken place already – Hemophilia Foundation of Northern California who walked on April 17th and raised over \$81,000 as a second year walk site, the New England Hemophilia Association who walked on June 5th and has raised an amazing \$105,497 as a first year walk site (and still counting) and the always impressive New York City Hemophilia Chapter who walked on June 6th and has raised over \$194,000 so far! We fall walk sites certainly have some big shoes to fill and we are so happy to see such a successful start to what is sure to be a great walk year at the 14 locations around the country.

Our website is up and ready with teams and sponsors signing up! The walk brochures and posters will be available for our walk **“Kickoff Karnival” scheduled for August 7th** at Bond Park in Cary, NC. The event will feature team sign up competitions, awards for most team members who attend, fun foods and lots of other games and activities to get us inspired, informed and ready to walk!

The goal this year for the NC Hemophilia Walk on October 16th is \$90,000 and we’re up to the challenge. There is already great energy from some of our new and returning team captains who gathered at the HNC Annual Meeting for a terrific strategic planning session. Information is available through the office and on the HNC website for some really unique fundraising ideas, how to recruit walkers, sign up a team and get started!

We also welcome sponsors to help support the event and there are a variety of sponsorship levels available. Companies who commit to sponsor by the end of July will have their logo included in the brochure and on the poster. Sponsorship are welcome anytime and all companies will be recognized with their logo on the walk website and on the back of the walk tee shirts that will be distributed on the day of the event. If you work for a company, own a company or frequent an establishment that would like to support the walk, please contact HNC for a packet of information or visit the HNC website at www.hemophilia-nc.org.

Sponsorship Packets and Team Captain Packets are available through HNC by calling 800-990-5557 or by email at info@hemophilia-nc.org. It’s not too early to get started and we encourage you to call us for more information!



CSL Behring Announces 2010 Junior National Championships

September 25, 2010

Durham, NC

SAVE THE DATE

CSL Behring is hosting its 9th annual Gettin' in the Game Junior National Championship (JNC) competition in golf and baseball. The JNC is a series of one-day athletic events for children with bleeding disorders, such as hemophilia or von Willebrand disease (VWD), and their families. Children with bleeding disorders connect with and compete against each other. The competitions also encourage them to be committed to physical activity that helps keep their muscles healthy and joints strong.

This year's JNC program will include four regional championships and they are coming to North Carolina – **September 25 – Durham, NC**. The event will be hosted at the Durham Bulls Athletic Park and the golfers will enjoy an afternoon on the course at the Hillandale Golf Course.

As part of the JNC, professional golfer Perry Parker and competitive baseball player Jesse Schrader, who both have hemophilia A, will provide coaching to the kids and their families on the fundamentals of each sport. The athletes also offer participants guidance and advice for remaining active while managing their condition. Members of the local bleeding disorders community will also be on hand to provide education, support and information about the importance of effectively managing the condition.

At this event, you will have the opportunity to show off your baseball or golf skills in a friendly competition with your peers. Golf competition is open to those children with bleeding disorders. Baseball and other games are open to all. While you are playing, your family can take part in other games, try their hand at arts and crafts, or join the field-side chat held by Hemophilia Moms. Great fun for the whole family!

- For you, the main event is the afternoon competition in baseball or golf. Show off your athletic ability to win:
 - A golf bag (with a set of irons) and a trophy
 - A bat bag (including a bat, glove, and baseball cap) and a trophy
- You can win in 2 ways – by being the best in your region at your sport, or by having your name selected in the raffle held at the end of the day

Winners from each regional event – the baseball competition winner, the golf competition winner, and the raffle prize winner – will be recognized at that event.

When the regional competitions have all been held, the golf winner with the lowest overall score, the baseball winner with the highest overall score, and the winner of a drawing that includes all of the regional raffle winners will win a trip for themselves and two accompanying adults to New Orleans for the 2010

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Coming Soon to Your Area!

Saturday, September 25, 2010
Durham Bulls Athletic Park
Hosted by HNC
Look for your invitation in the mail by early August!

Stay Tuned For More Details...

The Gettin' in the GameSM Junior National Championship, presented by CSL Behring, is the event that combines sports with a wide variety of other activities that connect families affected by bleeding disorders.

At this event, you will have the opportunity to show off your baseball or golf skills in a friendly competition with your peers. While you are playing, your family can take part in other games, try their hand at arts and crafts or join the field-side chat held by Hemophilia Moms. We've got something for everyone.

Biotherapies for Life™ **CSL Behring**

HNC Family Retreat

Labor Day Weekend – September 4-6, 2010

Pine Knoll Shores, NC

Keep your dates free for our annual HNC Family Retreat coming up at the end of the summer. We have moved the retreat to the holiday weekend this year based on availability at the center and hope that some of you, who haven't been able to attend due to work schedules in the past, can come out and enjoy the weekend at the beach with fellow HNC families! We know this is a very popular event and have received a number of calls already from interested parties. Invitations will be coming out shortly via mail and email so look for it soon! We will be returning to the Trinity Center in Pine Knoll Shores and have a full agenda planned for the retreat with activities and programs for adults and children.



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A black and white photograph of two men, Andrew and his son, standing in front of a car. They are both wearing dark shirts with their names embroidered on them. Andrew is on the left, and his son is on the right. They are both smiling. The background shows the open door of a car.

Andrew, an actual patient with his son.

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We extend a sincere thank you to our supporters...many of whom contributed several times during this period.

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Hemophilia of North Carolina Expands Operation

With the increased growth of HNC over the past several years, we have outgrown the home office. On June 1st we officially moved into our new office that is located in the Morrisville Chamber of Commerce Building and now have plenty of room for all our files, volunteers and storage. The facility also offers a shared board room, business center and a great meeting room to host our programs and events. It is also a business hub for the town of Morrisville and surrounding areas.

The address for the new office is:

Hemophilia of North Carolina
260 Town Hall Dr., Suite A, Morrisville, NC 27560

We will continue to have the post office box address until the end of year and transition over between now and then. We ask that you please update the address in your books, phones, computers or wherever you store this information. Our phone number (both local and toll-free), fax number, email address and web site address will all remain the same.

With the additional capacity of the office, we are also growing the staff at HNC and the following individuals have come on board to assist with our programs & services –

Susan Fletcher, PhD – will join us part-time as Programs Coordinator and will be helping with specialized programs in the area of aging and women with bleeding disorders along with grant writing. Sue Fletcher has dysfibrinogenemia (Factor 1: bleeds and clots). Using her personal experiences and professional education, she is dedicated to increasing public awareness about women with bleeding disorders. Sue is working on research projects related to how and when adolescent girls and women with bleeding disorders enter the medical system, psycho-social issues related to women and bleeding disorders, and aging with hemophilia. Her CV is available upon request. Sue can be reached by email at sue.fletcher@hemophilia-nc.org or by phone at the office.

Guillermo Sanchez – through the support of an educational grant by Bayer Healthcare, Guillermo will be joining us as part-time Project Director of our Latin Union Program and will work closely with the HTC's and HNC to develop educational programs, increase outreach and provide communications to improve the health and well-being of the Latino population with bleeding disorders in North Carolina. Guillermo was born in San Luis Potosi, Mexico, and has severe hemophilia. He moved to the United States in 2003 with his wife, Abi. He holds a master's degree in psychology and has experience working with domestic violence, mistreatment, and sexual abuse. He has coordinated the Latin Union Program for HNC for the past year, conducting outreach and planning the content of educational sessions. Mr. Sánchez also has skills in the area of educational brochure development and design. Mr. Sánchez's mother founded and is the current director of the hemophilia service organization in San Luis Potosi. He therefore has a thorough understanding of the important role that HNC can play in helping consumers advocate for better

treatment and community services. He has a strong desire to assist the Latino population in North Carolina and help HNC accomplish its mission. Guillermo can be reached by email at hemofilia.union.latina@gmail.com or by phone at 704-605-4376.

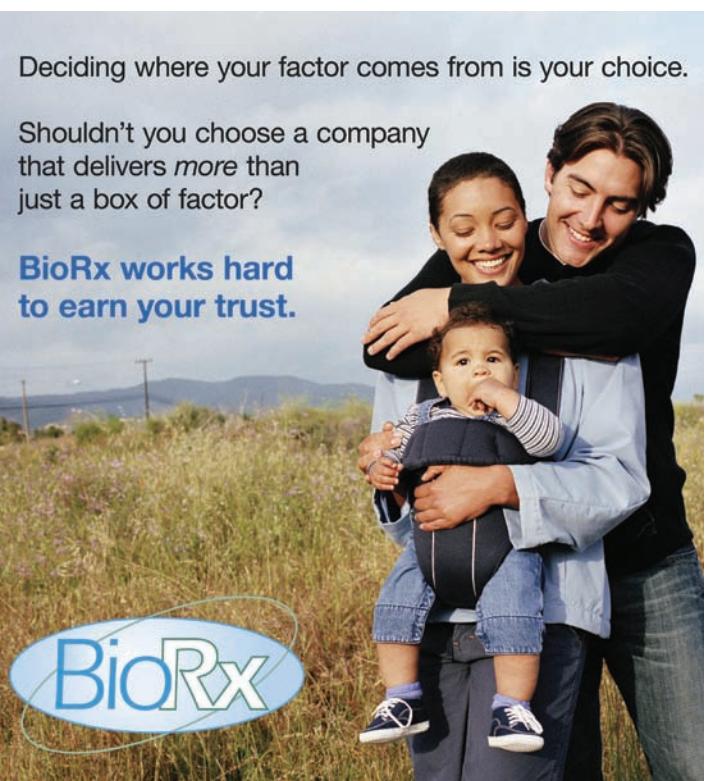
Charlene Cowell – will join us as a seasonal summer intern and assist with administrative needs, program development (teen & family programs), fundraising and our expansion into social media. Charlene is currently a junior at UNC Charlotte with a major in psychology. She has volunteered with HNC since 2007 at events, worked on the development and implementation of programs and assists with the mailings that come from the HNC office. Charlene is familiar with many of the individuals and families in the community and looks forward to her summer at HNC. Charlene can be reached by email at charlenecowell@gmail.com or by phone at the office.

We thank everyone for their generous support of time, talent and resources. Without this, our expansion and growth would not be possible and we look forward to another great year for HNC in helping to further our mission to improve the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research and supportive programs & services. It is our vision for everyone to achieve their full potential without barriers or limitations, until a cure is found!

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Gene Therapy for Hemophilia B Enters into New Phase of Development

A cooperative effort by researchers from the U.S. and the United Kingdom (UK) to develop a gene therapy for hemophilia B has resulted in a new phase of clinical development.

Netherlands-based Amsterdam Molecular Therapeutics (AMT), a company that specializes in gene therapy for different diseases and disorders, announced in March that the first patient has been dosed in a Phase I/II exploratory clinical trial with a gene therapy product for hemophilia B. The study includes the use of AMT's proprietary gene therapy technology. The principal investigator of the trial is Arthur W. Nienhuis, MD, a faculty member at St. Jude Children's Research Hospital in Memphis, TN.

The gene therapy in the trial uses adeno-associated viruses (AAV), small viruses that do not cause disease and produce mild immune responses, as vectors (delivery vehicles) to introduce a functioning factor IX (FIX) gene into the liver cells of subjects with hemophilia B. The goal of the therapy is to trigger long-term FIX protein production through a single administration of the therapy. This could

reduce or eliminate bleeding episodes in hemophilia B patients. Earlier pre-clinical studies of FIX gene therapy were promising, demonstrating the potential for long-term FIX production.

The seminal work on this therapy was started more than a decade ago by St. Jude researchers Andrew Davidoff, MD, and Amit Nathwani, MD, PhD, now with the University College London (UCL). The current trial involves the collaboration of St. Jude, UCL and a number of other institutions in the UK and the U.S.

The purpose of the current trial, which has been approved by both the UK Medicines and Healthcare products Regulatory Agency and the U.S. Food and Drug Administration, is to measure the safety and efficacy of different doses of the therapy. Upon a successful trial, AMT intends to follow up with additional clinical studies.

Source: *Medical News Today*, March 11, 2010

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Mayo Clinic Examines Circumcision-Induced Bleeding

In March, researchers at the Mayo Clinic (MC) in Rochester, MN, published a retrospective study of circumcision in patients with bleeding disorders. The purpose of the study was to examine the outcomes of circumcisions performed on patients who were evaluated at MC to determine the extent of related complications and develop guidelines for clinical management. The lead author of the study was Vilmarie Rodriguez, MD, Division of Pediatric Hematology and Oncology at MC.

Investigators looked at the records of 48 children and young adults who had been circumcised from 2000-2007. They ranged from 11 months to 21 years old, with an average age of 15. Of these, 21 had a known bleeding disorder at the time of circumcision: 15 had hemophilia A, 2 had hemophilia B and 4 had von Willebrand disease. Twelve of the 21 patients were treated with factor products prior to the procedure; three experienced bleeding complications.

The remaining 27 patients were diagnosed with bleeding disorders later in life. Among them, eight experienced bleeding

complications. The overall incidence of bleeding post-circumcision was 11/48 patients, or 23%. The results led investigators to report that this incidence rate in bleeding disorder patients is "comparable" to that reported for unaffected children. They also reported that some patients still experienced significant bleeding despite what was considered adequate factor therapy given before and after circumcision.

"Risks and benefits should be discussed with parents before the procedure, and it should be stressed that bleeding can still occur despite adequate factor replacement. The patient should be observed in the hospital during and after the circumcision procedure to allow prompt intervention if bleeding occurs," concluded the authors.

The study, "To Circumcise or Not to Circumcise? Circumcision in Patients with Bleeding Disorders," was published in the March 2010 issue of *Haemophilia*.

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Researchers Measure Satisfaction with Global Endometrial Ablation in Women with Bleeding Disorders

In an April 2010 study, researchers at the Mayo Clinic examined health-related quality of life (HRQoL) and satisfaction of women with bleeding disorders who had undergone global endometrial ablation (GEA) for excessive menstrual bleeding. The lead investigator of the study was Sherif A. El-Nashar, MBBCh, Department of Obstetrics and Gynecology, Mayo Clinic, Rochester, MN.

El-Nashar and his colleagues surveyed 36 women with bleeding disorders and 110 patients without bleeding disorders, all of whom had undergone GEA for heavy menstrual bleeding, or menorrhagia. During the procedure, the uterine lining is destroyed, leaving the uterus intact. Once scar tissue forms, the menstrual flow decreases as does pain. In all, 96 women responded (66%).

Results showed an improved HRQoL and high satisfaction were reported by both groups (95% for women with bleeding disorders and 84% for those without).

"The current report provides additional supportive data about the long-term, patient reported outcome after GEA. The best available evidence supports the use of GEA as a minimally invasive, safe, and effective therapeutic option for women with acquired or congenital bleeding disorders who have acute or chronic menorrhagia," concluded the authors.

The study, "Health-Related Quality of Life and Patient Satisfaction After Global Endometrial Ablation for Menorrhagia in Women with Bleeding Disorders: A Follow-up Survey and Systematic Review," was published in the April 2010 issue of the *American Journal of Obstetrics & Gynecology*.

Source: *HealthDay News*, May 5, 2010

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AANP Launches Educational Initiative for Young Women with VWD

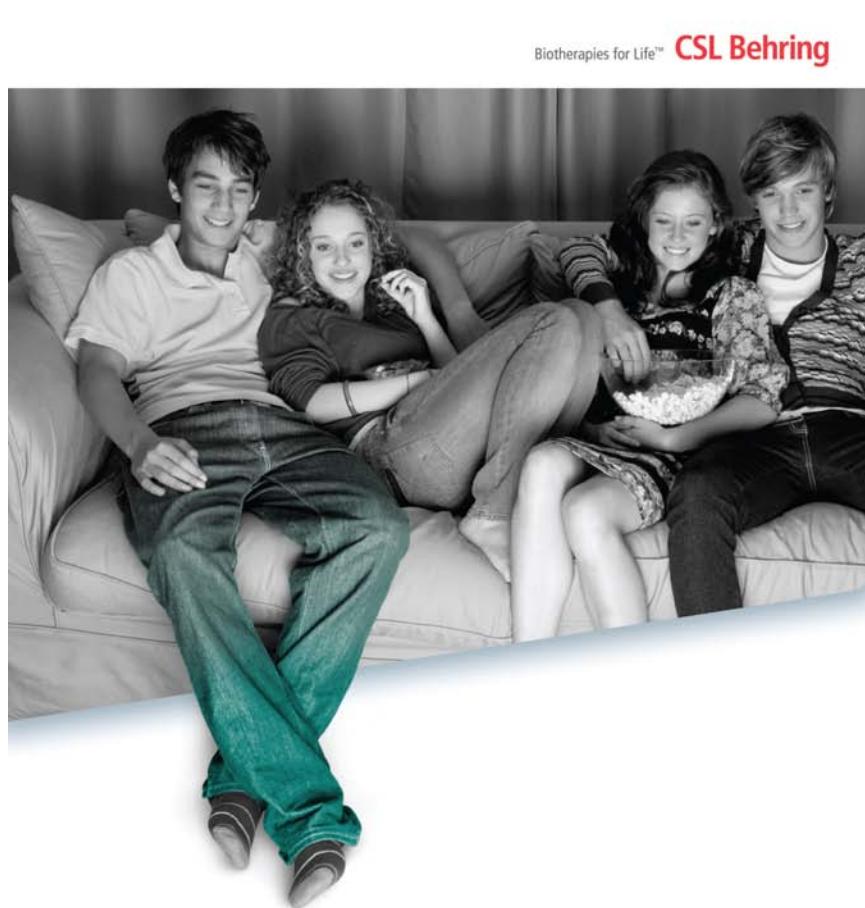
In May, the American Academy of Nurse Practitioners (AANP) announced the launch of its new educational program and awareness initiative to acquaint teenage girls, young women and their healthcare providers with von Willebrand disease (VWD). The VWD Young Women's Education Campaign focuses on five signs and symptoms:

- Easy bruising
- Frequent or prolonged nosebleeds
- Heavy, prolonged menstruation
- Prolonged bleeding following injury, childbirth or surgery
- Prolonged bleeding during dental procedures

Young women exhibiting one or more of these signs/symptoms are encouraged to visit their doctor. "Women struggle with the consequences of this disorder for an average of 16 years before they receive a proper diagnosis because sometimes healthcare

professionals interpret VWD symptoms as gynecologic, when in fact the underlying cause is hematologic," said Josie Weiss, PhD, FNP-BC, Associate Professor, Christine E. Lynn College of Nursing at Florida Atlantic University in Boca Raton and Fellow of the American Academy of Nurse Practitioners. "The teenage years are both the best time and provide the best opportunity to recognize von Willebrand disease because the onset of menstruation often reveals a commonly overlooked symptom—heavy and prolonged bleeding."

The AANP program includes educational materials for healthcare professionals and patients. The materials consist of VWD fact sheets, a screening questionnaire and links to hemophilia treatment centers. A virtual toolkit, including several downloadable resources, can be found on the AANP Web site at www.aanp.org.



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A Powerful Group of Advocates *continued*

Members gathered to promote legislative interests including reinstating the funding of a safety net program to assist families of Hemophilia patients with medical and other expenses (Hemophilia Assistance Plan), ensuring a seat at the table and supporting the temporary federal high-risk pool.

Our seat at the table asked for a presence as a seat-holder in all advisory committees that concern our care and lead to better health outcomes and cost efficient use of state funds for the care of people with bleeding disorders. Our request was a seat at the table when decisions are being made about hemophilia care in advisory committees, committee hearings, and administrative roundtables in the state of North Carolina. Our presence and participation will:

- Ensure they have accurate information on what is needed unfiltered by other interests
- Ensure that they do not make decisions with unintended consequences
- Ensure that they include the appropriate health care providers and vendors to achieve the most cost effective solutions
- Ensure that they are aware of what is truly needed before choosing an inappropriate or more costly option
- Ensure that health plans offer an appropriate site of care at the earliest time possible to reduce pain, suffering and cost

Our ask was to allow a member from the bleeding disorders community to participate in the discussion with all stakeholders in order to create the best outcomes and protect the states resources, both human and financial.

We see changes taking place already in this area with language in the current Appropriations Act (SB 897) - Specialty Drug Provider Network – Section 10.23. It states that the Department of Health and Human Services shall work with specialty drug providers, manufacturers of specialty drugs, Medicaid recipients who are prescribed specialty drugs, and the medical professionals that treat Medicaid recipients who are prescribed specialty drugs to develop ways to ensure that best practices and the prevention of overutilization are maintained in the delivery and utilization of specialty drugs. We are grateful to our legislators for responding to our request to modify the language from its original form and must work together to ensure that the needs of individuals with rare, chronic and expense conditions are met while finding cost effective solutions.

As you know, the Hemophilia Assistance Plan was cut abruptly and in its entirety in 2008 after more than 20 years. This plan was an important source of assistance through the HTC's and helped to fund items such as dental care, medical equipment and supplies, transportation to and from appointments, and annual visits to the centers. We have been advocating for its reinstatement since that

time and received some positive feedback from several legislators in helping to support the effort.

We also discussed the temporary federal high-risk pool and HB1730 – an act to authorize the NC Health Insurance Risk Pool (NCHRIP) to contract with the US Department of Health and Human Services to administer the newly created federal pool. Although the current \$1 million dollar lifetime cap in NCHRIP's proposal to HHS may not be adequate for some individuals with hemophilia, we are supporting this proposal due to the elimination of the \$100,000 annual cap on specialty drugs which currently exists in the NC high-risk pool. The temporary pool, with this modification, would provide critical support to many in our community who go without insurance until the full implementation of the Patient Protection and Affordable Care Act that will become effective in 2014.

Throughout the day, attendees visited with dozens of Representatives and Senators to share information on these issues and raise awareness for the community. Many of your legislators indicated they would support our requests and were interested in helping to raise awareness about the needs.

If you were unable to attend the event, we encourage you to contact your legislator and speak about those issues listed above that impact our community. If needed, HNC will assist with helping to facilitate these discussions and provide more in depth information on these concerns. Decisions are being made daily and time is of the essence to make sure we get that seat at the table!

HNC was also able to secure space in the courtyard of the Legislative Building to share information throughout the day. During lunch, HNC provided boxes lunches along with literature about HNC to legislators and their aides.

We owe a debt of gratitude to those that attended the day and their outstanding efforts made on behalf of the community. They spoke passionately for all those affected by a bleeding disorder and made some very valuable connections with Legislators and their aides that will help to benefit the community in the future. We can assure you that the changes taking place will affect *everyone* and our many thanks to those who made their voices heard!

We would also like to acknowledge the HNC Advocacy Committee Members and others who assisted in planning the day and providing the latest up-to-date information on our issues – Leonard Poe, Warren Ingram, George McCoy, Scott Andrews, Kim Bernstein & Kelly Fitzgerald. This is a very active group that is continually working to keep on top of changes that are taking place and make sure that the needs of the community are known to those who have an impact on our care and treatment.



62nd Annual Meeting To Be Held in New Orleans

The National Hemophilia Foundation (NHF) is pleased to announce that New Orleans, LA, is the site for our 62nd Annual Meeting, November 11-13, 2010.

We will be "Marching Forward," our 2010 theme, as our entire community of consumers, providers, industry representatives and others join together for three days of: Educational sessions and workshops, Networking opportunities and Social events, including a Mardi Gras style Final Night Event.

To receive a 15% discount on your registration fees, register online at www.hemophilia.org by 11:59PM Eastern Time, Monday, August 2, 2010. To register by mail or fax, please download and complete the 62nd Anual Meeting Adult Registration form. Note: faxed and/or mail-in registrations will not receive the discount. Hotel

information will be made available to you upon completion of your registration.

New Orleans is notable for nightlife in the French Quarter, where you'll find Cajun and Creole cooking, jazz and blues clubs and shopping galore. Families will want to check out the Audubon Nature Institute, offering the largest museum devoted to bugs—the Audubon Insectarium; the Aquarium of the Americas, where you can feed a stingray or tour a Caribbean reef; or visit the Audubon Zoo, where sea lion and elephant performances are a must-see.

Please note: the discount does not apply to the Activity Program for Kids & Teens or to the Babycare Program. Space for these popular programs is limited, so we urge you to register early. This year's deadline is Monday, August 30, 2010. Register online or download and mail/fax the Babycare/Activity Program for Kids & Teens form.

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American Plasma Users Coalition, A-PLUS, Seeks FDA-Community Research Agenda to Enhance The Safety of Our Nation's Blood Supply

The Department of Health and Human Services, Advisory Committee On Blood Safety and Availability will be reviewing the current Food and Drug Administration (FDA) policy recommending that men who have sex with another man (MSM) even one time since 1977 should be deferred indefinitely from donating blood.

Mark Skinner, speaking on behalf of the American Plasma Users Coalition, will deliver the attached statement before the Department of Health and Human Services, Advisory Committee on Blood Safety and Availability (ACBSA), being held June 10-11, 2010 at The Universities at Shady Grove, Rockville, MD.

The A-PLUS, American Plasma Users Coalition, is a national coalition consisting of organizations whose members depend on the blood supply to maintain their health and wellness is speaking with one voice regarding current Donor Deferral Policies, specifically the policy deferring men who have had sex with a man, MSM.

"We acknowledge that the scientific basis for the permanent deferral requires review. We believe that there are a number of factors which should be fully evaluated before making a revision to the policy. Such evaluation and research could lead to a policy revision that maintains or enhances the safety of blood and blood products."

Update: Advisory Committee on Blood Safety and Availability (ACBSA)

On June 10-11, 2010, the HHS Advisory Committee on Blood Safety and Availability (ACBSA) met to discuss the current Food and Drug Administration (FDA) policy on men who have sex with other men (MSM). FDA's current policy states that men who have had sex with other men at any time since 1977 are currently deferred as blood donors.

The ACBSA engaged in deliberations and discussed the following: important factors to consider in making a policy change; scientific information including risk assessments; whether any additional studies are needed before implementing a policy change or following a policy change; monitoring tools or surveillance activities that could be implemented, and whether those should be implemented before implementing any policy change; and, whether additional safety measures, if any, are needed to assure blood safety under a revised deferral policy.

The recommendations made by the HHS Advisory Committee on Blood Safety and Availability are carefully being reviewed by

the Department. Our goal is to uphold the safety of the blood supply and protect the public while considering the best science. Any decision to change the policy will be made only after careful consideration.

Source: www.hhs.gov/ophs/bloodsafety/advisorycommittee/index.html, June 17, 2010

Hemophilia Federation of America – Legislative Action Center

The following updates are posted on the HFA website at www.hemophilafed.org in the Legislative Action Center. For copies of the letters and regulations referenced below, please visit the site.

HHS Secretary Sebelius sends update on progress to Congress

In a recent letter Secretary Sebelius provided an update to Congress on the implementation of the immediate provisions in the new health care law. The Secretary provided an update on young adult coverage, pre-existing conditions exclusions, the early retiree reinsurance program, coverage rescissions, small business tax credits, lowering premiums, and the Medicare Part D doughnut hole.

Raise the Cap Coalition sends letter to HHS Secretary

Over 80 groups signed a letter emphasizing the importance of eliminating lifetime and annual caps in all plans, new and grandfathered, on September 23, 2010.

Update: Regulations issued for young adult coverage

Regulators have begun to define the young adult coverage provision and released interim regulations recently. This provision will go into effect September 23, 2010.

Highlights of the regulations include:

- Dependency can no longer be defined by student status, age, financial dependence, or residing with parents
- This impacts all healthcare plans and should allow all adults until age 26 to gain health insurance under their parents' plan
- If the young adult can gain employer-based coverage, they may be denied coverage under parents' plan

Unión Latina de Hemofilia

La creación de La Unión Latina de Hemofilia fue posible gracias a la combinación de dos elementos: por un lado, el reconocimiento por parte de los proveedores de salud acerca de la gran necesidad de crear una red de apoyo e información en español para ayudar a las personas con hemofilia y sus familias a alcanzar un mejor estilo de vida; y por el otro, el compromiso por parte de la Asociación de Hemofilia de Carolina del Norte en apoyar el desarrollo de todas las personas con algún desorden sanguíneo a desarrollar al máximo el potencial de todas las personas con hemofilia que viven en Carolina del Norte, mas allá de las barreras de la nacionalidad o el lenguaje.

En las reuniones realizadas hasta el día de hoy, los participantes han aprendido, no sólo acerca de la importancia de conocer la opinión de los profesionales en el área de la salud sobre el tema de la hemofilia, Von Willebrand y otros desordenes sanguíneos, sino además, la importancia de pertenecer e identificarse a un grupo, en donde se comparten experiencias, con el solo propósito de aprender a vivir con hemofilia a través de los errores y aciertos de ***los otros especialistas: las personas con hemofilia.***



The creation of the Hemophilia Latin Union was possible because of the combination of two elements: in one side, we have the recognition from the health providers about the huge need to build a network to support and provide information in Spanish to help the people with bleeding disorders and their families to reach a better lifestyle; in the other side, we have the commitment of the Hemophilia of North Carolina Chapter to support all the people with a bleeding disorder living in North Carolina to develop their complete potential regardless the barriers of nationality or language.

Since the first meeting everybody who has attended to the group, has learned not only the importance to know the medical expert's opinion regarding the hemophilia, VWD and other bleeding disorders, but the importance to belong and identifying themselves with a social group where they can share experiences with the sole propose to learn about what living with a bleeding disorder is about. Invaluable knowledge that only comes from ***the other experts: the people with bleeding disorders.***



Hemophilia Latin Union

Esta es una publicación para la Comunidad Latina de Hemofilia de Carolina del Norte y para todos aquellos interesados en crear un lazo de amistad e intercambio con esta Gran Familia Latina.



This is a publication for the entire Latino Community with Hemophilia living in North Carolina and for all those willing to establish a bond of friendship and exchange with this Great Latino Family.

Calendario de Reuniones -Meeting Calendar-

Sábado 14 de Agosto
Reunión del Grupo Latino
Raleigh, NC

Domingo 10 de Octubre
Participación en el "Festival Latino Americano"
Charlotte, NC

Sábado 16 de Octubre
Caminata de Hemofilia
Morrisville, NC

Sábado 18 de Diciembre
Festejo de Navidad
Grupo latino
Charlotte, NC

Para mas información llama
a Guillermo Sánchez:
704-606-4376
O escríbenos un email.

** Dear readers the following article can be found in English in The Concentrate- spring 2007 issue.

Un Nuevo Rostro En Escena.

Saludos a todos! Es un honor presentarme como la nueva Directora Executiva de Hemofilia de Carolina del Norte. Mi nombre es Sue Cowell, vivo junto con mi esposo y mis dos hijas en el área de Cary.

Me entusiasma trabajar con un grupo de personas que inagotablemente continúan con sus esfuerzos para

apoyar a la comunidad. Las necesidades de la comunidad de desórdenes sanguíneos de Carolina del Norte es tan grande como el estado mismo. Poseemos un firme y gran compromiso en la búsqueda de oportunidades para mejorar la calidad de vida de todos sus miembros. Nos seguiremos esforzando por alcanzar este resultado a través de seminarios educativos, nuestras reuniones anuales, y con la publicación de información actualizada en nuestra revista The Concentrate. Esperamos que aproveches estas oportunidades, diseñadas a partir de nuestra Misión y pensadas en ustedes.

Miremos hacia el futuro con un único propósito y trabajando unidos por nuestras metas. Son bienvenidas todas las sugerencias y cualquier otra información que consideres pueda ser de ayuda para nuestra comunidad. Gracias por tu apoyo.

Sinceramente

Sue Cowell
Director Executivo de HNC

Para nuevos lectores y miembros / For new readers and members

Misión: Hemofilia de Carolina del Norte es una organización no lucrativa, dedicada a mejorar la calidad de vida de personas afectadas por algún desorden sanguíneo, brindándoles apoyo en educación, promoción de estudios de investigación y promoviendo programas y servicios para esta comunidad.

Nuestra Visión: que todas las personas afectadas por algún desorden sanguíneo logran el desarrollo total, sin barreras o limitaciones, hasta que se encuentre una cura.

Centros de Tratamiento para la Hemofilia

(Hey friends in this article we are talking about the **Hemophilia Treatment Centers**, you can find information in English at cdc.gov, just look for the hemophilia word)

Los Centros de Tratamiento de la Hemofilia brindan atención médica especializada con un equipo de médicos, personal de enfermería y otros profesionales de la salud que tienen experiencia en el tratamiento de las personas con hemofilia y otros desórdenes sanguíneos. En un estudio de los CDC realizado con 3,000 personas con hemofilia se demostró que aquellas que acudían a un centro de tratamiento para la hemofilia tenían un 40% menos de probabilidad de muerte por una complicación asociada a la hemofilia en comparación con aquellas que no recibían atención en un centro de este tipo. De manera similar, las personas que contaban con un centro de tratamiento tenían 40% menos de probabilidad de ser hospitalizadas por complicaciones hemorrágicas.

Cada centro de tratamiento para la hemofilia permite el acceso a profesionales de la salud de varias disciplinas:

- Hematólogos (médicos que se especializan en la sangre).
- Ortopedistas (médicos que se especializan en huesos, articulaciones y músculos).
- Fisioterapeutas
- Personal de enfermería
- Trabajadores sociales y otros profesionales de salud mental

Los Centros de Tratamiento de la Hemofilia hacen énfasis en los servicios de prevención para ayudar a reducir o eliminar complicaciones generadas por esta enfermedad. Estos servicios incluyen el uso de medicina preventiva y la vinculación de pacientes a grupos comunitarios que brindan educación y apoyo a las familias. Por ejemplo, La Unió Latina De Hemofilia brinda sesiones educativas en español para sus miembros.

Consejo Rápido

¿Sabes que es el RICE?
Se recomienda que al identificar un sangrado en alguna articulación comiences a utilizar el método RICE (por sus siglas en inglés). Lo primero es la infusión del Factor e inmediatamente después:

Rest (Reposo)
Ice (Hielo)
Compression (Vendar)
Elevate (Elevar)

Si por cualquier razón no puedes tener la infusión inmediatamente procura utilizar el **RICE** para reducir un poco el sangrado. Pero recuerda la infusión del Factor es definitivamente el mejor tratamiento.





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

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Koāte®-DVI

Double Viral Inactivation
**Antihemophilic Factor
(Human)**

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.

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

For new members, please complete the following application form.

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

Please mail completed application 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.

2010-2011 HNC Calendar of Events

We are continuing to plan events through this year and into 2011. We would share some of these HNC dates in advance so that you can mark your calendars. As we add dates, we will update them on the list and the website.

Blood Brotherhood Program – July 17-18th

"Kickoff Karnival" for Hemophilia Walk – August 7th

HNC Teen Retreat – August 8-10th

Latin Union Program – August 14th

HNC Family Retreat – September 4-6th

Gettin' in the Game – Junior National Championships – September 25th

2010 Festival Latino Americano – Fundraiser – October 10th

2010 Hemophilia Walk – October 16th

HNC Holiday Celebration – December 4th

"Hearts for Hemophilia" Casino Night – January 22nd, 2011

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 active member – information update.



HEMOPHILIA OF NORTH CAROLINA

260 Town Hall Dr., Suite A, Morrisville, NC 27560
*Hemophilia of
North Carolina* (800) 990-5557 • info@hemophilia-nc.org
www.hemophilia-nc.org

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SAVE THE DATE

Saturday, October 16th, 2010
Lake Crabtree County Park ♦ Morrisville, NC

Don't miss this chance to come on out and have fun for a great cause.

Did you walk on a team last year? If so, think about starting your own team this year!

Do you frequent a business often? Ask if they would like to consider sponsoring the Walk!

Like to organize and plan activities? Consider volunteering for a spot on the walk committee!

Visit the HNC website at www.hemophilia-nc.org for more information about teams, sponsors and volunteering.

www.hemophilia.org/walk

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.