Hemophilia of North Carolina Celebrates Its 35th Anniversary at the Annual Meeting

On Saturday, May 31st, Hemophilia of North Carolina (HNC) celebrated its 35th anniversary at their Annual Meeting in Winston-Salem. Over 135 people attended the meeting that was held at the Lawrence Joel Veteran’s Memorial Coliseum Complex.

Members were invited to attend this meeting and join the organization in taking a look at the past, present & future of those affected by bleeding disorders. The agenda for the meeting included a morning panel of nationally and internationally renowned speakers and experts who shared their experiences through different eras. The panel included Harold R. Roberts, MD (Sarah Graham Kenan Professor of Medicine and Pathology at the University of NC – Chapel Hill), Warren Jewett, Sc.D (past president of NHF and current board member of HNC), Roberta Smith (serves on the CSL Behring Advisory Committee and the Advocacy Committee for the Utah Hemophilia Foundation) and Sally Owens (Acting Team Leader of the Prevention Research Team for the Centers for Disease Control Division of Hereditary Blood Disorders). The presentations were outstanding and offered a glimpse into the decades of treatment for bleeding disorders along with a promising future.

After lunch, keynote speaker Jeanne White-Ginder, mother of Ryan White, shared her personal triumphs and tragedies of life with Ryan. One week before Christmas in 1984, Jeanne was told that her son, a hemophiliac, had contracted AIDS from a tainted blood product. Jeanne’s presentation was heartfelt and deeply touched many of the members who shared her pain and loss.

The HNC business meeting was then presented and included a review of 2008 programs & services, a financial review, a look to future initiatives and an election of nominees for the 2009 Board of Directors and the appointment of Richard Atwood as the new President for HNC. Richard then presented Matt Barnes, outgoing President, with a plaque honoring his dedication and commitment to HNC.

The afternoon included segments on Bone Health and Inhibitors that were presented by Nursing Education Clinicians Aime Grimsley and Brenda Nielsen from the Hemophilia Treatment Center at the University of North Carolina-CH. Also presenting was Michael Keogh, the newly appointed Executive Director for the NC Health Insurance Risk Pool (NCHIRP).
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
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.

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.hacares.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

Hemophilia Treatment Centers

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

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

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

Carolinias 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
It’s been a very busy quarter with our Golf Tournament, Annual Meeting and Legislative Day. In addition, I’ve had an opportunity to spend time with families at the HFA 2008 Educational Symposium, learn from the experts at the NHF On the Road Conference and attend a very enthusiastic NHF Leadership Weekend where the new CEO, Val Bias, shared his powerful vision for NHF and the Chapters.

To say the least, all of these events have been inspiring and empowering. I see such great opportunities for the community and would like to bring all of them to our members in North Carolina. My ‘to do’ list is ever expanding with thoughts and ideas about programs and services that HNC can provide.

That said, I am now asking for your help to put these plans into action. There are too many opportunities to list on how to give back. They range from monetary donations to giving of your time, regardless of the amount. A great example is the wonderful individuals and families who participated in our recent Legislative Day and took one day from their busy schedules to visit the legislators and share their stories. The impact they made was invaluable as now each of those elected officials knows who HNC is and what your needs are as a community! Another example is the upcoming Hemophilia Walk. If you haven’t already visited the web site, check out http://www.hemophilia.org/walk and take a look at the team pages where members have posted pictures and share their stories. Setting up a team page takes very little time but has a huge impact in helping to support HNC. From the team page you can email friends & family to help support the Walk with a donation and join your team on the day of the event – all with only a couple clicks of a mouse!

I’m very excited about the response so far from our Regional Meetings. As of this publishing, we have only had one meeting in the Charlotte region but already have a member and local physician assisting with setting up additional programs & services to that area (see inside for more details).

Our organization is growing rapidly with over a 25% increase in membership just in the past six months! The lifeblood of any non-profit is in its volunteers. I hope that you will join me in our goal to continue to promote opportunities for improving the quality of life for all those affected by a bleeding disorder.

Sincerely,

Sue Cowell
HNC Executive Director
Celebrates Its 35th Anniversary Cont.

who described the new high risk pool that is being developed and implemented in January 2009. The afternoon concluded with a passionate speech by Leonard Poe, HNC’s Vice President Advocacy Chair, about getting involved and inviting the attendees to HNC’s 2008 Legislative Day on June 10th, 2008.

Throughout the day, the children were busy with programs from the Children’s Museum of Winston-Salem, Adrian the Magician, The Mad Science Group and a trip to the Game Frog Café.

After the meeting, everyone was treated to tickets to Bowman Gray Raceway for an evening of fun at the races!

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following sponsors for the 2008 HNC Annual Meeting

**Platinum Sponsors**  
Supporting all programs and food & beverages  
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Wyeth

Hemophilia of North Carolina is excited to participate in Camp Superfly again this year. Our team name is the North Carolina Monarchs.

Camp Superfly is a program that was introduced by Baxter in 2005 to bring a virtual camp experience into the homes. We support this program as an opportunity to have fun, learn and help HNC earn grants for summer camps.

Information has been mailed out to selected members who we feel would meet the criteria or we only have generalized information on. If you’ve received a packet and are not interested in participating, please contact HNC to let us know so we can redirect the next mailing to another member.

It’s easy to participate – just fill out the information and mail it in. HNC is competing with other chapters of similar size and grants being awarded this year go up to $15,000 for the 1st place team!
**Chapter News & Information**

**SAVE THE DATE**

**Hemophilia Walk 2008**

**Saturday, October 18th**

9:00am registration • 10:00am – 12:00 walk
Lake Crabtree County Park, Morrisville, NC

Teams are forming and sponsors are signing up! The North Carolina Hemophilia Walk 2008 is underway and the web site is filling with individuals and companies who have begun to fundraise and recruit walkers for this important event.

Remember you can start or join a team, sponsor a walker, volunteer, become a Team Captain, sponsor the walk or organize a group from your local area to participate! The opportunities to help support the walk are endless and will be very rewarding.

Walkers will receive complete support during their scenic walk along the lake with rest stops, traffic control and lots of activities. The park welcomes strollers, pets, wheelchairs and all trails are nicely paved for easy access!

Our goal for the walk in NC is $50,000. We are off to a great start with donations and sponsorships totaling $12,735 as of this publishing. We have a ways to go and encourage all of you to get involved to help HNC! Proceeds from this event will help HNC to support and expand many of its programs & services. In addition, it is invaluable in helping to raise awareness about the bleeding disorders community!

**Save the date for the official Kick-Off Meeting to be held on August 17th from 3pm-5pm** at the Hilton Garden Inn RDU Airport located in Morrisville, NC. All walkers and members are welcome to join this fun event to help in the official kick-off for the Walk.

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Teeing It Up For HNC!

With over 100 golfers, 26 teams and great weather, the 4th Annual HNC Golf Tournament was a huge success! The tournament was held again this year at The Preserve at Jordan Lake in Chapel Hill, NC on Friday, April 25th.

The teams had time to relax, get some practice in and enjoy a boxed lunch before they took off on to the course. Check in went smoothly with the help of our team of volunteers who assisted with registering the players, selling raffle tickets, mulligan packages, Beat the Pro chances and handing out the goodie bags & shoe bags to all participants.

Our special guest player, pro golfer Perry Parker, spoke to the teams and shared some valuable insights into living with hemophilia and the benefits of supporting the local Chapters for the families and individuals. Perry then challenged the golfers on hole #17 to Beat the Pro. Thirteen of our golfers succeeded in beating the pro and received embroidered golf towels, golf balls and a chance to enter a raffle for a newly released hybrid club. David Draper and Doug Kaiser were the lucky winners in the raffle.

The full field of teams moved along impressively and were back to the club house by 6:00pm to enjoy a delicious dinner prepared by XU Catering and their favorite beverage. Our special thanks to the Lexington Moose Lodge for their donation of all the non-alcoholic beverages that helped quench the thirsts of our athletes throughout the day!

Other winners included Fred Barnes (Longest Drive) and Van Graham, Tim Jones, Doug Kaiser & Terry Evans (Closest to the Pin).

Our live auction was next which was conducted by our favorite auctioneer, Terry Lamb. He rallied the players into a bidding frenzy for some great items including two golf packages, an autographed car from Bobby Labonte and a UNC sports memorabilia package that consisted of a signed basketball from Roy Williams & Woody Durham along with an autographed team photo.

We then moved on to our gift basket raffle. The baskets were stuffed full of items and the themes included Car Care, The Umstead Hotel & Spa, Wine & Bistro, Golf, Sports, Hatteras & Football baskets. These were some great prizes and we are grateful to all those who contributed generously towards the contents.

The night concluded with a heartfelt thanks from our President, Matt Barnes, to the players and contributors. Matt graciously acknowledged our tournament sponsors, CSL Behring and Wyeth along with all the other sponsors who generously supported our event.

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Our winners were announced and included:

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HNC Thanks Our Golf Sponsors

Tournament Sponsors
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- Mr. Wayne Holt & Team
- Mr. Nigel Mackman—“The Clotters”

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- Mr. Edward Wells & Team

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A Special Thanks to Our Golf Committee Members
- Matt Barnes
- Sue Cowell
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- Todd Holder
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Winter 2008
Meet the New 2009 HNC Board Members!

Hemophilia of North Carolina recently elected the Board of Directors for 2009. Richard Atwood, longtime member of HNC and current Secretary, was elected President with a two-year term. Kathy Register, current board member, has taken on the role of Treasurer. Warren Jewett, Jeannie Adair and Leonard Poe will remain active on the board. Matt Barnes and Andrea Brill will be stepping down off the board but will remain active members of the organization as part of the ongoing Fundraising and Outreach Committees. We would like to thank Matt & Andrea for their contributions to HNC and their tireless dedication and vision for the organization. The 2009 Board of Directors will include three new members who we are very excited to announce. Below are the names and short bios of those members –

Sally S. Wright, MSW, LCSW
Sally’s connectedness to the hemophilia and bleeding disorders community is as the social work clinical specialist at the Harold R. Roberts Comprehensive Hemophilia Diagnostic and Treatment Center, University of North Carolina at Chapel Hill. Sally’s CV is available upon request

Tracy Kelly, RN, PNP
Tracy Kelly, MSN, CPNP has a dual appointment as a Pediatric Nurse Practitioner in Hematology-Oncology at Duke Children’s Hospital and Health Center, and as a Clinical Instructor in the Duke University School of Nursing. Her patient population includes children with bleeding disorders. She is an avid tennis player who enjoyed participating in our first ever ‘Aces for Action’ tennis tournament in 2007.

Adam Trunkey
Adam Trunkey is the communications leader for the Information Protection Services group at IBM in Cary, NC. Previously, Adam was the Director of Communications for Arsenal Digital from May 2006 until Arsenal was acquired by IBM in December 2007. At Arsenal, Adam led the marketing and communications efforts to establish Arsenal’s mid-market and consumer data protection services. He also was a key architect in Arsenal’s re-branding campaign that culminated in the company’s acquisition. Adam has held a variety of positions in high tech communications. During his career, he has been responsible for executing communications and joint marketing programs that have established worldwide brand and awareness, impacted market share and received recognition.

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

BioRx, a specialty pharmacy, and Hemophilia of North Carolina announce the winners of the 2008 BioRx Educational Scholarships. The scholarships are funded by BioRx through an educational grant, which is administered by Hemophilia of North Carolina.

After a very thorough review of the 54 applicants for the BioRx Educational Scholarships, the committee of three HNC board members chose the winners.

The recipients of the 2008 BioRx Educational Scholarship Awards are:

Karin Azzarano [Meadowbrook, Pennsylvania]

Manuela Lee [The Woodlands, Texas]

Esmaeel Paryavi [Rockville, Maryland]

Each of the winners will receive a $2000 scholarship to pursue their educational fields in healthcare related fields. Our thanks to BioRx for making this opportunity available to these individuals.

For the latest information on scholarship opportunities, please visit the National Hemophilia Foundation at www.hemophilia.org and the Hemophilia Federation of America at www.hemophiliafed.org.
Chapter News & Information

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2008 Friends of HNC

We would like to acknowledge the following individuals who generously donated to HNC during the second quarter of 2008. We extend a sincere thank you to our supporters...many of whom contributed several times during this period.

Donations Made In Loving Memory of Keith Slack
Ms. Linda Robertson

Donations Made In Loving Memory of Janet H. McDonald
Mr. & Mrs. John Preyer

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Daniel R. Turnbull, DDS
Mr. Tom Wells

Hemophilia of North Carolina would also like to take this opportunity to thank our advertisers who make publication of The Concentrate available to our members at no cost to the organization. Thank you!

HNC Regional Meetings – Off to a Great Start!

HNC hosted its first regional meeting in Charlotte on June 18th. The number of attendees was small but mighty! Plans are already underway to develop programs and services to that area and HNC member, Megan Mauk has agreed to be the coordinator for what has been un-officially name “HNC Region South”. The meeting was filled with ideas on promoting educational events for individuals and families.

We look forward to the three other regional meeting planned for later this month and encourage you to attend future meetings if you could not make these. Information on all meetings and sites will be available on the web site at www.hemophilia-nc.org or by calling (800) 990-5557.

For information on contacting Megan regarding plans for the Charlotte region, call HNC at (800) 990-5557. Thank you Megan!
Save The Date!
Hemophilia of North Carolina’s 2nd Annual
“ACES FOR ACTION”
Charity Women’s Doubles Tennis Tournament
Saturday, September 20th
Cary Tennis Center, Cary, NC

For information on helping with the tournament or participating please contact Sue Cowell at (800) 990-5557 or info@hemophilia-nc.org.

“Hearts for Hemophilia”
HNC’S 2ND ANNUAL CASINO NIGHT
Friday, January 23rd, 2009
Museum of Natural Sciences, Raleigh, NC

SAVE THE DATE!

It’s sure to be a fun night for all! Look for your invitation in the mail this fall. For information on helping to plan the event, attend or sponsorships, please contact Sue Cowell at (800) 990-5557 or info@hemophilia-nc.org

HNC Resource Guide
UPDATE

Due to a busy spring schedule, the date for publishing the guide has been delayed until the end of summer so we can be as thorough as possible and include all the information and services available to the community.

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
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Through Progress
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Scientists Report Advances in Novel Gene Therapy Vector

A team of researchers at the University of Florida (UF) in Gainesville has reported a potential gene therapy breakthrough using an altered viral vector (a nondisease-causing vehicle that transfers genetic material) that is significantly more efficient than current vectors. The report suggests that by substituting a particular amino acid found on the surface of the virus, superior therapeutic benefits can be achieved for hemophilia and other genetic diseases. The lead author of the study is Arun Srivastava PhD, the George H. Kitzman professor of genetics and the chief of cellular and molecular therapy in the UF College of Medicine.

While adeno-associated viruses (AAV) are considered by many scientists as optimal gene therapy vectors—they can be used to infect cells without causing disease—they have several drawbacks. Often, trillions of AAV particles need to be administered for the corrective gene to eventually “take root” in the nucleus of a cell and carry out its therapeutic function. Past studies have shown that AAV and some other vectors delivered in such a high volume trigger an immune response in the host.

“We were very surprised. It’s amazing to think that changing one amino acid could produce these results,” said Srivastava. “Now the virus actually completely avoids being phosphorylated, so it doesn’t become degraded and it goes into the nucleus, and we get therapeutic levels of proteins. We can generate therapeutic levels of factor IX.”

Srivastava also said that this novel type of AAV could not only be more efficient but less expensive as well. A traditional AAV therapy can require more than 10 trillion AAV particles, whereas the new AAV therapy could use as few as 100 billion particles.

The next step will be to test the therapy in other animals. Srivastava’s team will collaborate with researchers at the University of North Carolina to test the new AAV vectors in dogs with hemophilia. If these studies are successful, they could pave the way for human gene therapy trials.

The study, “Next generation of adeno-associated virus 2 vectors: Point mutations in tyrosines lead to high-efficiency transduction at lower doses,” was published in the early edition of the May 29, 2008, online version of the Proceedings of the National Academy of Sciences.

Source: University of Florida news release dated May 19, 2008
Reprinted from NHF Enotes

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**Mist**

Mothers in Support Together

At long last, a place for moms of children with a bleeding disorder to participate in an exciting open forum.

Share your experiences, insights and concerns with other moms. A knowledgeable speaker will be on hand at every event.

Fun activities for all the kids in the family!

Moms, please contact LaDonna at:

**(866) 771-COAG (2624)** for dates and locations around North Carolina.
Modified FVIII Protein May Block Inhibitors

Researchers from The University of Texas Health Science Center at Houston are developing a chemically modified protein that could eventually be used as a therapy for difficult-to-treat hemophilia A patients with inhibitors.

Approximately 15% to 30% of hemophilia A patients develop inhibitors, a challenging complication with limited and expensive treatment options. When the body’s immune system recognizes infused clotting factor as a foreign substance, it releases antibodies, called inhibitors, in response. The antibodies attack the factor, inhibiting its effects.

Senior author Sudhir Paul, PhD, at The University of Texas Medical School at Houston, lead author Stephanie Planque, a PhD candidate, and their colleagues collaborated with Kathleen P. Pratt, PhD, of the Puget Sound Blood Center and Division of Hematology at the University of Washington in Seattle.

In laboratory tests, Paul’s team discovered that electrophilic factor VIII analog (E-FVIII), a modified protein, could neutralize inhibitor antibodies, thus clearing the way for follow-up infusions of factor VIII.

“It’s a two-step process,” said Paul. “The E-FVIII permanently inactivates the antibodies that inhibit blood clotting in 20% to 30% of patients receiving factor VIII replacement therapy. Once the antibodies are cleared, additional FVIII can be injected.” The study used blood donated by eight people with FVIII-resistant hemophilia A. The next step for Paul and his colleagues is to conduct clinical trials involving E-FVIII.

“Covalent inactivation of factor VIII antibodies from hemophilia A patients by an electrophilic FVIII analog,” was published in the May 2, 2008, issue of The Journal of Biological Chemistry.

This research was supported by grants from the Hemophilia Association of New York, Hemophilia of Georgia and the National Institutes of Health.

Source: ScienceDaily, May 21, 2008
Hemophilia 2008 World Congress

The WFH World Congress held in Istanbul, Turkey, in June broke records by attracting more than 4200 participants from over 115 countries. This makes it the largest WFH Congress ever.

The WFH will be posting congress information on their website over the next few weeks, including summaries of selected sessions, the book of abstracts, and the state of the art papers, so check regularly for updates on their web site at www.wfh.org.

HFA 2008 Educational Symposium

The Hemophilia Federation of America hosted their 2008 Education Symposium in Little Rock, AK from May 1-4, 2008. Nine members of Hemophilia of North Carolina attending including one family who was sponsored with grants made available by HNC and HFA.

The Symposium was filled with programs on the latest information for people with bleeding disorders including Insuring Survival, Navigating the Pain Maze, Enduring the Dynamics of Living with a Chronic Bleeding Disorder, Therapy Advances and much more. There were break out sessions for women, teens, dad’s and men. The final night of the Symposium was a treat at the Museum of Discovery.

As one of our members stated “the greatest benefit of coming to these events is the chance to meet others”. This was a great opportunity to learn from the experts, share ideas and network.
CDC Appoints New Division of Blood Disorders Director

Hani Atrash, MD, MPH, is the new Director of the Division of Blood Disorders (DBD) in the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). He succeeds Roshni Kulkarni, MD, who is returning to her professorship in pediatric hematology/oncology at Michigan State University. She will also remain a senior medical advisor in the DBD.

Atrash, an expert in program development and implementation of national public health initiatives, will work with DBD scientists and staff to enhance and expand the division’s blood disorder programs. They plan to increase DBD’s collaboration with other divisions at CDC, partners at state and local health departments, and private organizations.

Atrash’s joined the CDC was in 1979, working in the Epidemic Intelligence Service in the Family Planning Evaluation Division. During his first year, he was assigned to the Tennessee Department of Health. From 1981-1984 Atrash was assistant professor of epidemiology and biostatistics at the American University of Beirut (AUB). During that time he was assigned to the Bahrain Ministry of Health as Public Health Consultant and Manager of the Office of Professional Standards and Systems Analysis. He also served as epidemiologist for the country.

In 1985, Atrash returned to the CDC, joining the Division of Reproductive Health in the National Center for Chronic Disease Prevention and Health Promotion. He first served as visiting scientist (1985-87), then chief of the pregnancy morbidity and mortality section (1987-89) and finally as chief of the pregnancy and infant health branch (1989-2001). During his tenure, Atrash developed several nationally recognized programs in maternal and child health. He led the CDC activities on Safe Motherhood, working closely with state and local health departments, the American College of Obstetricians and Gynecologists and the World Health Organization.

In 2001, Atrash joined NCBDDD as Associate Director for Program Development, managing activities related to global health, workforce development and women’s health. He established key relationships with national organizations, state and local health departments and minority health organizations. During the last four years, Atrash spearheaded the new CDC program on Preconception Care.

Atrash is an accomplished scientist and prolific writer. He has authored and edited hundreds of published studies. He serves on a variety of key national advisory committees. Atrash has received numerous honors and awards within the CDC and at the national level for his work improving the health of mothers and children.

Atrash received his MD from AUB and his Masters in Public Health from the Rollins School of Public Health at Emory University.

Reprinted from NHF June 2008 eNotes
Dozens of the members of Hemophilia of North Carolina met at the State Legislative Building in Raleigh on June 10th for the 2008 Legislative Day. In total, 43 members visited with over 36 legislators on that day and discussed issues facing the bleeding disorders community. The attendees divided into 8 groups that canvassed the State Legislative Building and spent time with legislators in their districts.

The group began the day at the Holiday Inn Brownstone Hotel in Raleigh where they enjoyed breakfast and a session to discuss the talking points, advocacy tips and meet other members of their groups. After breakfast, everyone boarded the bus for Raleigh to visit with their legislators.

In addition to the visits, HNC members were recognized by both the Senate and the House in chamber sessions. HNC also made presentations to two legislators who have worked tirelessly on behalf of the bleeding disorders community. Senator Bill Purcell of North Carolina’s 25th Senate District and Representative Verla Insko of North Carolina’s 56th House District were awarded plaques honoring them as Legislators of the Year.

Senator Purcell, a pediatrician of over 50 years, earned the distinction through his work in health policy and as chair of the Senate Appropriations Subcommittee on Health and Human Services. Representative Insko earned the distinction through her work in health policy and as chair of the House Appropriations Subcommittee on Health and Human Services.

“To advance legislation in a complex policy area, such as health practice regulation or Medicaid funding, allies like Senator Purcell and Representative Insko, are an invaluable resource to Hemophilia patients and their families,” said association member Leonard Poe. Poe presented both Senator Purcell and Representative Insko the Legislator of the Year award as association members looked on.

“I am truly honored to receive this award today, and having some experience with treating Hemophilia patients during my time practicing medicine, I do care deeply about the welfare of blood disorder patients,” Senator Purcell said.

“I am truly honored to receive this award today. Although, bleeding disorders are rare it is so important for us to educate the public and the members of the Legislature about these disorders, so I thank you for the work that you do,” Representative Insko said.

Members gathered in Raleigh to promote legislative interests including the continued funding of a safety net program to assist families of Hemophilia patients with medical and other expenses. Additionally, the State’s Medicaid regulations allow patients the freedom to choose medications that work best for them and the group asked legislators to renew or make permanent the statue due to expire next year that addresses this issue.

One of the groups was successful in gaining a commitment from Senator Malone to be the primary sponsor to make this statue permanent.

HNC was also able to secure space in the lobby of the Legislative Office Building to share information with legislators and their staff throughout the day.

After the busy day in Raleigh, the group boarded the bus to return to the hotel for dinner and a discussion of the day’s events. Members who attended included individuals and families who not only shared their personal insight of living with a bleeding disorder, they also advocated on behalf of the whole community. Our heartfelt thanks for taking time out of their busy schedules and help bring about change. There is no doubt that the legislators in Raleigh now know who Hemophilia of North Carolina is and we will remain vigilant in our quest to monitor and affect legislation that impacts our community.

HNC would like to thank the government affairs staff at Bayer and Baxter who assisted in the planning of our 2008 HNC Legislative Day.
On the National & Legislative Front

National Alliance for Thrombosis and Thrombophilia

The National Alliance for Thrombosis and Thrombophilia (NATT; www.nattinfo.org) is a non-profit patient-led advocacy organization providing patient education and professional training on the signs, symptoms and prevention of blood clots and clotting disorders. The mission of NATT is to prevent, diagnose and treat thrombosis and thrombophilia through education, support, research, and advocacy. NATT is working closely on its Stop-the-Clot™ Education Projects with the Centers for Disease Control (CDC), Thrombophilia Centers, Anticoagulation Clinics, and Hemophilia Treatment Centers.

Earlier this year, a Stop-the-Clot Forum was held in Durham. The result of this forum was the formation of a regional interest group which is on a mission to create a NATT Chapter in the Carolinas. The proposed NATT Carolinas Chapter will follow the lead of the national NATT organization and will put aggressive plans in place to develop a NATT “Carolina” presence with a focus on creating blood clot awareness, conducting education sessions, and to identify advocates and financial donors among patients, providers, friends and legislatures. NATT Carolinas initial emphasis during 2008 will be to conduct two Stop-The-Clot Forums (one in Greensboro, N.C. and one in Chapel Hill, N.C.), to develop a communications and awareness strategy, and to create a NATT Carolinas website (www.stoptheclotnc.org).

Almost 300,000 Americans die each year from blood clots in the veins. Many of these lives could be saved if more patients and health professionals had better knowledge about the risks, symptoms and treatments and applied appropriate prevention strategies. In North Carolina, nearly 30,000 people develop a blood clot in the veins (deep vein thrombosis and pulmonary embolism) every year, and nearly 10,000 people die from it. This means that blood clots are killing more than 30 people each day in North Carolina. Please get involved and help save a life. People interested in being involved in the NATT Carolinas development can/should sign up through https://fafnir.cs.unc.edu/mailman/listinfo/nattnc. Also check www.stoptheclotnc.org in the near future about NATT-NC developments.
NHF 10th Annual Leadership Weekend

NHF hosted their 10th Annual Leadership Weekend from June 12-15, 2008. HNC Executive Director, Sue Cowell, attended the conference which was designed for chapters of NHF and help in building stronger relationships.

NHF’s newly appointed CEO, Val Bias, presented a very inspiring presentation about his vision for the national organization which includes working closely with the state chapters to bring about more awareness and the importance of continuing advocacy efforts in the face of challenges that are sure to be ahead. A variety of topics were discussed throughout the meeting including Chapter Services, the new 990 tax form, Using the Media to Raise Awareness, State Advocacy, Board Governance and presentations from NHF’s Educational Department about their upcoming initiatives and collaboration with CDC on the National Prevention Program.

On Saturday, a presentation for the new Campaign for the Future was given. This was the kickoff for this campaign and a proclamation was signed by parties who have committed resources to this project including the NHF Board of Directors, charitable foundations, corporations and individuals. The campaign is a five-year collaborative effort to fund the capacity building efforts of NHF and its network of chapters/affiliates.

HNF On the Road in Durham

NHF’s On the Road Conference came to Durham May 16th & 17th to celebrate 10 Years of Activism of Behalf of Women in the Bleeding Disorders Community. Attendees included chapters from all over the country, members of the medical community and members of Hemophilia of North Carolina.

Programs included discussions about the recent NHLBI Guidelines to improve the diagnosis, treatment and awareness of bleeding disorders in women, a look forward at the research and public health education and a discussion about NHF’s Project Red Flag. Speakers included local physicians Andra James, MD, MPH (Duke University), Tom Ortel, MD, PhD (Duke University), Raj Kasthuri MD (University of North Carolina at Chapel Hill) and Steve Humes, MPH (HTC Regional Coordinator – CDC Region IV North). In addition to the local speakers, many others from around the country presented valuable information to assist women affected by a bleeding disorder.

On Saturday evening, the Project Red Flag Visionary Awards were presented to five women who were recognized as pioneers in the activism for women. Those recipients included Renée Paper (posthumously), Sally Owens, Janice Cannizzo, Stephanie Seremetis, MD and Jeanne Lusher, MD.

Hemophilia of North Carolina is honored to have participated in hosting this wonderful event in our area and thanks NHF for providing such a valuable resource to members in our local community.

For more information on Project Red Flag or joining the NC Women’s Task Force, please contact HNC Executive Director, Sue Cowell at (800) 990-5557 or by email at info@hemophilia-nc.org.
The New York Times examined how a number of health insurers have begun to charge members a percentage of the price of certain expensive medications, rather than set copayments, to help reduce costs. According to the Times, the implementation of such “Tier 4” systems “means that the burden of expensive health care can now affect insured people, too.”

Under Tier 4 systems, members typically pay between 20% and 33% of the price of the medications, which can amount to thousands of dollars per month. Tier 4 systems include hundreds of medications for a number of common diseases -- such as multiple sclerosis, rheumatoid arthritis, hemophilia, hepatitis C and some cancers -- and, because those treatments have no generic alternatives, members must “pay the price or do without,” the Times reports.

Health insurers began to implement Tier 4 systems after the start of the Medicare drug benefit, and 86% of those plans include such systems. In addition, about 10% of group health plans include Tier 4 systems today, compared with almost none in 2003, Dan Mendelson of Avalere Health said. Karen Ignagni, president of America’s Health Insurance Plans, said that private insurers began to implement Tier 4 systems for employers who wanted to reduce costs. The Times reports that insurers believe this system can keep premiums down when “innovative and promising new treatments for conditions like cancer and rheumatoid arthritis and multiple sclerosis can cost $100,000 and more a year.”

However, Tier 4 systems often require members with serious illnesses to pay more for their medications, according to James Robinson, a health economist at the University of California-Berkeley. He said, “It is very unfortunate social policy,” adding, “The more the sick person pays, the less the healthy person pays.” Mendelson said, “This is an erosion of the traditional concept of insurance,” adding, “Those beneficiaries who bear the burden of illness are also bearing the burden of cost” (Kolata, New York Times, 4/14).
GINA Passage & Lifetime Caps Legislation

Written By: Ed Burke
Factor Foundation Vice-President Legislative and Community Affairs

The Genetic Information Nondiscrimination Act (GINA Bill) S-358 has overwhelmingly passed in the Senate on April 24th by a vote of 95-0. We celebrate the passage of this Bill because it protects our medical records from being used in a discriminatory manner with respect to the health insurance industry and employment.

As we celebrate the passage of S-358 we can now focus on the Health Insurance Protection Act S-2706. It was introduced by Senator Byron Dorgan (D-ND) on March 4, 2008. This Bill is designed to increase lifetime caps to ten million dollars over the next four years with an annual adjustment included for inflation. We all need to contact our Senators and ask them to co-sponsor this Bill. We all need to collaborate with other disease states to support this Bill.

At the time of this writing there is no companion Bill in the House although we have learned that there are several House members who support a companion Bill and are waiting for a House member in a leadership role to introduce a Bill very soon.

For over a year now The Factor Foundation of America has been working on legislation to address the current lifetime caps situation. The current legislation is an example of the unfair practices the health insurance industry places on all chronic diseases. In a brief historical update, lifetime insurance caps have not been raised since 1970 and the last time the issue of raising lifetime caps had a brief legislative window was in 1996. It was introduced by Congresswoman Anna Eshoo (D-CA) in the House and By Senator Jeffords (I-VT), in the Senate. The legislation died a quick and quiet death. Now, twelve years later, times have drastically changed. Issues of our choice of product, our choice of provider and our choice of physician are being dictated to us by the health insurance industry, the growing numbers of PBM’s and by the very HTC’s designed to treat us who are now providing factor in order to keep their doors open. The community of bleeding disorders along with many other chronic diseases have often desired to work regardless of the complications of our chronic disease. Sadly the health insurance industry is making it almost impossible for us to continue our dreams by forcing us into government care.

continued on page 22
GINA Passage & Lifetime Caps Legislation Continued

following the maxing out of our insurance cap and finding no other opportunities for employment with health insurance. We all have a constitutional right to life, liberty, and the pursuit of happiness. Those with chronic diseases are being denied the pursuit of happiness by the health insurance industry.

On Wednesday, November 28th 2007, The Factor Foundation of America submitted a proposal to the Subcommittee on Income Security and Family Support, which is chaired by James McDermott (D-WA) under the Ways and Means Committee. In the proposal, The Factor Foundation of America outlined the reasons to eliminate lifetime caps. We presented the studies gathered by PricewaterhouseCoopers that show a 1.3 Billion dollars annual savings by eliminating lifetime caps. This study was confirmed by the American Association of Actuaries. While we wait for the Subcommittee on Income Security and Family Support to move with our proposal, I traveled to DC to gather support for our proposal while learning what hurdles would be present to this legislation.

During the same time that The Factor Foundation of America was moving forward with their proposal, the Hemophilia Foundation of Minnesota and Dakotas had been pressing Senator Byron Dorgan, (D-ND) on the same issue. On Tuesday March 4, 2008, Senator Dorgan introduced S-2706, a Bill to raise lifetime caps to ten million dollars in four years, with an annual adjustment for inflation. We would like to offer a sincere thank you to Ms. Brenda Neubauer, and Mr. James Paiste, of the Hemophilia Foundation of Minnesota and Dakotas for their unrelenting advocacy work with Senator Dorgan.

Now that we have a Bill in the Senate it is time to concentrate our efforts on the House. I spent three days in DC, March 5-7, 2008 meeting with friends of the bleeding disorder community in Congress along with volunteers who participated in the NHF’s Washington Days. We have since then received an email from Congressman James Langevin, (D-RI) in support of a companion Bill in the House to the Senate Bill. We currently have several House members very interested in a House Companion Bill. Some of those individuals are, Rep. Jason Altmire, (D-PA), Rep. Robert Andrews, (D-NJ), and Rep. Betty S. Sutton, (D-OH). We are hopeful that Rep. Anna Eshoo, (D-CA) will introduce a new companion Bill in the House soon. We would also like to reach out across party lines because as you can see, all of the House members are Democrats. We all need to reach out to our Republican friends for true Bi-Partisan support on a companion Bill.

“*In youth we learn; in age we understand*”

—Marie Ebner-Eschenbach

You are invited to participate in our Mens Panel Discussion.

Share experiences, insights and concerns about living with hemophilia.

Each meeting will cover topics of interest to men in the hemophilia / bleeding disorder community.

Your peers offer years of problem solving, positive feedback and personal support.

If you have hemophilia, or are the father of a son with hemophilia, please contact Ed or Jeff at

(888) 571-3100
jharper@medprorx.com

for dates, locations and times around North Carolina.

Our goal is to help men:
- Share valuable life lessons.
- Provide insights, solutions & direction.
- Offer valuable employment, education and benefit experience ...and much more!
The Hemophilia of North Carolina organization gratefully accepts donations in support of its programs and services. Your dollars directly impact the bleeding disorder community by providing education to parents, scholarship opportunities and financial assistance for families in crisis.

For new members, please complete the following application form.

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

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

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

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 currently an active member – information update

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

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Opportunities for Programs & Participation:

Please tell us if you or a family member would be interested in assisting with any of the following programs or opportunities that are taking place in 2008:

Call for more details and volunteer opportunities at (800) 990-5557

- Tennis Tournament (September 20)
- Hemophilia Walk (October 18)
- Casino Night (January 23, 2009)
- 2009 HNC Annual Meeting
- 5th Annual HNC Charity Golf Tournament (2009)
- Regional Meeting Coordinators
- Women’s Task Force

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

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