NC Hemophilia Walk 2012 is Just Around the Corner!

It is time to lace up your walking shoes and get ready for 5th Annual NC Hemophilia Walk! The Walk will be held on Saturday, October 20th, 2012, at Lake Crabtree County Park in Morrisville. Check-in begins at 9:00 a.m. and the Walk kicks off at 10:00 a.m.

As of September 24th, we have raised more than $67,000 toward our goal of $80,000. We are getting very close to reaching this goal and we believe it will be surpassed with your help. We would like to thank all of our current sponsors and team captains.

Family Retreat Yields Plenty of “Fun in the Sun”

Over the Labor Day weekend more than 100 adults and children descended on the Trinity Center at Pine Knoll Shores intent on having “Fun In the Sun” at Hemophilia of North Carolina’s 2012 Family Retreat. By all accounts, they succeeded.

HNC Executive Director Tom Bennett greeted them with “We want you to go home with sand in your shoes, useful information in your head, and warm memories in your heart.”

The warm memories portion started Saturday night with a Kick-Off Carnival featuring face painting, balloon toys, cotton candy, popcorn and snow cones. A fun assortment of games included ring tossing, a “duck pond” and – best of all – a cupcake eating contest for all ages. The contestants stretched their stomachs and provoked gales of laughter as they raced the clock to stuff down the most sugary treats.
Contact Numbers

Hemophilia of North Carolina
(800) 990-5557

Executive Director, Tom Bennett
(919) 319-0014

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

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

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

About This Publication

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

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

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

Hemophilia Treatment Centers

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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
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

Resource Information

American Pain Foundation (APF)
1-888-615-PAIN (7246)
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
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www.inalex.com

HIV/HCV Newsletter
Hemophilia Association of the Capital Area
www.hacacares.org

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1-978-352-7657
www.kelleycom.com

Patient Notification System
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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

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.

VISION STATEMENT
Hemophilia of 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

The Certainty of Uncertainty

Which candidates and party will win the November elections? Will the next Congress uphold the Affordable Care Act or move to dismantle it? Will our new General Assembly vote to extend Medicaid benefits to those earning 138 percent of the Federal Poverty Level? Any number of political commentators may offer answers to those questions, but even the smartest of them is just guessing.

Regardless of what happens with the November elections, one thing is certain: Hemophilia of North Carolina (HNC) will take an active role in the effort to shape public policies that help members of the bleeding disorders community obtain care that is affordable, accessible and competent. Our Advocacy Committee is keeping a sharp eye on the planning for the proposed Health Benefit Exchange that will offer coverage for those who do not have private or employer-provided insurance and are not eligible for Medicaid. Public officials and their advisors are pondering questions such as who will oversee the Exchange, what health policies will be offered and how benefits will be defined. HNC will monitor these processes as closely as possible and serve as a voice for the bleeding disorders community.

Speaking of Medicaid, HNC has made the expansion of the Medicaid program its top legislative priority for the upcoming year. Extending coverage to those whose incomes are 138 percent of the Federal Poverty Level would bring almost 500,000 more North Carolinians into the program and be a great help to the bleeding disorders community. Planning for a Legislative Day – probably in February – is already underway, and HNC is seeking alliances with other patient advocacy groups who support the expansion for the same reason that we do. It is our objective to see that this vital help goes to as many people as possible. Please be on the lookout for new announcements about our Legislative Day and the ways you can help.

Support NC Hemophilia Walk 2012!

Our biggest fundraiser of the year, the NC Hemophilia Walk, is scheduled for Saturday, October 20, at Lake Crabtree County Park in Morrisville. This year’s goals are $80,000 and 1,000 walkers. As of this writing, more than $67,000 has been pledged. Form a team and do a fundraiser to help the cause and rally your teammates. If you don’t have a team, you are welcome to join mine, the Whodunits. Go to our Walk website www.hemophilia-nc.org/NHFWalk/2012/index.html to get more information, form a walk team, join a team or make a donation. You efforts can change someone’s life for the better.

Family Retreat 2012

The HNC 2012 Family Retreat drew more than a hundred adults and children to the Trinity Center at Pine Knoll Shores for a Labor Day Weekend packed with fun, fellowship and good information. A Carnival Night celebration complete with games, face painting, popcorn, cotton candy and snow cones brought smiles to the faces of adults as well as children. Many thanks to the attendees, volunteers and HNC team members – as well as to a distinguished list of corporate sponsors who are recognized elsewhere in this edition of The Concentrate. I got a personal treat

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**Walgreens Infusion Services**

Continued on page 4
From the Executive Director  

when I learned that the children in the Kids Program had made sun visors and posters welcoming me to HNC. My favorite poster was decorated with palm trees, jungle animals and a message that read: “Welcome Tom! You’re gonna have a wild time!” Thanks kids! Those sentiments are very sweet and oh so true!

Car Donation Program

If you hear a message on the radio urging you to donate your unneeded car, truck, boat, motorcycle or RV to charity – the charity isn’t HNC – but hold that thought! We don’t have any radio or TV announcements, but HNC now has its own car donation program. Simply go to the HNC web site www.hemophilia-nc.org, click on the link for “Donate Your Car” in the upper right-hand corner of your screen, and follow a few simple instructions, and you can help the bleeding disorders community and gain a break on your taxes – all at the same time!

A Closing Thought

One often hears references to the “bleeding disorders community.” I’ve used the term earlier in this report. The term is appropriate because many of those with bleeding disorders, and many of those who love them, feel a sense of kinship and common purpose. Well, every community needs a community center, and I submit that Hemophilia of North Carolina serves as your community center.

As for me, it’s an honor to be your Executive Director, and I’ll see you at the Hemophilia Walk on October 20.

Warmest regards, Tom Bennett

Biotherapies for Life™

We know that people with bleeding disorders face unique challenges in getting diagnoses, raising awareness, securing access to care, and finding the information and support they need. That’s why CSL Behring is dedicated to partnering with patients, research scientists, advocacy groups, healthcare professionals and government to improve the quality of life for individuals who need our therapies.
for helping us raise funds to benefit the bleeding disorders community.

This year the NC Hemophilia Walk will feature entertainment from Jecoreiography, a Slap Shot booth including a chance to win a signed hockey stick from the Carolina Hurricanes, the very popular photo booth, as well as lunch from Jason’s Deli. We will also be having a COSTUME CONTEST for children up to 17 years of age. We encourage all family members to dress up, but we will only be judging the children’s costumes. We are eager to see how creative our Walkers can get this year!

If you want to enjoy a morning of great fun and to make a positive difference in many people’s lives, then join us at the NC Hemophilia Walk 2012 on October 20th. To sign-up in advance, please visit www.hemophilia.org/walk.

The photographs on the front page show just a few of our exciting teams. We encourage you to visit their team pages along with all the others that are registered at www.hemophilia.org/walk.

We hope to see you see there!
Family Retreat Yields Plenty of “Fun in the Sun”  

On Sunday, a raffle ticket and a bit of luck sent some families home with beach toys and portable BBQ grills. One fortunate soul landed an MP3 player. That evening, a talent contest attracted an impressive roster of singers and musicians plus one comedian and a young man with an amazing facility for gospel rap.

The useful information portion included an array of speakers who displayed both expertise and empathy with their listeners.

◆ Lisa Greene, BS, CCP, spoke on “Communicating Effectively With Your Children” and used her own experience as the parent of two children with cystic fibrosis as a basis for her advice on the special challenges that face the parents of children with a chronic illness. She focused closely on proactive techniques that parents can use to deal with disciplinary problems. CSL Behring sponsored Ms. Greene’s presentation.

◆ Daysi Fardales, MSN, ARNP-C, a nurse-educator specialist, discussed steps for “Encouraging Early Independence” in children and adolescents. Perhaps the most inspiring story was that of a young teen who – though he’d never self-infused – found the courage to do so when his mother wasn’t available and the aunt who was minding him did not know how to help him cope with a bleed. Ms. Fardales was sponsored by Pfizer.

◆ Tiffany Holland, an HNC Board member and the mother of a four-year-old boy with hemophilia and von Willebrand disease, facilitated a “real world” sharing session called “Let’s Chat.” Ms. Holland spoke of how she felt and what she did when she first learned that her son has not one, but two chronic illnesses.

◆ Michael Trombley, MD, showed great candor in saying that many MD’s know relatively little about bleeding disorders. He offered tips and techniques for educating a physician without provoking a confrontation. He enlivened his talk with some of the magic tricks he uses to help put children at ease when they come in for a consultation.

◆ Lois Geer, MBA, BSN, RN, presented “Living Well With Inhibitors: A Guide for a Healthy Life.” Working a packed room, she facilitated a lively question and answer session with participants and distributed a handy resource guide on inhibitors. Her presentation was sponsored by Novo Nordisk.

◆ One thin partition away from Lois, Gina Raymond-Duncan, Manager for Coagulation Products for CSL Behring, led an equally energetic and informative program on von Willebrand disease. Her description of how clotting and clotting factors work was a masterpiece of straightforward teaching that offered something for everyone from von Willebrand novices to veterans.

The “sand in your shoes” portion of the retreat included a beach picnic for everyone, free time on the shore, and a treasure hunt for the children. Speaking of the children, the Kids Track also featured crafts and a visit from a small, docile – but live – alligator that arrived in the custody of interpreters from the nearby North Carolina Aquarium. Ted-E-Bear Hospital, facilitated by Judy Igelman and Tatyana Shchetinina, put a cuddly stuffed friend in every child’s arms.

None of this would have been possible without the generous support of the following “Admiral of the Fleet” sponsors: Novo Nordisk and Pfizer – Hemophilia, and “Commander” sponsors: Baxter, Biogen Idec – Hemophilia, CSL Behring, CVS Caremark, Drugco Health, HPC – Hemophilia Preferred Care and Walgreens Hemophilia Service.

All of the HNC staff and a dedicated cadre of volunteers worked in some capacity on the Family Retreat. For example, Tiffany Holland and Nicole Bailey baked and frosted several hundred cupcakes. Special mention should be made of the planning, organizing and other “heavy lifting” done by Charlene Cowell, HNC’s new Operations & Member Services Manager.
Save December 1st for the HNC Annual Holiday Celebration!

Save the afternoon of Saturday, December 1st, because that’s the date for the HNC Annual Holiday Celebration, an event that is cherished by youngsters and adults alike.

The festivities will be held from 2:30 p.m. to 5:30 p.m. at the Hilton Charlotte University Place, which is located at 8629 J.M. Keynes Drive in Charlotte. Don’t be surprised if the event features fun, games, gifts for the children, delicious food and—perhaps—a visit from a certain benevolent old gentleman whose initials are S.C. and who is known to be a world-class reindeer pilot.

Registration information and other details will be dispatched to everyone later in the season, but for now, the important thing is to save the date!
SOAR Retreat Blends Work and Fun in Blowing Rock

Almost 30 women gathered at the Chetola Resort in Blowing Rock for the annual SOAR (Support, Outreach, Advocacy, Resources) Retreat. Attendees voiced praise for the meeting and buckled down to the task of planning a program for the upcoming year. The members of SOAR continue to make a huge difference in the lives of women with bleeding disorders, and they are fired-up for the next year. In addition to planning, the retreat featured communication and leadership sessions, as well as an art therapy session led by Sherri Redfield. New HNC Executive Director Tom Bennett and his wife Carol attended the Saturday luncheon where they chatted with the SOAR members and voiced strong support for SOAR.

In the course of the retreat, Crystal Hoernlein accepted a new role as Program Director for SOAR. Best of luck and many thanks to Crystal for taking on this big job! Thanks also to Gina Raymond-Duncan and CSL Behring for sponsoring and planning such a wonderful event.

A new SOAR video is in the final stages of completion. It can be viewed by searching NC SOAR on YouTube. Sharing the video with the bleeding disorders community is the first step in a plan to use it to educate people all across the country. Be on the lookout for it on the HNC website. The video has already generated a warm response from those who have seen it, and it is anticipated that the video will generate additional positive feedback. It is a moving and professional film crafted by videographer Susan Barco. We owe a debt of gratitude to Susan and to the stars of the video: Crystal Hoernlein and her family, Erica and Jaden Cook and their family, as well as Claire and Sherri Redfield. This video project has been funded by the PACT grant.

Because SOAR is SOARing to new heights, attendees painted hot air balloons to loft them into the next year. Here they display their creations from the art therapy session.

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Teens “Join Up and Climb High”  By Sue Martin, Hemophilia of South Carolina (reprinted with permission)

When the large charter buses pulled into YMCA Blue Ridge Assembly in Black Mountain, NC, July 21, 27 teens, ages 13-18, and their junior counselors, chaperones, volunteers and staff from across the states of North and South Carolina were eager to get started on a three-day adventure of fun and lasting memories.

The internationally recognized facilitator Pat “Big Dog” Torrey, with his adventurous spirit and Leading Edge Program whose Motto of “More a-ha! Less Kum-bay-ya,” was awaiting their arrival. Staff and volunteers from Hemophilia of South Carolina, The South Carolina Hemophilia Treatment Center and Hemophilia of North Carolina, which hosted the event, were equally excited to get started. From the coastlines of the two states to the mountains, teens associated with bleeding disorders and their friends made lasting memories and received lifelong lessons with impacts that will reach far into their futures.

The cabin style sleeping arrangements and Odyssey Challenge Course Adventure provided the teens ample time to connect with those who have a unique similarity. From s’mores and campfires to group physical activities and educational lessons, the teens learned about overcoming fear, growing their confidence, reaching outside their comfort zones and the positive growth and learning that come from failure, attitude adjustments and so much more. The Odyssey Challenge Course provided lessons in trust, positive group encouragement and challenging oneself beyond our comfort zones, all at 60 feet above the ground. Free time included the pool, craft store, the beautiful mountain venue and of course the basketball gym for the dichard athletes.

On Monday morning, the retreat concluded with the session, “On your Own.” The interactive teamwork competitions and role-playing educational activities were facilitated by Jennifer Meldau, MSRN, CPNP our nurse on call for the weekend from the SC Hemophilia Treatment Center at Richland Palmetto Health, and Stacy Dunleavy, MSW. A game of Jeopardy with factor facts, first aid, sports and growing up as categories and role-playing with jobs and school scenarios brought the retreat to a close. Gathering up bags and exchanging numbers for some, the teens were definitely worn out for the ride back home, enlightened, strengthened and full of confidence to meet the challenges that may come their way.

“The retreat was awesome! It was good to get out and have fun and thanks to “Big Dog,” I had an awesome time,” said Bradley Odac. “I liked everything about the trip from the ropes course to the group activities,” said Dentavis Mc Fadden.

The retreat could not have been this successful without the great collaboration of the two Chapters and we all wish to thank everyone for their dedication: Hemophilia of South Carolina, Hemophilia of North Carolina, the South Carolina HTC staff and the wonderful hard work of Charlene Cowell, the NC Teen Retreat Coordinator. We also would like to acknowledge the following planning committee members: Charlene Cowell, Tom Bennett, Kathy Register, Sue Martin, Stacy Dunleavy, and Jennifer Meldau and our volunteers, Ric Martin, Ian Ayal, Matt Bordelon, Charles Cowell, Geoff Register and Spencer Brill.

Hemophilia of North Carolina gratefully acknowledges the support from the following sponsors for the 2012 Teen Retreat:

**NC Transportation Sponsor**

**Food & Beverage Sponsor**

**Activities Sponsor**

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**Hemophilia of North Carolina**

By Sue Martin, Hemophilia of South Carolina (reprinted with permission)
NC Hemophilia Walk 2012 Kickoff Event Draws Big Crowd

On August 11th more than 115 enthusiastic people, including representatives of 16 teams, gathered at the North Carolina Zoo in Asheboro for the NC Hemophilia Walk 2012 Kickoff. Attendees enjoyed plenty of food and fun while picking up effective fundraising tips.

The children worked on zoo-themed crafts and attended a presentation by two North Carolina Zoo employees that included live animals and animal artifacts. While the children were learning how strong an elk must be to carry two massive antlers on its head, the team leaders were busy learning how to raise funds using social media and other outlets. After lunch and learning, the families spent the afternoon touring the zoo.

Crystal Hoernlein, Chair for the 2012 Walk, explained how she was able to raise so much money for the Walk last year. She is leading by example and holding an even bigger event this September. Brey Curtis and Robb Balch were in attendance to represent Baxter, the National Presenting Sponsor. In addition to Brey, Tracey Sloop, who represents Grifols, the Local Presenting Sponsor, shared some motivational words with the crowd.

Team M.L.D. led by Ashley Davis and her family won the Kickoff Grand Prize of an iPod. Team M.L.D. had raised $2,200.00 by August 11th. We hope their example will encourage other teams to increase their efforts!

“Thank you” to all who attended and those who have already signed up for the Walk. We are looking forward to seeing you on October 20th!

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HOPE for Families is Growing

The HOPE (Help, Opportunities, Partnership and Empowerment) Program, originally created for the newly diagnosed or families new to the area, is expanding to include an even greater portion of our membership. HOPE is now open for all families who have a child with a bleeding disorder under the age of 12.

This program will offer peer-led support programs as well as provide an opportunity to share your stories and struggles with others who will understand. This program will also help you get acquainted with the bleeding disorders community. If you have any questions about the HOPE Program or would like some additional information, please contact the HNC office at info@hemophilia-nc.org or call 1-800-990-5557.

Donate Your Vehicle to HNC!

Got a car, truck, boat, motorcycle or RV that you no longer need? You can donate that vehicle to Hemophilia of North Carolina, help the bleeding disorders community and get a tax deduction too! Simply go to the HNC web site www.hemophilia-nc.org, click on the link for “Donate Your Car” in the upper right-hand corner of your screen, and follow a few simple instructions. The vehicle does not have to be in running condition.
Unión Latina de Hemofilia

Segundo Retiro de Familias Latinas

El Grupo de la Unión Latina de Hemofilia se despidió del verano ofreciendo el segundo Retiro de Familias, en donde además de celebrar el mes de la Herencia Hispánica, las familias tuvieron la oportunidad de aprender mas acerca de los desordenes sanguíneos y su tratamiento. Las actividades dieron inicio con las afectuosas y sinceras palabras de bienvenida por parte de Tom Bennett, Director Ejecutivo de HNC. Tom, además de reiterar el compromiso por parte de HNC hacia las familias Latinas afectadas por algún desorden sanguíneo, nos compartió uno de sus motivos por los cuales siente una especial simpatía por la comunidad Latina. El primer programa educativo fue acerca de la importancia que el cuidado dental tiene para las personas con algún desorden sanguíneo como parte fundamental para llevar una vida saludable. La tarde continuó con la interesante presentación acerca de la importancia de estar informados con todo lo relacionado al desorden sanguíneo que nos afecta, como estrategia para detectar sangrados y elegir el mejor tratamiento disponible para cada persona y ocasión. Después de la deliciosa cena mexicana, los participantes participaron en una actividad que les mostró la importancia de la construcción de redes de apoyo, para mantener el control y prevenir crisis familiares que puedan presentarse al vivir con desordenes sanguíneos.

Además de agradecer de nuevo a HNC por darnos la oportunidad de participar en el segundo Retiro Familiar, nuestro mas sincero agradecimiento a Rita Brown por la coordinación del Retiro y, como siempre, a Baxter por su patrocinio.

The Latin Union Group said goodbye to the summer offering its Second Family Retreat where, besides the celebration of the Hispanic Heritage Month, families had the opportunity of learning a little bit more about bleeding disorders and how to treat them. The activities began with a warming and sincere welcome message from HNC Executive Director, Tom Bennett. He reiterated the HNC commitment with the Latino community affected with bleeding disorders in terms of educational programs and support services. With his heart-touching words, Tom shared with the participants one of his personal reasons for the special sympathy he feels towards the Latino community.

The first educational program was about the importance of the dental health for people living with bleeding disorders as a fundamental part of a healthy lifestyle. The evening continued with an interesting lecture about how important is to be informed in regard to the bleeding disorder that specifically is affecting you, as a strategy for the early recognition of bleedings and the importance of choosing the right treatment for each person and type of bleeding. After having a delicious Mexican style dinner, the families participated in an activity which demonstrated the importance of building supporting networks, as a way to reach and maintain control in their life and prevent personal and family crisis. Once again The Latin Union Group would like to thank HNC for offering us the opportunity of having the Latino Family Retreat. Our special thanks to Rita Brown for coordinating and make this event possible. And, as usual, thanks to Baxter for being our sponsor.
Para nuevos lectores y miembros

**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 alcancen el desarrollo total de sus capacidades, sin barreras o limitaciones, hasta que se encuentre una cura.

---

Aviso: El siguiente es un artículo con fines educativos y de información, antes de tomar cualquier decisión de tratamiento consulte con su médico del Centro de Atención a la Hemofilia (HTC, por sus siglas en inglés)

¿Qué es la **Profilaxis** en la Hemofilia?
Se define como profilaxis al tratamiento inyectable intravenoso de concentrado de factor en forma regular, 2 ó 3 veces por semana con el objetivo de mantener los niveles de factor (FVIII y FIX) por encima de 1 UL y así prevenir los sangrados. Existen dos tipos generales de profilaxis: La primaria que consiste en impedir el daño en las articulaciones; y la secundaria cuyo objetivo es detener o minimizar este daño. Existen varios esquemas y dosis a utilizar según los distintos grupos de estudio internacionales y dependiendo del criterio y experiencia del Centro de Atención a la Hemofilia a donde se acude.

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Los estudios demuestran que la profilaxis mejora la calidad de vida de las personas, por su tendencia a reducir hemorragias graves, y por su capacidad de detener – e incluso revertir un poco- el daño en las articulaciones.

**Si estas interesado en saber mas acerca de la profilaxis y de saber si es un tratamiento adecuado y de beneficio para ti o tu hijo, recuerda preguntárselo a tu hematólogo la próxima vez que visites tu Centro de Atención a la Hemofilia.**

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**Consejo Rápido**

Cuando se vive con algún desorden sanguíneo los gastos médicos pueden ser una carga muy grande para las familias. Incluso con un buen seguro médico los pagos del co-payment, medicamento y visitas al medico pueden afectar la economía del hogar.

Te recomendamos que pidas hablar con un **consejero del departamento de finanzas de la institución medica a la que asistes** (Financial Counselor, ellos pueden ayudarte a seguir planes de pago, descuentos y otro tipos de ayuda financiera.

Lo importante es que no dejes de asistir al medico cada que lo necesites, y asistas puntual a tus citas para revisión medica e rutina.

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**Walk**

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We would like to acknowledge the following individuals who generously donated to HNC during this past quarter of 2012. We extend a sincere thank you to our supporters, many of who contributed several times during this period.

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- BioRx, LLC
Battle Hymn (of the hemophiliac)  
By Dale Michael Brisson - 1994

Mostly, I remember the screams  
Twelve years old, lying  
in the inner-city Miami  
emergency room.

Cursing my pumpkin knee  
waiting, waiting, waiting  
for the drip drip drip  
of plasma relief.  
Twisting in a pool  
of personal agony and shame.

Then, they wheeled her in  
young, black and dying.  
Screaming the screams of death  
shriek piercing painful screams.  
Screaming, writhing, screaming  
As the clorox she swallowed  
Burned from the inside out.

The walls could feel her pain  
the world could hear her screams  
straight from the bowels of hell  
torturous agonizing demonic screams.  
Wrenching my gut, beating my brain.  
The doctors pulled the curtain and chain  
as if that could shield me  
from the terror just two feet away.

I tried to cover my ears  
I tried to pray it away.  
But the screams were too near  
and relief was so far.  
Her insides burned, her body writhed.  
She screamed louder and louder  
until, with one last gasp  
her torture was replaced  
by a cold, deafening silence.

I lay, twelve, going on fifty  
two feet from death  
and over the years...  
I've heard the screams in my ears.  
Mostly, when I least want to hear.

My blood brothers and I  
have fought a lonely battle.  
Soldiers of the emergency room circuit  
fighting the trenches of ignorance.  
The names, faces and places are different  
but our stories are all the same.  
We shared the stainless steel needles  
and drips that honed our spirits.  
We are veterans of a war not asked for,  
a battle undeclared.  
Some soldiers get medals, bands and parades.  
We get crutches, canes and AIDS.  
When we were boys  
we used to enjoy  
beautiful dreams of running.

Running, running, running  
with the wind in our face.  
Running, running, running  
fluid and grace.  
But they were just dreams  
of the boys we never were  
and the men we had to be.

Once, we thought the battle was over.  
We were deceived by the ease of newfound freedom,  
when trips to the hospital  
became a few steps to the refrigerator.  
The new miracle fix-it bottle  
taking the place of the lengthy  
drip drip drip  
of plasma and pain.

But we were ambushed  
snipers hid behind syringes  
aiming poison at our veins.  
My comrades fell to the left and right.  
The infectious screams were all around.  
Yet, when the smoke cleared...  
somewhere, somewhere, I was spared.

My blood brothers, my comrades, my compadres  
more important than how you died  
was how you lived.  
Warm smiles masking the pain  
raucous laughter in gentle rain.

I used to march in the back  
with my head held low  
wanting no one to see  
no one to know.  
Now I have the courage  
to yank back the curtain  
and outshout the screams  
and I see my brothers  
blood brothers running in my dreams.  
Running, running, running  
with the wind in their face.  
Running, running, running  
fluid and grace  
Running in that distant painless place.

The boys that never were  
and the men they had to be.  
I have grown so much from their strength.  
Now, my orders are clear.  
I will lead the charge  
without shame, without fear.  
Bearing the colors, the fabric of pride.  
Wearing my bent and battered body  
like a medal of honor.  
Limping  
with the wind in my face.

Special thanks to Dale Michael Brisson, a long-time member and supporter of HNC, for putting into words what others have felt for so long.
**Madman or Guinea Pig?**

**Gene Therapy vs. Long-Lasting Factor**  
*By Laurie Kelley*

“Are you a madman or a guinea pig?” asked a man from France at the final symposium of the World Federation of Hemophilia Congress in Paris, France, last Thursday. He addressed his question before the 500 or more attendees in the huge amphitheatre at the Palais de Congres to our own George McCoy, from North Carolina, one of the fascinating speakers on the panel debating and comparing long-lasting factor to gene therapy.

Great question, particularly as George had just revealed that he was the very first human ever to be injected with recombinant factor VIII, back in March 1987. That was the year my son Tommy was born; I was riveted to George and his reply. The whole audience was. But more on that in a bit!

The session opened with Dr. Paul Giangrande, director of Oxford Haemophilia Centre in England and world-renowned hematologist, purposely supporting continued recombinant therapy, and listing the many pros of our current treatment. Paul reminded us of the Hippocratic oath Primum non nocere: First, do no harm, and cited the long and many years of improved quality of life and quantity of life on these therapies.

(Dr. Giangrande also prefaced his presentation with an outrageously humorous skit on how he gets roped into presenting so many talks at symposia, all seemingly taking contrary positions! He feels it is his duty to provide food for thought on the pros and cons of all treatment; here, he was asked directly by WFH to make the case for recombinant therapy)

Long-lasting factor, Dr. Giangrande said, which many manufacturers are working on, is based on recombinant technology, a stable and known technology, which is considered safe. It provides breadth of product for factor VIII, IX, and inhibitor patients. WFH president Mark Skinner even said earlier at the Congress that treatment should aim for a trough level of 15% – which recombinants can provide. Giangrande added that we know the manufacturers already so we know in essence from where the product comes and what we are getting.

Giangrande then cited some of the downside of what we know and can expect from current gene therapy, still in clinical trials: more hospital visits and blood tests. He asked if patients truly were giving informed consent – Most parents
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Gene Therapy vs. Long-Lasting Factor  continued

Lillicrap of Canada. High gave a positive and detailed summary of currently gene therapy – very exciting presentation!

So back to George McCoy, who then spoke, eloquently, sincerely and humbly. He described his childhood, and how he was diagnosed at age two. One of four boys, his eldest brother Richard had hemophilia for years and no one knew. Sadly, he died. George’s speech was moving and thoughtful, especially when he cited WFH founder Frank Schnabel, who described patients with hemophilia as “tortured pieces of human geography confined to a wheelchair.”

Dr. Gil White contacted him about being the first rFVIII patient ever in March 1987, and hence the question: is he a madman or a guinea pig? George simply replied that he would do it all again if he had to – he would volunteer for gene therapy if – or when – the time comes. And he stressed that we need volunteers for gene therapy now.

He closed with the beautiful thought: “What brings us here is the will to live, the will to prosper, the will to learn. We all do need each other.” And while all the speakers weighed in on whether they would elect gene therapy over long-lasting factor for their hypothetical grandchildren with hemophilia, were they to have one, it was Dr. High who made a memorable statement: we need access to all therapies, both gene therapy and long-acting, for individual patients with individual biological make-ups, for those in developing countries – access to all products and treatments for us all. George was right: we all do need each other, and this past week at WFH reminded us all that 300,000 have little or no access to hemophilia treatment. The burden – to me the joy – is on us to help them all.

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Why North Carolina Should Expand Medicaid Under the Affordable Care Act

1. AFFORDABLE CARE ACT EXPANDS COVERAGE TO MIDDLE CLASS: Under the Affordable Care Act, NC will expand coverage to most of the 1.5 million people without health insurance in our state. For middle-income families - making up to $88,000 a year for a family of four - reform provides subsidies to help pay insurance premiums and caps out-of-pocket expenses.

2. AFFORDABLE CARE ACT MEANS NC GENERAL ASSEMBLY WILL HAVE TO DECIDE TO EXPAND MEDICAID: After the Supreme Court decision on the Affordable Care Act the NC General Assembly will have to decide whether to expand coverage to those of more meager means – about $15,000 in earnings per year for an individual under NC’s Medicaid program.

3. RIGHT NOW, HUNDREDS OF THOUSANDS OF POOR PEOPLE DO NOT QUALIFY FOR MEDICAID: Under the current NC Medicaid program if a person between the ages of 18 and 64 does not have a serious disability or is not the parent of young children they cannot qualify for Medicaid coverage regardless of how poor they are. Under the Affordable Care Act NC can now choose to expand Medicaid to our lowest-income citizens.

Continued on page 21
4. THOUSANDS OF LOWEST INCOME PEOPLE AFFECTED: About 500,000 low-income citizens—many in the poorest and most rural parts of our state—will have their ability to get affordable health coverage hinge on NC’s decision to expand Medicaid. Many of these newly insured people have at least one member of their family working full-time, often at a small business that can’t afford to offer insurance.

5. THE FEDERAL GOVERNMENT WILL PAY 93% OF DIRECT COSTS OF EXPANSION—BETWEEN $15 and $20 BILLION OVER FIRST SIX YEARS: Over the next six years to expand Medicaid to the poorest people in NC, the federal government will pump billions of dollars into NC’s economy—money that goes directly to doctors, hospitals and other health care providers, especially in the lowest income and most rural parts of our state. For the first three calendar years the federal government will cover 100 percent of the expansion costs.

6. BECAUSE STATE AND LOCAL GOVERNMENTS ALREADY PROVIDE HUNDREDS OF MILLIONS OF DOLLARS IN CARE FOR THE UNINSURED, NC WILL SAVE MONEY BY EXPANDING MEDICAID: While NC’s share of the Medicaid expansion will be about $830 million over the first six years, state and local governments already spend billions helping hospitals, community health clinics and other providers take care of people who don’t have health insurance now. With the Medicaid expansion the vast majority of people will be able to pay their medical bills and state and local governments will save millions.

7. MEDICAID EXPANSION NEEDED TO SAVE RURAL HOSPITALS: In many rural areas of our state,

Continued on page 22
hospitals provide free care to patients who can’t afford hefty medical bills. Because health reform legislation depends on new patients possessing Medicaid cards, the law phases out millions in federal funds to help support hospitals that provide large amounts of free care. Many hospitals will also see reduced reimbursements for Medicare as lawmakers try to rein in spending. North Carolina hospitals can weather these changes with an influx of newly insured Medicaid patients. But if Medicaid is not expanded, several hospitals may close their doors, resulting in a dramatic decrease in the availability of quality care in rural communities.

8. THE STATE CAN USE FEDERAL DOLLARS TO FUND ONGOING EFFORTS: By expanding Medicaid the state can attract federal funds to help meet its goal of providing more care to low-income seniors and disabled adults in their homes and communities.

9. BY REFUSING TO EXPAND THE STATE MAY SUFFER NEGATIVE CONSEQUENCES: While the Supreme Court said that the federal government may not revoke all of a state’s Medicaid funding for refusing to expand the program, the Centers for Medicare & Medicaid Services does have other enforcement mechanisms to encourage the expansion.

10. MEDICAID SAVES LIVES: Research shows that the uninsured have a 25 percent greater chance of premature death than the insured. Recent studies show that a Medicaid expansion of 500,000 enrollees is associated with 2,840 fewer deaths per year.

Source: NC Justice Center -- August 23, 2012
Membership Information

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
260 Town Hall Dr., Suite A
Morrisville, NC 27560

OR send an email to info@hemophilia-nc.org with all the information OR fill out a membership form at www.hemophilia-nc.org under “Membership”.

If you would like to make a donation, 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

☐ Currently active member - information update

Name:__________________________________________________________
Address:_____________________________________________________
City:_________________________________________________________
State:________________________ Zip:_____________________________
Home Phone:___________________________________________________
Cell Phone:____________________________________________________
Email:________________________________________________________

Check One

____ I am a person with a bleeding disorder.
Type __________ (VIII, IX, VWD, etc.)
Inhibitor? _____Yes _____No

____ I am a family member of a person with a bleeding disorder.
Relationship __________________________________________________
Age (if child): _________
Type __________ (VIII, IX, VWD, etc.)
Inhibitor? _____Yes _____No

____ I am a medical professional.
____ I work in an industry providing products or services to persons with bleeding disorders. Company name: ____________________________
____ None of the above, but I am interested in bleeding disorders and HNC activities.
See You There!

National Hemophilia Foundation and Hemophilia of North Carolina Present

Hemophilia Walk '12

Every step makes a difference

Saturday, October 20th
Lake Crabtree County Park

www.hemophilia-nc.org

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, a member of the NC Center for Nonprofits and a member of the Better Business Bureau.