

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2011



Come Walk with Us!

Our walk is off to a great start with over \$42,000 received in local donations and hundreds of people already signed up to walk this year! We'd like to take this opportunity to share with you why we walk and who we walk for. Although this event provides critical funds for many of the programs and services that HNC offers throughout the year, one of the most important things it does is raise awareness about the bleeding disorders community, the challenges they face and the benefits of having a support system in place when people need help or just another person to talk to. These are just some of our team members and we encourage you to visit their team pages along with all the others that are registered at www.hemophilia.org/walk. We hope you'll join us on October 15th at Lake Crabtree County Park to celebrate, remember and support the community!



Team Jacob - Vampire Bait
The Hoernlein Family



Zackary and the Factor VIII's
The Hargett Family



The Taylor JAGS's Team
The Taylor Family



M.L.D. Team
The Davis Family



The Woodge Factor
The Sebolt Family



SOAR Team
Supporting Girls & Women
with Bleeding Disorders



King Droplet's Driplets
Captain Reid Coleman

HNC Adult Retreat in Charlotte



Many of our adult members joined us for the 2011 Adult Retreat hosted in Charlotte, NC on July 30-31st. Inalex Communications returned this year and provided our workshop, *Managing Your Stress: You have the POWER!*, which helped teach reliable and effective methods for identifying life stress and reducing it. Ken Glickman, a well-known marketing professional and public speaker, presented the workshop and offered some great tips on using relaxation and tools to reduce frustrations and anxieties quickly. Our many thanks to Inalex Communications and founder, Joe Caronna, for offering these wonderful workshops to the community.

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Chapter News & Events
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Industry Information
On the National & Legislative Front

Save The Date

Women's Dinners

Durham/Raleigh Area

- October 5, 2011
- November 2, 2011

Concord/Charlotte Area

- November 3, 2011
- December 8, 2011

Winston-Salem Area

- December 5, 2011
- January 9, 2012

Latin Union Retreat

October 8-9, 2011
Charlotte

Hemophilia Walk

October 15, 2011
Morrisville, NC

NHF Annual Meeting

November 10-12, 2011
Chicago, IL

HNC Holiday Celebration

December 3, 2011
Charlotte, NC

HNC Casino Night Fundraiser

January 21, 2012
Durham, NC



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

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

Contact Numbers

Hemophilia of North Carolina
(800) 990-5557

Executive Director, Sue Cowell
(919) 319-0014

National Hemophilia Foundation Office
(800) 42-HAND1
www.hemophilia.org

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

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

About This Publication

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

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

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

Hemophilia Treatment Centers

East Carolina University Brody School of Medicine
600 Moyer Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676
Fax: (252) 744-8199

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

Wake Forest University Baptist Medical Center
The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone: (336) 716-4324
Fax: (336) 716-3010

Additional Medical Resources

Carolinas Medical Center Pediatric Hematology/Oncology
1000 Blythe Boulevard
Charlotte, NC 28203
Phone: (704) 381-6800

Duke University Medical Center Hemostasis and Thrombosis Center
DUMC Box 3422
Durham, NC 27710
Phone: (919) 684-5350
http://htc.medicine.duke.edu/

Presbyterian Blume Pediatric Hematology & Oncology Clinic
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

Resource Information

American Pain Foundation (APF)
1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
http://painaid.painfoundation.org

American Society of Pediatric Hematology/Oncology
847-275-4716
www.aspho.org

Bleeding Disorders Legal Hotline
1-800-520-6154

Centers for Disease Control & Prevention
1-800-311-3435
www.cdc.gov

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

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

Inalex Communications
201-493-1399
www.inalex.com

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

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

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

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

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

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

As I'm sure you know from our communications, HNC participates in many conferences and workshops outside of North Carolina. At these programs, we have an opportunity to share information and ideas with other Chapters and organizations including many of the programs and services we offer here in the state. As a parent of two girls I know how proud I am of their accomplishments and successes. I can't help but feel the same way about HNC when we talk about what we're doing in the community. With an army of volunteers, our small staff and a dedicated, passionate Board of Directors we've had so many milestones over the past couple of years that are just too many to mention in one paragraph. After our recent planning meeting with the board, we are continuing to pave the way in new areas and strengthen our commitment to improving the quality of life for persons affected by bleeding disorders through advocacy, education, promotion of research and supportive programs and

services. Despite all these accomplishments, there is still so much more work to be done and I'm always very encouraged by the passion, commitment and support that so many people have provided with a shared vision for everyone to achieve their full potential without barriers or limitations, until a cure is found. I hope that those of you who have helped provide so much support can share in the proud feeling of these accomplishments and successes – you are truly making a difference and we thank you!

Sincerely,
Sue
 Susan Cowell
 HNC Executive Director

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Call Shirley Moorehead at: 866-243-4621



Another HNC First: Research Study on Aging with Hemophilia

HNC initiated an Aging Research Team last year to help address the needs of our older population. Sue Fletcher, PhD, Research and Programs Coordinator of HNC, who also serves as the primary investigator and two co-investigators: Raj Kasthuri, MD, hematologist at the University of North Carolina Hemophilia Treatment Center and Cherie Rosemond, PT, PhD, GCS and Research Fellow at the University of North Carolina Institute on Aging. Sue Cowell, Executive Director and consumer representatives Terry Lamb and Sharon Ingram are also on the team.



Who can participate?

Both persons with hemophilia ages 50 and over and their partners/spouses are encouraged to participate. This includes persons living outside of North Carolina so please share this information with family and friends.

What is involved?

Participants will complete two surveys at their own convenience and in the privacy of their own home. The surveys include questions about medical issues as well as daily life activities. Some participants completing the surveys will be randomly selected to participate in a telephone interview.

What about privacy?

All information will be kept confidential and no personal information will be released to any third parties, including Bayer Healthcare Pharmaceuticals. Any information that may identify the participant (e.g., name, diagnosis, location, personal data) is omitted from all documents.

Is there any compensation?

Each participant will receive a \$50 gift card for completing the surveys. Those selected for the telephone interview will receive an additional \$50 gift card.

We encourage all eligible persons to participate and support HNC's growing research efforts. Please contact Dr. Sue Fletcher at 1-800-990-5557 (toll free) or email at sue.fletcher@hemophilia-nc.org.

Please pass this information along to anyone you may know who may want to participate.

We are proud to announce the team has received funding from Bayer Healthcare Pharmaceuticals to conduct an important research project on health related quality of life and aging with hemophilia. This is the first time a chapter has received such funding and we hope to include as many members as possible in the study.

What are we studying?

We are investigating the quality of life of persons aged 50 and over with hemophilia. The goal of the project is to understand issues impacting daily life and the relationship between age-related changes and hemophilia-related changes. This information can lead to improved patient well being and improved medical management. We will also look at the role of the spouse/partner relationship as it relates to quality of life. The study will fill an important gap in our knowledge of growing older with a bleeding disorder and will help establish a comprehensive best practice model to meet the medical, psychological and social needs of this population.

HNC Adult Retreat in Charlotte *continued*

On Saturday evening we enjoyed dinner and activities at the US National Whitewater Center where many of the participants braved the rapids for an exciting rafting trip!

On Sunday, we had a session presented by Jeff Adams of Charlotte Saves on budgeting and credit management. Charlotte Saves is a non-profit group that assists people with credit counseling, money management and other financial tips. Jeff provided some great information and practical tips on how we can all manage our money.



Hemophilia of North Carolina is grateful to the following sponsors for their ongoing support of the bleeding disorders community, and for their generous contribution, which made it possible for us to host this event at no cost to HNC member families.

We are looking forward to offering more of these retreats and would welcome your suggestions on other workshops that are offered by Inalex Communications. Feel free to visit their web site at www.inalex.com to view the topics and let us know which ones might be of interest to you.

Adult Retreat Sponsors



Hemophilia of North Carolina Welcomes Sydney & Nicole

Please join HNC in welcoming two interns again this year from NC State University who are in the Master's of Social Work program. They will be assisting with various projects ranging from planning events, grant writing, fundraising, research, evaluations and administrative duties. Sue Fletcher, PhD, Research & Special Programs Coordinator for HNC is the Field Supervisor for this program.

Meet Sydney - My name is Sydney Milligan and I am a first year MSW (Masters of Social Work) graduate student at NC State. I received my Bachelor of Science degree in Community Health Education from the University of North Carolina at Wilmington. I am also a Certified Health Education Specialist (CHES) certified by the National Credentialing of Health Education Commission.

My professional interests include medical social work and public health social work. I worked for the non-profit organization, Men's Health Network in Washington, DC before moving back home to North Carolina to attend graduate school. I was able to advocate for men's health, provided nutrition and exercise counseling as well as provide free testing for prostate cancer during my time in D.C. As an intern for the Hemophilia of North Carolina (HNC), I hope to make a much bigger impact for this community. I will be developing a program for newly diagnosed families that will provide much-needed support and resources to them. You will also see me at other HNC events such as the Hemophilia Walk,

the teen retreat and SOAR meetings. I hope to reach out to all HNC members and be of service any way I can. I've already come to be quite passionate about the work I do for the agency and I know that it will carry with me for a lifetime. Feel free to contact me at sydney.milligan@hemophilia-nc.org.

Meet Nicole - My name is Nicole Bailey and I'm excited to be interning with Hemophilia of North Carolina this year. I am currently obtaining my MSW (Masters of Social Work) at North Carolina State University and will be graduating in May 2012. I received my Bachelor of Social Work at Campbell University with a concentration in school social work in 2010. After graduation, I would like to pursue a career in medical social work. I am currently employed with Walgreens and have been for 7 years.

As an intern at HNC I will be working closely with the SOAR program. I will be developing and evaluating a support system for women and girls with bleeding disorders to make sure they are getting the support they need from the HNC community. I will also be working with Sue Cowell and Sue Fletcher to plan the Women's Dinners. I am very excited to be a part of this organization and am looking forward to a very fulfilling year at HNC. I am here to serve you, so feel free to contact me if I can help you and/or your family in anyway. My email is nicole.bailey@hemophilia-nc.org.

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The CARE program is open to all hemophilia A patients and inhibitor patients regardless of brand of therapy.

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Member Profile *Caleb Taylor*

Greensboro Student Wins Top Honors at National Theatre Festival



As a theatre major at the *Performing & Visual Arts Academy @ Weaver* in Greensboro, seventeen-year-old Caleb Taylor has managed to amass quite a resume as an actor, stage tech, and lighting designer. After taking highest honors in lighting design at the North Carolina Festival, Caleb went on to represent the state at the International Theatre Society Festival in Lincoln, Nebraska. His project of realized lighting designs for his school's production of a Lady GaGa inspired *PIPPIN* garnered much attention and earned Caleb top honors.

After winning at the state festival, Weaver was also able to showcase their one-act play entry, *TRIFLES*, at the national event. Caleb was a featured performer playing the sheriff of a small town where a mysterious murder has occurred.



In addition to competition & showcase performances, Caleb participated in college auditions with representatives from more than fifty prestigious universities from around the country. Again his lighting designs made him much sought after and earned him a record number of call-backs and scholarship offers. Caleb plans to pursue lighting design in college after graduation.



It was a fast-paced and busy week rounded out by workshops with industry professionals and main stage performances of musicals such as *The Drowsy Chaperone*, *Jekyll & Hyde*, and *Anything Goes*.

Caleb has never allowed his Hemophilia to keep him at home; he's been self-infusing for several years now and was able to continue his prophylaxis even while touring with Weaver to Scotland (summer 2010 to perform in the Edinburg Fringe Festival) and to Nebraska. For his senior project he will be directing *THE YELLOW BOAT* (a play about eight year old hemophiliac Benjamin Saar); performances are October 21 & 22 at Weaver; all proceeds will go to Hemophilia of North Carolina.

the yellow boat
 by David Saar
 directed by Caleb Taylor

October 21 & 22
 7 pm
 Weaver Academy
 300 S. Spring Street
 Greensboro, NC
 \$10 suggested donation

all proceeds to benefit  Hemophilia of North Carolina

For information and tickets contact:
 Weaver Theatre Department - (336) 370-8282 or
 Keith Taylor at taylorlk@gcsnc.com

2011 Friends of HNC

*We would like to acknowledge the following individuals who generously donated to HNC during this quarter of 2011.
We extend a sincere thank you to our supporters...many of whom contributed several times during this period.*

Donors

Richard Atwood • Lynwood Best • Mark & Jo Anne Buckley • Wayne & Morgan Cook • Sue Fletcher, PhD
H.B. & D.E. Fusik • Charlotte Harrison • Mr. & Mrs. W. Allen Heafner • The Hoernlein Family
Drew Huggins, PharmD, RPh • Hemophilia Federation of America • National Hemophilia Foundation
Charles & Kathy Register • Ryan & Maria Schnaith-Ivan • Nicholas Sanservino • Robert Tharp
Bob & Heidi Traficanti • Brent W. Weston, MD • Betty Wimberly

**Donation Made In Honor of Zackary Hargett & parents, Brandon & Tiffany Hargett
Robert & Barbara Rogers**

**Donations Made In Loving Memory of my family so affected in the early eighties –
Dale Drye (1955, age 25), Lynn Boger (1989, age 9) & Matthew Branson Speight (1997, age 22).
We will continue to fight for safe blood products for all.**

Monroe & Jean Poplin

Donations Made In Loving Memory of Tyrone Cowans – Friends of Tye

Celebrating Our 2011 Corporate Sponsors

Cash and In-Kind contributions received from July 1, 2010 – June 30, 2011. We thank our sponsors for their continued support of the community.

Diamond (\$15,000 or more)

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MedPro Rx, Inc • Novo Nordisk • Pfizer

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Accredo – Hemophilia Health Services
National Hemophilia Foundation – Grant
PACT Grant – Hemophilia Association of NJ & Baxter
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Inalex Communications • Matrix Health
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Miller Motte College • Octapharma • Pet Mania
The Preserve at Jordan Lake • Rita's Water Ice
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Apex Wings • Gatehouse Tavern/Girasole Trattoria
Georgina's Restaurant • Hemophilia First LLC
Instant Imprints • JC Penney
Kelly NC Erosion Control • Lexington Moose Lodge
NC State Athletic Department • Panera Bread
Pepsi Bottling Company • Rudy's
Tee to Green • Townsend Bertram & Co.
Toys & Co. • Twin Oaks Nursery
UNC Athletic Department • Village Jewelers

Special Contribution for Scholarships (\$8,000)

Bio Rx, LLC

Save The Date HNC Casino Night Fundraiser

Saturday, January 21st, 2012
Bay 7, Durham, NC

We're moving this year! Our new venue is located in the American Tobacco Campus in Durham near the Durham Bulls Athletic Stadium & Durham Performing Arts Center. With the new location, our hours will be extended for a great night of fun! Join us for an exciting night of good fun and fast action for a great cause. Full tickets for the evening will include dinner & music, beer & wine, auction items, great prizes plus "funny money" play chips for your to gamble the night away at blackjack, roulette, craps and poker! We'll also be offering an option this year to join us for part of the evening and your ticket will include dessert, gaming and limited drink tickets. *For information on helping to plan the event, attend or sponsorships, please contact Sue Cowell at (800) 990-5557 or info@hemophilia-nc.org.*



Our teams have been very busy recruiting walkers, hosting fundraisers and sharing information about the walk with family & friends. Congratulations to the Hargett Family on their Family Fun Night event for their team, **Zackary and the Factor VIII's**. They raised nearly \$4,000 from the event through the wonderful support of their family & friends. Team **Factor 1 in a Million** also hosted their annual Wine Tasting – 4 Wines 4 Courses – this week, which is always a terrific event that everyone looks forward to. Captain Ann Skinner and family raised over \$1,500 through ticket sales and auction items – congratulations!

Many of our other teams have events they are hosting and all of this information and more, is posted on the HNC website at www.hemophilia-nc.org. We welcome back Alina Machado from ABC 11 as our emcee again this year. We'll also have a host of activities for both the adults & children. Check out the information on our new Kids's 5-4-5 Challenge and Fun Run this year along with free team tee shirts. Miller Motte College will also be back for some great chair massages! If you have questions or need information please contact us by calling 800-990-5557 or email at info@hemophilia-nc.org. We are looking forward to another great event this year and hope to see everyone on October 15th at Lake Crabtree County Park!

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Congratulations to our NC Junior National Championship Representatives

As this newsletter goes to print, two of our members who were chosen to represent North Carolina in the Junior National Championships will be on their way. Our congratulations to Rohan Shirumalla who will be representing us in golf and Bennett Barnes who will be representing us in baseball. They will be participating in the games on September 23-25th in Dallas, Texas.



Look for Your Invitation to... *Hemophilia of North Carolina's Holiday Celebration*

Saturday, December 3rd – 2:30pm-5:30pm
Charlotte Motor Speedway – The Speedway Club



Come join us at the end of year Holiday Celebration on December 3rd. There will be food & fun for all ages as we use this opportunity to look back over the past year and get together with old and new friends as the year comes to a close. Our guest speaker for the celebration will be Dr. Paulette Bryant from Blume Pediatrics. The celebration will include a visit from Santa & his elf, buffet lunch and plenty of time to meet & greet! Our celebration will be followed by car passes to drive through the holiday light experience of Carolina Christmas at the Speedway. Look for your invitation to HNC's Holiday Celebration in the mail soon! Registration will also be available online so be sure to Save the Date and come share the holiday spirit!

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Unión Latina Hemofilia



Hemophilia Latin Union

First Annual Retreat of the Latin Union!

I think it's wonderful that HNC is able to offer its first retreat for the Latin Union program. Our group has grown so much over the past year and we've planned the event based on information we've heard from our members. It will be a terrific opportunity to offer some great educational programs and give families the chance to connect and share experiences.

Sue Cowell, HNC-Executive Director

¡Primer Retiro Anual de la Unión Latina!

Considero algo maravilloso que HNC este preparada para ofrecer su primer retiro como parte del Programa de la Unión Latina. Nuestro grupo de familias latinas a crecido significativamente en el ultimo año. El retiro se ha diseñado en baso a lo que las familias que lo integran nos han sugerido. Sera un excelente espacio apara ofrecer tanto programas de educación como la oportunidad de que se compartan experiencias y poner en contacto a las familias.

Sue Cowell, HNC-Directora Ejecutiva

El Grupo de la Unión latina esta rediseñando sus estrategias para tener más acceso a las familias que viven a lo largo del estado de Carolina del Norte. Una de estas estrategias es realizar reuniones educativas en distintas ciudades del estado, en donde personas con algún desorden sanguíneo, familiares e invitados especiales (maestros, personas cercanas a la familia, etc.) aprendan acerca de temas relacionados con cada uno de estos desordenes y tomen un rol activo en las actividades de HNC para aumentar y mejorar los servicios de apoyo y defensa de todas las personas latinas con algún desorden sanguíneo. Si estas interesado en que una de estas reuniones se realice en tu ciudad por favor llámanos o escríbenos un email... y muy pronto estarnos visitándote!

!En tu ciudad! - In your city

The Latin Union Group is redesigning its strategies to increase the outreach with the purpose to reach more Latino families living across North Carolina. One of these strategies is bringing educational meetings to different cities, where people affected with bleeding disorders, their family and special guest (teachers, people close to the family, etc) learn more about these disorders and to adopt an active roll in all the HNC activities to improve and increase the support and advocacy of the Latino community living with bleeding disorders. If you are interested that these meetings come to your city please call us or send us an email... and we will there soon!

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



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

Calendario de Reuniones -Meeting Calendar-

Sábado 8- Domingo 9
de Octubre

Retiro de Familias Latinas

y
Participación en el "Festival Latino Americano"
Charlotte, NC

Sábado 15 de Octubre
Caminata de Hemofilia

Lake Crabtree
Morrisville, NC

Meta de este año:
\$65,000.
&
1,000 participantes.

¡Ven y ayudanos a alcanzar la meta!

Para mas información llama
855-462-5286

O escríbenos un email.
union.latina@hemophilia-nc.org

“La Educación es el arma mas ponderosa que puedes utilizar para cambiar al mundo”

– Nelson Mandela



Afortunadamente la Comunidad de Desordenes Sanguíneos cuenta con diversas opciones para aplicar por becas de estudios escolares. Para ayudarte en la búsqueda de estas opciones, nuestra pagina www.hemophilia-nc.org tiene una lista de compañías y requisitos para aplicar por becas. Quizás la lista no abarque todas las opciones, por lo que te recomendamos ir también a la pagina de National Hemophilia Foundation (NHF) y Hemophilia Federation of America (HFA) para buscar opciones adicionales. Recuerda que tu consejero en High School y la oficina de asistencia financiera de tu colegio, pueden ayudarte a encontrar este tipo de becas para que continúes con tu educación.

Para nuevos lectores y miembros / For new readers and members

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

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

Unión Latina

Hemofilia de Carolina del Norte

Retiro Anual de la Unión Latina

8-9 de octubre 2011
Charlotte, NC



Reúnete con otras familias y aprende de la comunidad de desordenes sanguíneos para aprender más acerca de inhibidores en hemofilia y otros asuntos saludables. También, aprenda como desarrollar una red de apoyo en Carolina del Norte. Después, experimenta el Festival Latino Americano, una celebración de la comunidad Latina!

Este evento es completamente gratis. Todas las comidas, alojamiento en hotel y entradas para eventos son cortesía de HNC. La presentación será únicamente en español.

Asistencia para transportación seria disponible.

Mas información : 1-855-HNC-LATN (1-855-462-5286) o
escríbenos a: union.latina@hemophilia-nc.org antes de
Viernes, el 23 de septiembre

Consejo Rápido

Además de los tiempos de coagulación y la dosis de factor que debes utilizar
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Cual es tu estado general de salud?
Si eres adulto, ¿Cuál es tu nivel de azúcar en la sangre?, ¿Porcentaje de masa muscular?, ¿Estas en sobre peso?, ¿Si tienes algún problema con la próstata?, ¿Mujeres, exámenes regulares para la detección de cáncer de seno?...

Acuérdate que es muy importante contar con un **Medico Familiar** que te realice exámenes generales de rutina para detectar cualquier otra condición médica.

Y que este enterado de tu hemofilia.



SOAR is Soaring!

HNC's Support, Outreach, Advocacy and Resources (SOAR) program for girls and women with bleeding disorders is reaching new heights!

We will be hosting special dinners for women across the state to focus on issues related to self-confidence, intimacy, genetics and family planning. There will be a series of two dinners in three different cities- Durham, Winston-Salem and Concord.

The first set of dinners will be a "get-to-know you" event, providing an opportunity for women to share their experiences in dealing with a bleeding disorder, particularly how it relates to intimate relationships. Dr. Sue Fletcher will be giving a presentation on self-confidence and members of SOAR will be sharing their stories on how having a bleeding disorder impacts intimate relationships. Other health care professionals will be in attendance to answer questions and share helpful tips.

The second set of dinners will include presentations on genetics from Dr. Tamison Jewett and family planning from a local obstetrician. The goal for these dinners is to provide participants with basic information to help make informed decisions. Plenty of time will be provided for questions and answers.

Triangle Area

Wednesdays, October 5, 2011 and November 2, 2011
6:00pm-8:30pm
Maggianno's, 8030 Renaissance Parkway #890, Durham, NC 27713

Charlotte Area

Thursdays, November 3, 2011 and December 8, 2011
6:00pm-8:30pm
Embassy Suites Concord, Rocky River Grille
5400 John Q. Hammons Dr., Concord NC, 28027

Triad Area

Mondays, December 5, 2011 and January 9, 2012
6:00pm-8:30pm
Bonefish Grill, 300 S. Stratford Road, Winston Salem, NC 27103

Our hope is that women will attend both dinners. All women with bleeding disorders, symptomatic carriers and/or mothers of teenage girls with bleeding disorders are encouraged to attend. The dinners will be held in private dining rooms to allow for a discussion of sensitive topics. Additional information and registration forms are available on the website at www.hemophiliaa-nc.org. You can phone, fax or email your registration information.

We'd like to thank NHF Victory for Women for their financial support of these dinners.

Other important SOAR news!



Core members of SOAR recently attended a leadership retreat and spent a beautiful summer weekend hard at work to help address the needs of girls and women within our community. The group celebrated their success Friday evening by sharing the number of presentations we've given with a focus on the individuals that have directly benefited from our efforts to increase awareness about girls and women with bleeding disorders. Saturday was spent learning more about advocacy and self-empowerment followed by a realistic look at our strengths and weaknesses. Lots of brainstorming and discussion resulted in renewed commitment and motivation!

Members decided on specific items that need our attention and organized teams of women to tackle them. Of special importance is the team to develop a peer to peer support program, matching SOAR members with those newly diagnosed; a team to develop brochures, flyers and presentations to help increase awareness of girls and women with bleeding disorders; a team dedicated to outreach and identifying new opportunities to share our stories; and a team strictly focused on using social media to enhance our message and our programs. We also have teams focused on SOAR organization, branding, advocacy, HTC relations, fund development, training new SOAR members to share their stories, and the special needs of our teen members. Sounds like a lot of work you say? Thankfully we have a wonderful, dedicated group of women eager to keep working!

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Genome “Editing” Corrects Hemophilia B in Mice

Researchers at The Children’s Hospital of Philadelphia (CHOP) used genome editing, a gene therapy method, to treat hemophilia in mice. This is the first time genome editing has been successfully done on study animals with clinically relevant results. The study was led by Katherine A. High, MD, director of CHOP’s Center for Cellular and Molecular Therapeutics. She is also a Howard Hughes Medical Institute Investigator. High has been conducting hemophilia gene therapy clinical trials for more than a decade. Results of the study were published in the online version of Nature on June 26.

The novel therapy uses zinc-finger nucleases (ZFNs), genetically engineered enzymes that act as “molecular scissors” that edit DNA sequences. ZFNs replace targeted DNA sequences responsible for hemophilia by cutting through the double helix (the double-stranded DNA molecule that resembles a spiral staircase) to initiate the cell’s emergency repair mechanism. Once the repair begins, healthy genetic material is inserted to replace the defective gene, in this case for the factor IX (FIX) gene that causes hemophilia B. CHOP researchers joined with investigators from Sangamo BioSciences, a clinical stage biopharmaceutical company in Richmond, CA, to test this “cut-and-paste” method of gene therapy delivery by injecting ZFNs into the livers of mice with hemophilia B.

Prior to the study the mice had no detectable levels of FIX. After receiving the therapy, they experienced a rise in FIX production to approximately 5%, enough to reduce clotting time to near normal levels. This lasted throughout the duration of the eight-month trial. The treatment was well tolerated and there were no significant side effects.

These results, although seemingly modest, could downgrade a person’s diagnosis and symptoms. “If you have 5% of factor 9, you will have mild hemophilia instead of severe hemophilia and the difference is huge,” said High. “People with mild hemophilia usually only bleed if they are in surgery or suffer a trauma.”

The difference between the use of other therapies and ZFNs is their precision. Conventional gene therapy techniques may randomly deliver a replacement gene into unfavorable locations. In contrast, ZFNs can target a specific site on a chromosome.

“Our research raises the possibility that genome editing can correct a genetic defect at a clinically meaningful level after in vivo delivery of the zinc-finger nucleases,” High said.

However, this therapy is still in the early stages of development and could take years to finalize. Studies on larger animals, such as dogs, and clinical studies in humans are necessary before such a therapy might become available.

The study, “In Vivo Genome Editing Restores Haemostasis in a Mouse Model of Haemophilia,” was published online in Nature on June 26, 2011.

Source: The Guardian and Nature online, June 26, 2011; CHOP news release June 27, 2011



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Providing Clear and Consistent Information to Consumers about Their Health Insurance Coverage

Affordable Care Act Ensures Insurers and Plans Provide Simple Summaries of What is Covered and What You Pay for Health Services

Today, many consumers don't have access to information in plain English to help them understand the coverage they have or the differences in the coverage and benefits provided by health plans when they shop for a new plan. The same is true for employers who offer coverage to employees or who are shopping for health coverage to offer their employees. Thanks to the Affordable Care Act, that will change. Under proposed rules announced today, health insurers and group health plans will provide the 180 million Americans with private insurance with clear, consistent and comparable information about their health plan benefits and coverage. Specifically, the proposed regulations provide rules implementing Affordable Care Act provisions that would ensure consumers have access to two forms that will help them understand and evaluate their health insurance choices. These forms include:

- An easy to understand Summary of Benefits and Coverage; and
- A uniform glossary of terms commonly used in health insurance coverage such as "deductible" and "co-pay".

The proposed summary form and glossary were developed through a public process led by the National Association of Insurance Commissioners (NAIC) and a working group composed of stakeholders. These stakeholders include representatives of health insurance-related consumer advocacy organizations, health insurers, health care professionals, patient advocates including

those representing individuals with limited English proficiency, and other qualified individuals. During its process, the working group met monthly, invited public input, and conducted consumer testing of the language and forms, sponsored by both consumer and industry groups. Today's guidance proposes to adopt the recommendations submitted by the NAIC after that process. We welcome further input on them before they go into use starting March 23, 2012.

These innovative tools of disclosure have been consumer-tested to ensure they will have measurable impact on the ability of consumers to more fully understand their health coverage. Recent studies, including one from Consumers Union, the nonprofit publisher of Consumer Reports, show that forms like the ones proposed today help consumers fully understand their insurance coverage and its value, making it easier to find the coverage that is best for their needs. Consumers in these studies took particular note of the practical detail provided in the Coverage Facts Label and how this detail enabled them to make a cost-benefit analysis before purchasing coverage.

For more information, visit www.healthcare.gov/news/factsheets/labels08172011a.html

Source: www.healthcare.gov, last updated: August 22, 2011

Best Hospitals 2011-2012: *the Honor Roll*

By U.S. News Staff, Posted: July 18, 2011

A place on the Best Hospitals Honor Roll is reserved for medical centers that demonstrate unusually high expertise across multiple specialties, scoring at or near the top in at least six of 16 specialties. Just 17 of the nearly 5,000 hospitals evaluated for the 2011-12 rankings qualified.

HNC would like to congratulate **Duke University Medical Center** on their #9 spot!



Medicare's Fall Open Enrollment

From the Medicare Rights Center:

Did you know that there are new dates to remember for Medicare's Fall Open Enrollment Period? Starting in 2011, Fall Open Enrollment (also known as the Annual Coordinated Election Period, or ACEP) begins on October 15 and lasts through December 7.

During this period, people with Medicare have the right to change their Medicare health and drug coverage options without restriction. They can make as many changes as they need, and the last change they make on or before December 7 will take effect on January 1, 2012.

Stay up to speed on these and other changes to Medicare with resources developed by the Medicare Rights Center at www.medicareinteractive.org

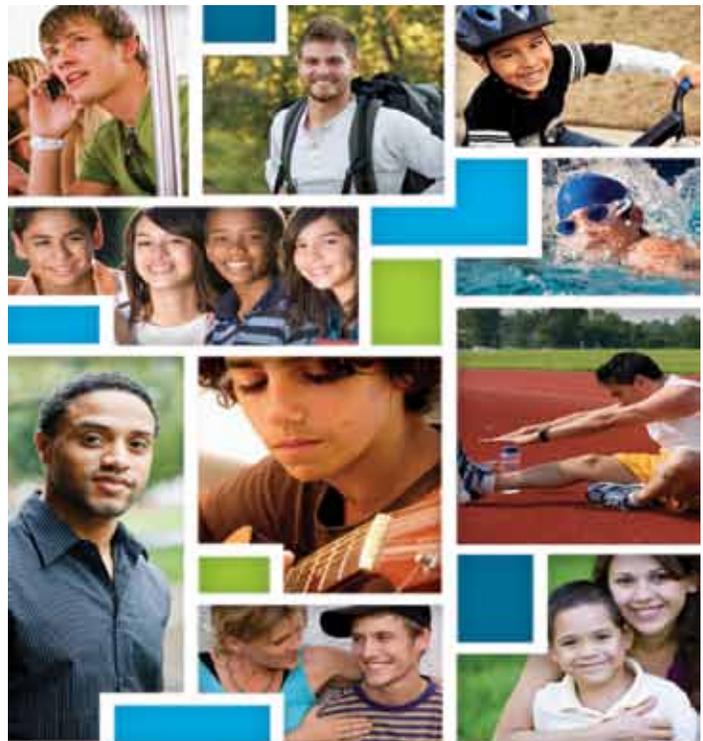
This is a searchable online guide, Medicare Interactive, features hundreds of answers to real Medicare questions, as well as case examples and links to numerous state-specific resources. Medicare Interactive provides clear, up-to-date guidance on questions such as:

- Can I change my Medicare health plan at any time?
- What questions should I ask before joining a Medicare private health plan?
- How do I enroll in the Medicare prescription drug benefit (Part D)?
- How do I compare Medicare private drug plans?
- Do I need to review my Medicare prescription drug plan choice every year?
- What insurance can I buy to fill gaps in Original Medicare?
- Can I buy a Medigap policy at any time?

In addition, a recording of the recent webinar explaining the Fall Open Enrollment Period is now available on our online training service, Medicare Rights University, free of charge. You can view the webinar any time here: www.medicarerightsuniversity.org/webinars/fall-open-enrollment-period

And finally, you may also want to check out some of the helpful fact sheets, tips and timelines found on the web site, www.medicarerights.org. These materials help explain picking the right plan, health reform and how it affects people with Medicare, changes in 2012, and more:

- Questions to Ask Before Joining a Medicare Private Health Plan
- Health Reform Implementation Timeline
- Medicare-Covered Preventive Services
- New Open Enrollment and Disenrollment Periods
- Medicare Advantage Disenrollment Period (MADP)



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HERO: An online study of the impact of hemophilia A & B on patients and families

The National Hemophilia Foundation (NHF) would like to inform you of the HERO (Hemophilia Experiences Results Opportunities) survey and provide you the opportunity to take part if you so choose.

HERO is a study conducted in 12 different countries and will include about 1200 patients and caregivers. The aim of the study is to explore the psychosocial issues in hemophilia A & B and their impact on the various aspects of life, both for patients and their families and partners. The data collected will enhance the understanding of what it is like to live with hemophilia. Ultimately, HERO may inform strategies to improve hemophilia management.

The study findings will be made known to healthcare providers, patients, and patient advocacy organizations through presentations at hemophilia conferences, publications in scientific journals, leaflets and websites. As examples of how we might report the results back to patients and caregivers, we might make these results available at the NHF Annual Meeting, hold discussions at chapter meetings, or present the results in an article in our HemAware magazine.

HERO is being led by the HERO International Advisory Board (IAB) composed of prominent health care professionals and hemophilia

patients from around the world. Kantar Health, a research company based in the UK, will be administering the questionnaire and analyzing the results on behalf of the HERO IAB and the sponsor. None of the questions posed in the questionnaire are of a marketing nature.

The survey would require approximately 40 minutes of your time. You would be asked personal questions about your family, including hemophilia history and demographic information (race, religion, income, region in which you live, etc.); your/your child's hemophilia; your and your family's feelings about hemophilia; how hemophilia impacts your/your child's life, work and activities (includes questions about sexual life for men with hemophilia); and your/your child's physical and emotional health.

You would not be charged to participate in the survey. As a token of our appreciation for taking time to participate, upon completion of the survey you will be mailed a gift card with a value of \$75. At the end of the questionnaire you will be asked to provide the postal address where you would like the gift card to be sent. Please ensure that your details are entered correctly. Your postal address will not be linked to your survey responses.

Continued on page 17

PATIENT RESOURCES

"Multiple ankle surgeries couldn't stop me from golfing." — David

"Playing music helps keep me active." — Frank

"Health insurance can be time-consuming, but I find time to deal with it." — Jay



Get their perspectives

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HERO: An online study of the impact of hemophilia A & B *continued*

Note: The survey can only accept one respondent per household, therefore only one member of your household can receive the gift card.

There is no immediate direct benefit to you/your child associated with your participation. However, we believe that the information obtained will be valuable to the community. There are no significant risks to your participation in this study; however, answering some of the questions could cause you to feel uncomfortable or upset.

Please note: Personal identities of the survey respondents will be treated with the strictest confidentiality, in accordance with relevant Data Protection laws. You will remain completely anonymous as your answers to survey questions will not be connected to you individually, but rather aggregated and analyzed together with the rest of the respondents.

Participation in this survey is voluntary. You have the right to refuse participation in the study or to withdraw at any time.

If you agree to participate, please visit the link below. Upon entering the website, you will be asked to provide your email address so that you can be sent your own unique link to the survey. Your email address will not be linked to your survey responses.

United States patients' version (English):
<http://online.tns-global.com/wix/p934338439.aspx?country=1033&l=9>

United States parent version (English):
<http://online.tns-global.com/wix/p934419923.aspx?country=1033&l=9>

Should you have any questions or complaints about the survey, please contact the project team at HERO-USA@kantarehealth.com

We are looking for 200 participants so if you are interested please do not delay.

If you have questions about what it means to be in a research study, you can call Quorum Review (a research ethics board that reviews this study) at 888-776-9115, or visit the Quorum Review website at www.quorumreview.com.

Best regards,
Val D. Bias
Chief Executive Officer
National Hemophilia Foundation



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HHS Proposed Rules on Exchange Implementation Requirements

On July 11, 2011, the U.S. Department of Health and Human Services (HHS) issued proposed rules on the American Health Benefit Exchange implementation.

The regulations focus on a subset of crucial issues, but are not exhaustive. The preamble explicitly notes that the proposed rules do not address several key issues which are expected to be in future rule making, including: Individual eligibility standards for: Exchange participation, advance payments of the premium tax credit, cost-sharing reductions, appeals of eligibility determinations and exemption from the individual responsibility requirement; Definitions of essential health benefits, actuarial value and other benefit design standards; and Quality reporting for Exchanges and Qualified Health Plan (QHP) issuers.

HHS will accept comments on the proposed rules within 75 days of publication in the Federal Register, on July 15. The proposed rules are available online at: <http://www.gpo.gov/fdsys/pkg/FR-2011-07-15/pdf/2011-17610.pdf>.

HNC VP Advocacy, Leonard Poe, has prepared comments on behalf of Hemophilia of North Carolina that will be submitted by the deadline.



Please save the date for NHF's 2012 Washington Days, which will be held on March 7-9. We will again be staying at the Crystal Gateway Marriott, a short metro or cab ride away from DC airports and Capitol Hill. We will follow the same format as past years: the briefing and reception will be held on Wednesday evening, March 7th; state teams will make Capitol Hill visits on Thursday, March 8th; and a state advocacy workshop will be conducted on Friday, March 9th.

Your participation this year is vital. Given the focus on reducing government expenditures and the continued controversy over health reform and its implementation, it will be critically important for the bleeding disorders community to advocate for policies that benefit us. By telling your story, you put a face on real issues that affect individuals and families dealing with bleeding disorders.

Stay tuned for more information on registration and our specific advocacy issues for Washington Days 2012.

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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

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: _____
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Home Phone: _____
Cell Phone: _____
Email: _____

Check One

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



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and a member of the Better Business Bureau.*