

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SPRING 2015

HNC will host TWO Walks this year!

Based on the overwhelming success of the Hemophilia Walk in Morrisville since 2008, HNC has listened to our members and we're happy to announce a second Walk this year. No matter where you live in North Carolina, we hope you'll get involved! The newest addition will be a Hemophilia Walk on June 20th at the ZMAX Dragway in Concord. Our Morrisville Walk will be on October 17th at Lake Crabtree County Park.

We're really looking forward to seeing a sea of colors with team t-shirts and a collection of new, creative team names with the Concord Walk! As with the Walk in Morrisville, we hope that this will be an opportunity to raise critical funds for the organization and just as important, in raising awareness of bleeding disorders across the state of NC. Involve your friends, family, coworkers and/or classmates! With social media at our fingertips, together we can make a big splash as we race to the finish line in the Charlotte area!

You can read more about both the Walks and how to get involved on our website (www.hemophilia-nc.org) or by calling the office!



Save The Date

World Hemophilia Day Event

Charlotte, NC
April 17, 2015

HNC Annual Meeting

Fayetteville, NC
May 2-3, 2015

HNC Dinner on Inhibitors

Charlotte, NC
June 5, 2015

Blood Brotherhood BBQ

Beach (location TBD)
June 13, 2015

HNC Concord Walk

Concord, NC
June 20, 2015

HNC Teen Retreat

Location & Date TBD
July 2015

HNC Men's Retreat

Parkton, NC
July 17-19, 2015

NHF Annual Meeting

Dallas, TX
August 13-15, 2015

HNC Adult Retreat

Pine Knoll Shores, NC
August 28-30, 2015



*Hemophilia of
North Carolina*

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

MISSION STATEMENT

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

Contact Numbers

Hemophilia of North Carolina

(800) 990-5557
(919) 319-0014
(919) 319-0016 (fax)

National Hemophilia Foundation

(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.

An electronic version may be found on the HNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the HNC office.

We maintain a membership mailing list. However, we never release any personal information without your permission.

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

Hemophilia Treatment Centers

East Carolina University Brody School of Medicine

600 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676
Fax: (252) 744-8199

University of North Carolina At Chapel Hill School of Medicine

Campus Box 7016
Physician Office Building
170 Manning Drive
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736
htcenter.med.unc.edu

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
htc.medicine.duke.edu

Novant Health Blume Pediatric Hematology & Oncology Clinic

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

Resource Information

National Hemophilia Foundation

www.hemophilia.org

Hemophilia Foundation of America

www.hemophiliafed.org

American Pain Foundation (APF)

1-888-615-PAIN (7246)
Hemophilia Chronic Pain Support Group
painaid.painfoundation.org

American Society of Pediatric Hematology/Oncology

847-275-4716
www.aspho.org

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

LA Kelley Communications

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

Patient Notification System

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

Patient Services Incorporated (PSI)

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

World Federation of Hemophilia

1-800-520-6154
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.

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.



From the HNC Office

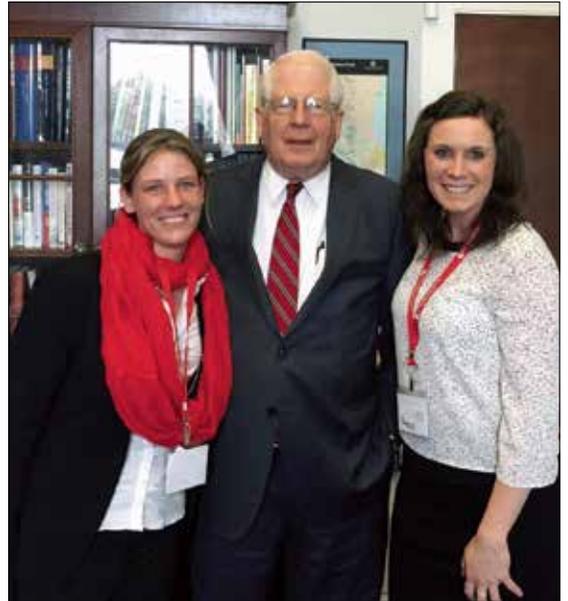


Charlene Cowell,
Executive Director

I have a feeling I'm not the only one ready for spring and some much needed sunshine. Over the next few months we're going to have so many activities throughout the state and I cannot wait to see everyone's smiling faces! One of the many reasons that I love what I do is because of events like these. The feeling of community and inspiration at an event like the Hemophilia Walk is indescribable to say the least! With yet another

Walk on the horizon in Concord, I look forward to doubling this effort so that individuals and families from all over the state can join together. At these events we're always adding new community members, strengthening our voice and building awareness in NC.

See you soon,
Charlene



Charlene Cowell, HNC Executive Director, with Representative David Price and Nicole Bailey, HNC Advocate.

Mail Containing Information on Products and Services (Third Party Mailings)



Important Update for HNC Members! We know that most members of our community are interested in learning about products and services that may be available to them. As a part of our mission to provide education to our community we will occasionally send you mail on behalf of pharmaceutical companies, home health care agencies, or specialty pharmacies. In each of these third-party mailings, there will be an insert stating HNC's policy:

Hemophilia of North Carolina (HNC) is providing this information as a service to our membership. We are not the sponsors, nor do we endorse, any of the events or products described in this enclosure. HNC always recommends that you consult your physician or local treatment center before pursuing any course of treatment. This mailing was addressed by HNC staff; your name and address have not been given to any third party.

If you prefer not to receive third-party mailings from HNC, please send us email at info@hemophilia-nc.org or call 800-990-5557 and ask to be removed from this mailing list. (Doing so will exclude you from third-party mailings only, not from other HNC mailings).

FREE

Medical Alert StrapWrap™

Designed especially for people with bleeding disorders, StrapWrap attracts the attention of emergency personnel while it protects confidential medical information inside. StrapWrap fastens with Velcro so you can use it on a seatbelt, backpack or baby carrier.

To receive your complimentary StrapWrap, please contact:

Chris Barnes ■ 919.749.3196

www.biorx.com
866.442.4679

HNC's Casino Night Moves to Charlotte



Hemophilia of North Carolina (HNC) hosted our 8th annual "Hearts for Hemophilia" Casino Night event on Saturday, January 24, 2015. With a new location in Charlotte, we had a lot of first-time guests joining us this year as well as some familiar folks. The location was at Banquet One and provided a perfect setting for a fun-filled night that included games, dinner, and auctions.

As guests arrived they were greeted with a warm smile and \$20,000 worth of "fun money" to play the night away. The games this year included blackjack, craps, texas hold'em poker, and roulette. After a delicious dinner guests were able to lose it all or win big, all while supporting a great cause.

Between some friendly competition at the gaming tables and great company, folks found themselves really enjoying the evening. Meanwhile the silent auction items were a hit as the evening rolled on. Our table full of great gifts for auction included a luxurious hotel stay in Washington DC, painting from artist Patrice Rucker, other handcrafted artwork, several themed gift baskets, tickets to the NC Symphony, some signed sports memorabilia, and as always an opportunity to send a kid to camp.

During the evening, we hosted our live auction with another chance to win even more great items. Most importantly during the live auction there was an opportunity to make a bid of financial contribution to our emergency assistance program, a vital way of how HNC is able to assist the bleeding disorders community. Also in the live auction were tickets to the Richard Petty Driving Experience, a tasty margarita basket, and a Keurig 2.0!

With plenty of opportunities to win great gifts, there weren't many guests going home empty handed. Each attendee received an authentic deck of casino playing cards as a thank you for their support and for being our guest for the evening. HNC raised over



\$18,000 and all proceeds will help us to continue our goal of promoting opportunities to improve the quality of life for those affected by a bleeding disorder. It is our vision for everyone to achieve their full potential without barriers or limitations, until a cure is found. Those that supported our event continue to make this vision a reality.



The HNC Board of Directors would like to acknowledge the hard work and tireless effort of many that helped make this event possible. Thanks to our entire list of sponsors and individuals for continuing the casino night tradition!



Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2015 HNC Casino Night:

King of Hearts

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CSL Behring

Biotherapies for Life™

novo nordisk®

Jack of Hearts

octapharma

For the safe and optimal use of human proteins

Pfizer Hemophilia

Queen of Hearts

Bayer HealthCare

biogen idec®

BioRx

emergent
solutions™

Wild Card

KEDRION
BIOPHARMA

Advocating in the snow at NHF's Washington Days

On February 25-27th the National Hemophilia Foundation (NHF) hosted its Washington Days event where over 300 advocates met with legislators to talk about issues impacting the bleeding disorder community. It is a unique opportunity to get involved with advocacy at the national level with people from all over the country. Among the advocates walking a snow covered capitol was our group from North Carolina. While it was frigidly cold outside, the staff and legislators were warm and attentive. You can read about the talking points from the day later in this newsletter, under the "On The National and Legislative Front" section.

After the long and successful day on the hill, NHF also provided a workshop and presentations on state level advocacy. This invaluable opportunity provides training and resources for advocates at the state level, something HNC is very committed to. We want to thank all of those involved at Washington Days and those advocates at the state level back home for continuing to ensure our community is well-represented.



You can get involved with national advocacy by joining the NC constituency next year at NHF's Washington Days. Also there is the opportunity to get involved with advocacy at the state level here in North Carolina by joining our Advocacy Committee and attending our state Legislative Day in Raleigh. NHF's motto for Washington Days couldn't be more fitting "Nothing About Us Without Us, Coming Together as One Voice." So let your voice be heard!



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 0215-00025301-2 April 2015



Reid Coleman, one of HNC's dedicated advocates, standing at the Senate podium.

Advocating for the Community at HNC Legislative Day

Hemophilia of North Carolina (HNC) held its 2015 Legislative Day at the General Assembly in Raleigh on March 12. March serves as Hemophilia Awareness Month across the country to highlight the importance of education about this rare condition.

Over 20 members of the bleeding disorders community from all over the state came together to share their stories with their elected officials and make them aware of important issues that affect them.

At a training dinner on March 11th, Kelly Fitzgerald from PSI, Matt Igelman and Luke Waller from HNC, and Katie Verb from Hemophilia Federation of America spoke to participants and encouraged them to get involved in the advocacy process. Issues addressed included helping legislators understand the value of expanding Medicaid, and also making sure that any Medicaid reforms consider the high cost of hemophilia care. Without Medicaid expansion, some people with bleeding disorders may not be able to afford health insurance, leaving them at risk for not getting needed medical care. Some proposals for Medicaid Reform are based on the idea of limiting payments for medical care, which could hurt people who need expensive medical treatment. It is very important for decision makers to know how their decisions will affect people with bleeding disorders.

HNC members themselves are one of the most important sources of information about bleeding disorders, which is why HNC holds Legislative Day each year. When we tell our stories and help our elected officials understand our unique needs, we become a face to them rather than just another line item.

The next morning, March 12, George McCoy, HNC Advocacy Committee Member, shared personal experiences from decades of being involved with legislators. He encouraged members to be courteous, but also to remember they have a right to be there. He pointed out that not every legislator will agree with what is said, and may even be less than receptive. Even so, our message is important and needs to be delivered clearly, patiently and firmly.



George McCoy, reminding folks why today is important



HNC members with Representative Paul Stam

Participants visited with over 15 members of the North Carolina General Assembly. Our special thanks to the following members of the North Carolina General Assembly for taking the time to meet personally with us: Senator Louis Pate, Senator Josh Stein, Senator Paul Lowe, Senator Stan Bingham, Senator Jane Smith, Senator Ronald Rabin, Senator Buck Newton and Representative Leo Daughtry, Representative John Bell, Representative Robert Reives, Representative Rayne Brown, Representative Jonathan Jordan, Representative Martin Grier, Representative Duane Hall, Representative Chris Malone, Representative Paul Stam. Other members who directed staff to meet with us include Senator Bob Rucho, Senator Kathy Harrington, Senator Chad Barefoot, and Representative Jacqueline Schaffer, Representative John Torbett, Representative Charles Graham, and Representative Evelyn Terry.

After individual meetings with legislators, everyone gathered together to review the day's events. Jennifer Guy from the National Hemophilia Foundation spoke to the group and stressed the need for year-round advocacy. She emphasized the importance of meeting with legislators more than once, and especially meeting with them back in their home districts, not just in Raleigh. She also reminded us that although legislators write laws, it is the state employees who work throughout government who write the rules for programs and make other important decisions that affect the bleeding disorders community. She urged us to have a plan for including those folks in our outreach and education efforts.

HNC's Legislative Day was a great success this year, but it will be even better when you join us and bring your stories and your energy to this ongoing work. You can learn how to become involved by contacting the HNC office. We look forward to hearing from you!

Hemophilia of North Carolina is grateful to



for their support of HNC's advocacy efforts.

More HNC Legislative Day photos



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INDIVIDUAL TREATMENT FOR PEOPLE WITH INDIVIDUAL NEEDS

- Hemophilia, von Willebrand (Related Bleeding Disorders)
- HIV/AIDS
- Immune Deficiencies (Related Disorders)
- Hepatitis B
- Hepatitis C
- Rheumatoid Arthritis
- Osteoporosis
- Pulmonary Arterial Hypertension
- Pulmonary Disease
- Psoriasis
- Cystic Fibrosis
- Crohn's Disease
- Blood Cell Deficiencies
- Renal Disease
- Growth Hormone (Related Disorders)
- Multiple Sclerosis
- Short bowel Syndrome
- Congenital Angioedema



HPCSpecialtyPharmacy.com



A family's way of making their mark with legislators



Luke Waller with Representative John Bell



Two of HNC's Young Advocates with Rep. Leo Daughtry and Jan Copeland

2014 Volunteer of the Year – Sharon Ingram



Hemophilia of North Carolina (HNC) is an organization that was formed by members who saw the vitality of community and has thrived through the continued vision and the tireless efforts of members. Each year, we are honored to select a Volunteer of the Year. This is an opportunity for us to recognize an individual who has given selflessly of their time and talents over the year

(and usually longer) to enhance and empower HNC and the members we serve.

This year we would like to honor Sharon Ingram, a woman who has devoted many hours to helping with programs and supporting the community. Sharon and her family have been involved with HNC since 2007. Without hesitation, the Ingram family will hop into the car and drive across the state to attend programs, even if it means 7+ hours of driving. They've shared their experience on so many levels including at teen programs, women's group, Blood Brotherhood meetings and the Latin Union group. Sharon is frequently asked to share her expertise at national conferences. Sharon's passion for empowering others is contagious and inspiring. She always has a place in her heart for everyone!

Hemophilia Federation of America (HFA) Symposium

March 26-28

This year, the Hemophilia Federation of America (HFA) held its annual Symposium in Dallas, Texas. Over 800 people were in attendance, including families, chapter members and community supporters. Each year the Symposium acts as a resource to all those in attendance and allows participants to not only learn from the speakers, but also from one another. HNC is proud to be a member organization of the HFA and to have had more than 10 members in attendance this year!

HFA is a non-profit 501(c)3 organization incorporated in 1994 to address the evolving needs of the bleeding disorders community. HFA is an active consumer advocate for safe, affordable, and obtainable blood products and health coverage, as well as a better quality of life for all persons with bleeding disorders. For more information about HFA, visit their website at www.hemophiliafed.org.



Some of the NC members out in St. Louis.



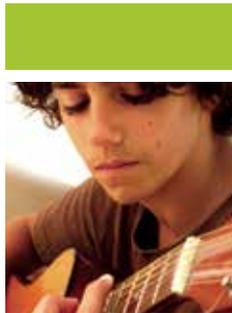
Charlene and Ahmed enjoying the dinner and dance party.

HNC is On the Road Again

We're always trying to bring educational opportunities around the state and most recently held two educational dinners, one in Morrisville and one in Charlotte, with Biogen Idec entitled "Navigating Educational Scholarships and Financial Aid." Teenagers, their parents and adult students received a timely message full of useful information about applying for college admission and scholarships to cover their expenses. We're thankful to Biogen Idec and our other sponsors that make these opportunities possible.

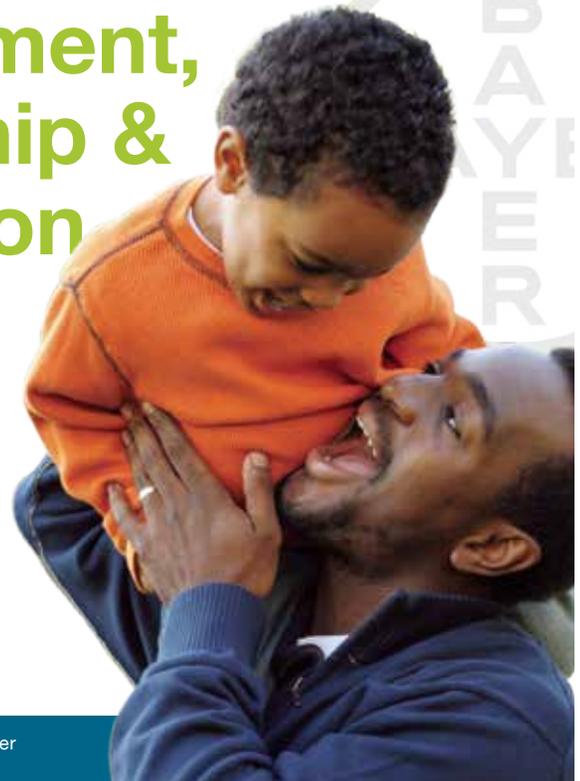
If there are events, including educational dinners, that you would like to see in your area, please don't hesitate to talk to HNC staff

about it. You can always reach us by phone toll free at 800-990-5557, or by email at info@hemophilia-nc.org.



BAYER HEALTHCARE AND THE HEMOPHILIA COMMUNITY

**commitment,
leadership &
innovation**



For information on Bayer's Educational Patient and Community Resources, contact your Hematology Account Executive by calling **1-888-79-BAYER**.

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Upcoming Events



World Hemophilia Day Celebration *The Art of Community*

April 17, 2015 – 6:30-9:30pm

Hyatt Place Charlotte Downtown, Queen City Room, 222 South Caldwell Street, Charlotte, NC 28202

Please join us as we raise awareness for hemophilia and honor progress in our community! In celebration of the bright future ahead, we will partner with Biogen Idec to light the Wells Fargo's Duke Energy Center and host a painting activity at which each family will have the chance to

create their own work of art. The canvas design was selected to serve as a beacon of inspiration, and hope it will be a constant reminder of all that we can accomplish together. Registration is available on the HNC website at www.hemophilia-nc.org.



HNC Men's Retreat

July 17-19, 2015

Rockfish Camp & Retreat Center, Parkton, NC

Whether you're an adult male living with a bleeding disorder or a dad with a son affected, come and join us for the weekend on July 17-19 in Parkton, NC. We'll be at the Rockfish Camp and Retreat Center, which you may remember from the 2014 Adult Retreat. This retreat will be designed to help our Blood Brothers and the dads of future Blood Brothers to connect with one another through roundtable discussions and with programming provided by Inalex Communications. Our hope is that this retreat will be one of many opportunities for dads and Blood Brothers to unite. Registration and more details, including what fun activities we'll have, will be available on the HNC website as we get closer to the date.



Calling All Teens!

Details are still being worked out but we wanted to make sure you're all preparing for another exciting Teen Retreat in July! As always this is a fun, educational weekend designed especially for teens in the community. If you've never been to one of our Teen Retreats, please check out the HNC

Facebook page for photos and information. The Retreat is a great opportunity to make new friends, share laughs, challenge yourself and prepare for your future.

Teens will be allowed to bring 1 friend or family member with them (she/he must also be a teen). All of the details will be available on the HNC website as soon as possible, but please contact the HNC office if you're interested in hearing more about the weekend.



HNC Adult Retreat

August 28-30, 2015

Trinity Center, Pine Knoll Shores, NC

We've just added our annual HNC Adult Retreat to the calendar for August 28-30th so pull out your marker and save the dates! The American Management Association (AMA) will return this year because of popular demand. This AMA series is designed to present effective life skills for individuals living with a bleeding disorder.

We're switching it up this year and going to the Trinity Center, which has historically held our Annual Family Retreat. We're looking forward to being so close to the beach, only a tunnel walk away, while enjoying each other's company!

This retreat is available to adult members (age 18 and over) with a bleeding disorder or parent(s) of a child with a bleeding disorder. One guest is permitted to accompany that attendee. Information and registration will be available on the HNC website as we get closer to the event.



Upcoming Events *Continued from page 10*



HNC 42nd Annual Meeting

May 2-3, 2015
 Holiday Inn Fayetteville-Bordeaux

Come out and join us for Hemophilia of North Carolina's 42nd Annual Meeting! As always, this is HNC's largest meeting and a great opportunity for you to network with fellow members and to hear from the experts. After the meeting, we invite you to stay for dinner and some special entertainment. HNC members are invited to stay overnight as HNC's guest, and then have breakfast on Sunday and head home fresh and fulfilled.

Registration, the agenda and more information is available on the HNC website but here are some highlights:

- Childcare for ALL ages
- Teen Track – Fun park and more!
- Overnight stay
- First-time attendee session and other opportunities
- Traductores estaran disponible en la reunion para asistirle en Español
- Breakout sessions
- Raffles and Door Prizes



NEW HNC BYLAWS
Changes to the HNC Bylaws will be presented to the membership for approval.

The HNC Board is proposing a new bylaws structure that will help HNC continue to grow and better support its mission. The current bylaws were a good fit when HNC was a smaller organization, but HNC has grown substantially in the last decade. With that growth has come the need for more appropriate bylaws, including robust safeguards and accountability, and a move from a membership organization to a self-perpetuating board. The end goal, of course, is for HNC to best serve all people in North Carolina with bleeding disorders.

The complete proposed new bylaws, along with a side-by-side comparison with the existing bylaws, can be found on the HNC website at www.hemophilia-nc.org

Don't Miss Out!

There will be a unique program, never having been done before, of three nationally acclaimed authors with hemophilia from NC on the same stage, so don't miss out on being a part of this historical occasion. Thanks to Jim Grimsley, Craig McLaughlin and Shelby Smoak for joining us!

Meet NAVA, your new best friend

Like a best friend, Baxter's NAVA program will be your...



Guide who provides personalized service, connecting you with resources when you need them.

Mentor who can share insights, thoughts, and experiences about life with a bleeding condition.

Partner who provides one-on-one coaching to help you plan and achieve your goals.

Baxter's NAVA program is free for anyone whose life has been touched by a bleeding condition, regardless of treatment.

Join for free at nava.baxter.com, or by calling 1-855-322-NAVA (6282) today and let's make this the start of a beautiful friendship.



Which way next?
 Navigating life with bleeding conditions



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Celebración del día mundial de la Hemofilia

El arte de la comunidad



17 de Abril, 2015 – 6:30-9:30pm
Hyatt Place Charlotte Downtown , Queen City Room
222 South Caldwell Street, Charlotte, NC 28202

Te invitamos a que formes parte de nuestra comunidad para crear conciencia sobre la hemofilia y honrar el progreso de nuestra gran comunidad! Como parte de la celebración de un magnifico futuro por delante, alumbraremos el Wells Fargo's Duke Energy Center con el apoyo de Biogen Idec. Además llevaremos a cabo una actividad de arte y pintura en donde cada familia tendrá la oportunidad de crear su propia obra de arte.

El diseño de la obra de arte servirá como fuente de inspiración y recordatorio de las grandes cosas que podemos lograr si trabajamos juntos. El registro ya está disponible en nuestro sitio web.

HNC Reunión Anual

2-3 de Mayo, 2015
Holiday Inn Fayetteville-Bordeaux
1707 Owen Drive, Fayetteville, NC 283042



¡Ven y reúnete con nosotros para celebrar la Reunión Anual nro 42 de la Asociación de Hemofilia de Carolina del Norte! Como siempre esta reunión es una gran

oportunidad para que conozcas a otros miembros de la comunidad y te informes de temas con las presentaciones de expertos. Después de la reunión te invitamos a cenar con nosotros y ver un entretenimiento especial. Los miembros de la Asociación de Hemofilia de Carolina del Norte (HNC) están invitados a pasar la noche como invitados de la Asociación y tomar desayuno al día siguiente para que después partan de regreso a casa refrescados y satisfechos.

La registracion, agenda y más información sobre este evento lo puede encontrar en la página web de la Asociación pero acá le mencionamos algunos puntos importantes:

- Cuidado para niños de TODAS las edades
- Sesiones para adolescentes – ¡podrán jugar bowling y mucho mas!
- Pasar la noche en el hotel
- Sesiones para personas que por primera vez participan en el evento y otras oportunidades
- Traductores disponibles en la reunión para asistir a las personas que hablen Español
- Diferentes Sesiones
- Rifas y premios a la entrada

Fondos de Viaje para la Reunión Anual estan ahora disponibles



La Fundación Nacional de Hemofilia (NHF) se complace en ofrecer **Conexiones para Fondos de Aprendizaje** a todas aquellas personas interesadas en participar en la Reunión Anual nro. 67 en Dallas,

Texas, desde el 13 hasta el 15 de Agosto, 2015. Estos fondos cubren los gastos de pasajes de avión/millage de auto y/o los gastos de hotel hasta un máximo de tres noches y cuatro días.

La Reunión Anual de Hemofilia brinda oportunidades para que la comunidad con desórdes de la sangre se conecte e intercambie información en una gran variedad de temas. Estos temas van desde los aspectos básicos de la hemofilia y la condición de Von Willebrand hasta los más recientes descubrimientos en la investigación y avances médicos. Además, la conferencia ofrece la maravillosa oportunidad de conocer, conectar y apoyar a individuos y familias que estan afectados por las condiciones sanguíneas.

Elegibilidad: A fin de proveer una Reunión Anual más inclusiva, la NHF ofrece un número limitado de los **Fondos de Aprendizaje** para individuos y/o familias con desórdenes de la sangre que desean participar de la Reunión Anual por primera vez o familias que no han participado de la Reunión desde hace tres años. La NHF ofrece asistencia especialmente a aquellas personas que no pueden participar debido a obstaculos personales u otras razones. Los fondos se ofrecerán en base a estos factores, y en base a la necesidad.

Aplicación y Fecha de Entrega: Por favor aplicar en la página Web (www.hemophilia.org) Usted necesitará escribir un document (ensayo) antes de llenar la aplicación. Usted debe guardar su document en el formato Word. Las aplicaciones estan disponibles en inglés y español. Su aplicación debe ser completada en la página Web antes del 1ro de Mayo, 2015. Para más información por favor contacte a Sonia Rogers, su correo electrónico es sroger@hemophilia.org

Formas de sobrellevar el estrés familiar: Cuándo superarlo solo y cuándo buscar ayuda profesional

Nadie quiere tener estrés pero no hay forma de evitarlo. Y si a eso se le añade una enfermedad crónica como un trastorno hemorrágico, los síntomas pueden empeorar, afirmó Peg Geary, MA, MPH, trabajadora social e investigadora clínica sobre la hemofilia en el New England Hemophilia Center de UMass Memorial Medical Center en Worcester.

Cuando no se controla, el estrés puede afectar los pensamientos, sentimientos, conducta y salud de la persona. Puede causar desde dolores de cabeza y fatiga, hasta ansiedad y aislamiento social, según la Mayo Clinic. El estrés también puede producir síntomas físicos y conductas inusuales en el adulto o niño afectado.

Sin embargo, le agradecerá saber que las familias con problemas de hemofilia u otros trastornos hemorrágicos a menudo controlan el estrés mejor que otras, aseguró Geary.

Los centros locales de tratamiento de la hemofilia tienen muchos recursos y personal experto preparado para ayudar. “Desarrollan una variedad de mecanismos para sobrellevar la enfermedad, como conseguir apoyo para la familia”, explicó Geary. Muchas familias llegan a tratar la hemofilia como algo normal y transmiten una actitud positiva, agregó. “Si los padres pueden aceptar la hemofilia e incorporarla a su rutina, sirven de ejemplo para sus hijos”. Pero incluso si tiene la capacidad básica de sobrellevarla, puede aprender más. Lea los consejos de Geary.

Esté atento a los niños. “Un poco de estrés es normal, como cuando su hijo está nervioso por una prueba al día siguiente o si está conociendo a gente nueva”, indicó Geary. El truco es reconocer cuándo el estrés normal pasa a ser un problema mayor. A veces los chicos se sienten abrumados o alterados, y no quieren hablar del tema. Quizá su hijo esté ansioso porque no puede participar en deportes con contacto físico y todos los demás sí”, dijo Geary. Señaló que en los niños, ser diferente es fuente de estrés. Pero si usted presta atención, puede detectar indicios sutiles. “Usted conoce a su hijo mejor que nadie y sabe cuándo algo no está bien”, dijo Geary. Si ve cambios en la conducta de su hijo, como más ira u otras señales de estrés, tome nota.

Sugiera conversar pero no lo abruma. Si nota un problema, trate de interactuar con sus hijos de manera que no se sientan amenazados, aconsejó Geary. Puede preguntarles delicadamente si algo los está molestando. “Pero no trate de forzar a su hijo a hablar”, recomendó. “Simplemente espere a ver si surge el tema en la conversación”. Si es así, puede comenzar el diálogo con ejemplos de cómo enfrentó usted una situación estresante de más joven, dijo Geary. Luego escuche a su hijo y ayúdelo a llegar a una solución.

Proteja a sus hijos y ayúdelos a ayudarse a sí mismos. Es fácil caer en la tentación de consolar a los hijos tras cada problema, pero tal vez no sea lo mejor para el niño, advirtió Geary. “Es posible proteger a los chicos al punto que no desarrollan la capacidad de enfrentar situaciones”, dijo. “Luego, cuando se hacen adultos, no saben enfrentar el estrés y la presión”. O sea que déjelos estudiar para el examen y superar la ansiedad solos. Luego reconozca que sus sentimientos son válidos y confirme que cierto grado de estrés es normal, pero que pueden enfrentarlo. Así llegarán a ser adultos independientes.

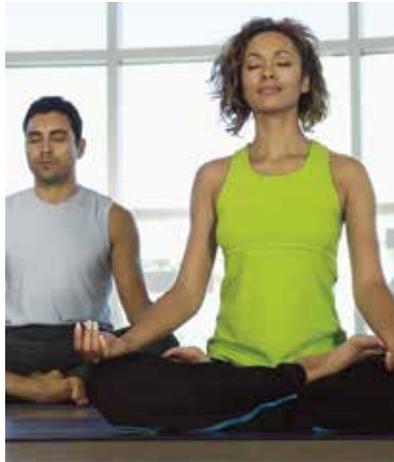
Mantenga un equilibrio. Cuesta ver que los chicos están ansiosos, pero no infle los problemas innecesariamente. Si lo hace, sus hijos harán lo mismo, y la idea no es que se pongan más nerviosos, dijo Geary. Si usted se está sintiendo estresado, trate de resolver el problema con sus propios recursos. Siempre puede decirle a su hijo adolescente, por ejemplo, que está preocupado sobre las infusiones que tendrá que ponerse cuando se vaya a acampar. Pero trate de analizar y enfrentar sus emociones antes de ayudar a sus hijos a hacer lo mismo con las propias. “Si los padres pueden tratar el estrés como algo normal y enfrentarlo, podemos esperar que los hijos sigan su ejemplo. Recuerde que es a usted a quien imitan”, dijo Geary.

Pruebe nuevas soluciones. Quizá haya oído en las redes sociales sobre otras técnicas para superar el estrés, dijo Geary. Los diarios de estrés, que le permiten anotar sus sentimientos en un lugar seguro, pueden ayudar a algunas familias. La capacitación sobre atención plena (mindfulness), durante la cual usted se concentra totalmente en el presente, lo puede ayudar a aliviar el estrés. Las técnicas físicas, como la respiración profunda, meditación y yoga, también pueden ayudar. Y recuerde la importancia de ceñirse a una alimentación sana y dormir suficiente. Ya que todos responden de manera diferente, es posible que cierta técnica ayude a algunas personas más que a otras. O sea que pruebe más de una.

Recurra a un profesional cuando lo necesite. A veces las pequeñas causas de estrés pasan a ser grandes problemas, incluso cuando trata de superarlas. Si el periodo de estrés pasa de durar unos cuantos días a varias semanas, tal vez necesite buscar ayuda. Hágalo también si usted o un ser querido está tan abrumado que le cuesta estudiar o trabajar. Y si algún familiar o usted está considerando hacerse daño, hable con un trabajador social, terapeuta u otro profesional de confianza, aconsejó Geary.

“Si participa en un centro de tratamiento de hemofilia, debe recurrir a este primero”, recomendó Geary. Allí encontrará personal que lo conoce a usted y a su familia. Y un médico o trabajador social puede recomendarle recursos útiles rápidamente”.

Source: <http://www.hemaware.org/node/1276>



SOAR Walk Team and Tu-Tu Madness!

Get your tu-tu's ready ladies!! We are starting up a second SOAR walk team this year and look to have a real strong representation from our women & girls. HNC is expanding to two walks, June 20 in Concord and October 17 in Morrisville. As in the past, we will have a booth at each walk dedicated exclusively to SOAR so that we can provide information to the community as well as sell our famous tu-tu's to help raise funds to support the program.

We're always looking for a few good women to help volunteer! Opportunities specifically for the walks include making tu-tu's (how about a tu-tu making party at your house – they're easy to make and a lot of fun to do in a group), staffing the booth on walk day and of course, helping to raise funds by creating your own walk team or joining a SOAR team. It's a great opportunity to get your friends and family involved too!



Support • Outreach • Advocacy • Resources
An HNC Program for Girls and Women with Bleeding Disorders

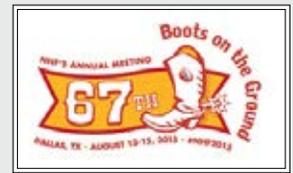
SOAR's Mission Statement: *To improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential.*

Membership Information: For more information about SOAR, or to be added to the SOAR mailing list, please send your name and contact information, along with any questions you may have, to soar@hemophilia-nc.org.

Calling all women! Apply now for grant to NHF's 67th Annual Meeting



The National Hemophilia Foundation (NHF) is pleased to offer the **Anna DeSimone Grant** for women who want to attend its 67th Annual Meeting in Dallas, TX, August 13-15, 2015.



The grant was established to honor the memory of Anna DeSimone, a tireless advocate for issues affecting women with bleeding disorders, former staff member of NHF and founding member of the Foundation for Women and Girls with Blood Disorders.

Each year one woman with a bleeding disorder is chosen to attend the Annual Meeting for a maximum of three nights and four days with expenses paid. At the Annual Meeting the grant winner can take advantage of the wealth of information and educational opportunities, and get to know other woman coping with a bleeding disorder.

Who's Eligible: Any woman with a bleeding disorder who wishes to attend the Annual Meeting can apply for the grant. NHF would especially like to provide assistance to a woman who is unable to attend due to personal obstacles or other barriers.

The **Anna DeSimone Grant** covers airfare or mileage, hotel, and, registration fee.

Submit your application online! You will need to write an essay before you fill out the application. You should save your essay in a Word document.

Your application must be completed online by 11:59PM Eastern Time on Friday, April 17, 2015.

www.hemophilia.org

Raising Awareness Through Nurse Practitioners

HNC was a proud participant at the North Carolina Nurse Practitioners (NP) Spring Symposium, held March 29-31 at the Grove Park Inn in Asheville. SOAR members, Crystal Hoernlein and Cheri Clark joined Gina Raymond and Charlene Cowell to educate NPs of multiple disciplines on the signs and symptoms of various bleeding disorders, specifically highlighting the issues faced by women with bleeding disorders. The HNC ladies discussed the challenges many men and women face in getting a proper diagnosis and the importance of the HTC model. Approximately 300 NPs attended the statewide event and more than 250 stopped by the HNC booth! Comments from the attendees included, "This information is so helpful," and "Thank you for helping me

understand more about the symptoms of VWD." Thanks go out to Crystal and Cheri along with Gina from CSL Behring, who sponsored this outreach opportunity.



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As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.

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 www.CSLBehring-us.com COA13-08-0045 9/2013

Our Young Voices

Spring, 2015



Our Young Voices is the latest supplement added to *The Concentrate*. It is designed to be a platform for the voice of youth that are a part of the Hemophilia of North Carolina (HNC) community. This supplement will feature creative writing, drawings and news *for* our youth, *from* our youth. If you are a young voice of HNC and would like to submit a written piece or visual art for upcoming issues, please contact HNC Staff at info@hemophilia-nc.org.

Having Hemophilia *By: Dallas Smith*

When I tell people I have Severe Hemophilia A and what it does, most people say things like "I feel sorry for you", that bothers me. It's not that I don't want people to care, it's just that I don't want people to pity me without realizing that I'm never going to let my disorder drag me down, or keep me from reaching my potential. Not too many people would see the situation that my twin brother and I face as a positive one, but I see it as a God given blessing. I am able to meet people that I never would have met, do things that I never could have done, and experience a side of a story from the perspective hardly anyone else gets to see. I want to thank the people that have made me a part of their lives, being concerned about my safety, but at the same time seeing me for who I am, and not for what I cannot do. You are the people that are really a blessing.

Having hemophilia does not define who you are, it is what you do about it that defines who you are. I have decided not to let hemophilia take control of me, but the question remains, what about you?

– JerDan Smith



The Smith Brothers with some good company!



Aiden is a 9 year old with severe hemophilia. Although he's attended summer hemophilia camp the past four years, Aiden has finally decided to take charge of his hemophilia by self infusing! Aiden hopes to see all his blood brothers and sisters at the camps this summer!

Mom said I'm not old enough for a girlfriend because I won't self infuse... Can I borrow the car keys now, Mom?!



Victory Junction Camp in Randleman, NC

Victory Junction is a year-round camping facility that serves children, ages 6 to 16, with chronic medical conditions or serious illnesses, at no cost to their families. During the summer, Victory Junction offers disease-specific sessions for up to 128 children per session. During the fall, winter and spring, family weekends are offered to up to 32 families per weekend. For more information, go to www.victoryjunction.org or call 336-498-9055.

June 21 – 25, 2015:

Bleeding Disorders/Sickle Cell Week

Camp Carefree in Stokesdale, NC

Since 1986, Camp Carefree has provided a free, one-week camping experience for kids with bleeding disorders. Camp Carefree provides the needed freedom to play, learn, and have fun with others who encounter similar difficulties. The program also includes camps for well siblings who live with a chronically ill sibling (Sibling Camp) and for well children with a seriously ill or disabled parent (Kids Camp). For more information, go to www.campcarefree.org or call 336-427-0966.

June 21 – June 27, 2015: *Siblings Camp*

July 19 – July 25, 2015: *Kids Camp*

July 26 – August 1, 2015: *Hemophilia and vWD Camp*

Camp Rainbow at Camp Don-Lee, Arapahoe, NC

Camp Rainbow is a week-long summer camping experience for children with cancer or hemophilia treated by the Brody School of Medicine at East Carolina University. Camp Rainbow is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Camping experience goals include: building self-confidence and independence, emotional and social development and well being, and learning and sharing support with others who are living with a chronic blood disorder. For more information, please call the ECU Hemophilia Treatment Center at (252)744-4676.

June 14 – June 20, 2015: *CampWeek*

All of these Summer Camps are absolutely necessary for future generations. Please consider supporting them with donations of money and/or time.



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HNC Concord Walk

June 20, 2015
ZMAX Dragway
Concord, NC

Are you ready to represent your Walk team in the Charlotte-area this year? We're expanding and hosting two Hemophilia Walks this year and cannot wait to take Charlotte by storm! We'll be speeding down the drag strip for our 5K, while enjoying some laughs with friends, family and other supporters. Everyone will be able to celebrate on the winning lap and soak in the success of the day! So grab your walking shoes and join us in making the first of many Concord Walks a victory!



Info will be available at www.hemophilia-nc.org to help you kick start your team! The site features information for sponsors, teams and volunteers. Printed Sponsorship and Team Captain Packets are also available through HNC by calling 800-990-5557 or by email at info@hemophilia-nc.org. We are looking forward to another great event this year and hope to see everyone there!



HNC Morrisville Walk

October 17, 2015
Lake Crabtree County Park
Morrisville, NC

Be sure to mark your calendars for the 8th Annual Hemophilia Walk in Morrisville! The largest fundraising event for HNC is taking place on Saturday, October 17th at Lake Crabtree County Park in Morrisville. Registration begins at 9:00am and the walk is 10:00am.

The day will feature a 5K walk, food, music, games and all-around fun for family and friends (even the 4-legged ones). It's never too early to get involved — start your walk team today! Info will be available at www.hemophilia-nc.org to help you kick start your team! The site features information for sponsors, teams and volunteers.



Printed Sponsorship and Team Captain Packets are also available through HNC by calling 800-990-5557 or by email at info@hemophilia-nc.org. We are looking forward to another great event this year and hope to see everyone there!



Big Day & Big Truck

City, Red Cross grant wish for boy with challenges

By Lisa Boykin Batts, Times Life Editor

Landon Davis loves garbage trucks.

Once he hears the heavy truck headed down his street each Thursday, the blond 4-year-old stands at his front door and looks. Then he goes outside with his mom and watches the truck go from house to house, picking up big green trash cans with a robotic arm. It fascinates him.

“I watch the trash men go to every single house,” Landon said on an exciting Tuesday afternoon.

The child, who has severe hemophilia with inhibitors as well as a rare heart condition, got a real treat.

James Mangum drove up to Landon’s house in a very clean City of Wilson garbage truck Tuesday. He lifted the very surprised boy into the cab of the truck, and the two of them pressed the right levers to pick up and empty a trash can.

Landon looked around in the truck and at the group of family members and strangers gathered in his yard; among them were representatives of the American Red Cross and the City of Wilson, who made the adventure possible.

Mangum said he sees the little boy looking at the truck each week when he runs the route on his street.



Officials with the Eastern North Carolina American Red Cross knew all about Landon’s love of garbage trucks. And earlier this month, while Landon was at UNC Hospitals for three

weeks, they let his mother, Ashley, know that the City of Wilson wanted to surprise the boy with an upclose look at a garbage truck.

Ashley said it was a wonderful surprise for them and lifted their spirits while Landon was hospitalized with a port infection. He ended up having the port removed and another one surgically implanted. Landon receives clotting treatment daily through his port.

The American Red Cross is very familiar with the Davis family and Peace Church who work with them every year to do a blood drive in Landon’s honor. Landon receives blood products every

day and has had four whole blood transfusions. He needs surgery to correct the heart defect coarctation of the aortic arch, which means his aorta is more narrow than it should be. Surgery for Landon could be life-threatening, however, because of hemophilia.



The Red Cross doesn’t routinely grant wishes but wanted to do something special for Landon at Christmas.

“They’re just such a special family,” said Kristin Cartwright, donor recruitment manager. “We were honored to do it for them. He’s just a real tough boy.”

Tim Farmer, environmental services manager for the city, said he and his co-workers were glad to do something special for Landon. There are very few small children who like garbage trucks, he said.

“It’s been awesome. We get very few calls of this nature, but this makes it worthwhile.”

In addition to sitting in the truck, Landon got several gifts as well from the American Red Cross and the city. Included in his presents was a toy garbage truck with an official City of Wilson logo on its side. Landon was eager to remove the truck from its package and showed those standing by how to make it work.

Landon’s father, Mark, said it was wonderful to see Landon happy and smiling Tuesday. Landon was a little shy around so many strangers, but that wouldn’t last long, his dad said.

“He will be talking about this forever.”

Not only does Landon enjoy watching garbage trucks, he also likes helping his dad push the trash cans to the street and back the next day.

“He’ll get mad if I do it without him,” Mark said.

Source: <http://www.wilsontimes.com/News/Feature/Story/35026478>
BIG-DAY-BIG-TRUCK December 17, 2014

Blood Brotherhood Update



On the chilly evening of March 14th the NC Blood Brotherhood group gathered for a delicious dinner at Tobacco Road Sports Cafe in Chapel Hill. Everyone enjoyed great company and shared stories as we patiently awaited the ACC Championship game. Once the game started the place was packed with Tar Heel fans, as they took on Notre Dame for the championship. All the cheering could not help the home team prevail, and UNC lost the game in the end. However the NC Blood Brothers won another great opportunity to get together!



As always thanks to the Hemophilia Federation of America (HFA) for presenting this opportunity in NC and other states. For more information on Blood Brotherhood nationally, including information on the private online forum for adult men with bleeding disorders, and the online Blood Brotherhood Chats, visit: www.hemophiliafed.org/programs/blood-brotherhood.

The next meeting of our Blood Brotherhood group will be May 2nd at the HNC Annual Meeting in Fayetteville. Look forward to seeing you there and travel assistance is available!

Also, Save the date for HNC's Men's Retreat – July 17-19 in Parkton, NC – and read more information on page 10.

2015 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2015. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

Donors

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Jaya Knox

In Honor of William Hodges

W. Mark Allen • Brian Fox • Linda Hodges • Jeff & Evelyn Lane
Michelle Parker • Christine Reedy • Laurie Roach





- Help
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- Empowerment

HOPE Update for Families

By: Gillian Schultz

As a parent of a four year old son with hemophilia and a seven year old son who is unaffected, I am always looking for ways to keep my kids busy! Early in our hemophilia journey, I didn't know how I could possibly have Noah participate in the same activities as his older brother Riley. But it was also obvious early on that Noah wanted to do everything that his brother did. I learned that he did not need to be limited by hemophilia. Recently Noah transitioned from the Big Wheels Tricycle to a regular bike with training wheels, he rides a scooter, we all go to the park, in the summer go swimming, go to birthday parties, and Noah participates in a toddler soccer program at his daycare. Noah is always on the go, but he does also like to sit down and color and read which is especially helpful when he needs to be calm for something.



We read together every night before bed and at other times throughout the day. I keep books for my kids in their bedrooms and down in our living room, so that there are always opportunities to read. Did you know that there are many books about hemophilia for kids of all ages too? Laurie Kelley has many different books starting with little board books to teach our youngest ones about hemophilia. Both of my kids love these books. There are also comic books and many more books from other companies about hemophilia. These have been a great resource to have to teach Noah about his hemophilia and Riley about his brother's hemophilia. We have picked up most of the books at events over the past few years. If you would like some suggestions on books for your children, contact the HNC office. Right now, Noah's favorite book is Paw Patrol: Itty Bitty Kitty Rescue, but this changes on almost a daily basis! Since his older brother can read independently, Noah also likes to "read to himself."

I am looking forward to the variety of events that HNC has planned so far for this year. April 17 is World Hemophilia Day. There will be activities in Charlotte sponsored by Biogen Idec to celebrate Hemophilia Awareness as the Duke Energy Center is lit red to honor World Hemophilia Day. There will be a HOPE session for parents at the HNC Annual Meeting in Fayetteville on May 2. I'm also excited for the first Charlotte Hemophilia Walk on June 20. I have ideas for other programs throughout the year, so stay tuned to the HNC website and Facebook page for upcoming events. If you have your own ideas for any HOPE event, please let us know!

HOPE in an HNC program for families with children from birth to age twelve diagnosed with a bleeding disorder. Open to any member of HNC, programs are geared specifically towards the unique needs of these families to include education and support so that they may HOPE to lead a fulfilling life.

For more information, please contact me Gillian Schultz, the HOPE Program Coordinator at gillian.schultz@hemophilia-nc.org or Charlene Cowell, Executive Director of HNC at info@hemophilia-nc.org or by calling the HNC office at (800) 990-5557.



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Travel Grants for National Meeting Now Open



The National Hemophilia Foundation (NHF) is pleased to offer **Connections for Learning Grants** for those who want to attend its 67th Annual Meeting in Dallas, TX, August 13-15, 2015. This covers airfare/mileage and/or hotel accommodations for up to three nights and four days.

NHF's Annual Meeting enables the bleeding disorders community to come together and exchange information on a wide variety of topics, from the basics of hemophilia and von Willebrand disease to the latest research findings and new drug breakthroughs. Further, the three-day conference provides the premier opportunity for networking and support for individuals and families affected by bleeding disorders.

Eligibility: To provide a more inclusive Annual Meeting, NHF offers a limited number of **Connections for Learning Grants** to individuals and/or families with bleeding disorders who wish to attend the Annual Meeting for the first time, and returning families who have not attended NHF's Annual Meeting for the past three years. NHF would especially like to provide assistance to those unable to attend due to personal obstacles or other barriers. Awards will be based on these factors, and on need.

Application & Deadline: Please apply online (www.hemophilia.org). You will need to write an essay before you fill out the application. You should save your essay in a Word document. The forms are available in English and Spanish. Your grant must be completed online by **Friday, May 1, 2015**. For more information, please contact Sonia Rogers at vroger@hemophilia.org.

NHF Inhibitor Education Summits



National Hemophilia Federation's Inhibitor Education Summits were designed to specifically cater to the needs of patients, caregivers, and members of the support network of people with inhibitors. NHF understands the day-to-day challenges that come with having hemophilia with the added complication of an inhibitor.

Come join this dynamic event and interact with expert healthcare professionals as well as other patients and their families for a weekend of education designed to improve your overall health and quality of life.

The Summits provide:

- Travel and lodging assistance provided for eligible patients and their caregiver(s)
- Both locations accessible to wheelchairs and other mobility devices

- Four different educational tracks tailored to suit your needs as a patient or caregiver
- An Interactive Education Camp for Youths, including an off-site activity (Ages 4-12)
- Childcare for infants-3 years old

Please call 877-560-5833 or send an email to inhibitorsummits@hemophilia.org for more information, or if you need assistance during the registration process. Atención: los representantes hablan español.

NHF Inhibitor Education Summit, Denver, CO
July 9-12, 2015

NHF Inhibitor Education Summit, Atlanta, GA
July 16-19, 2015



Have you taken the CHOICE survey?

CHOICE (Community Having Opportunity to Influence Care Equity) is a project driven by Hemophilia Federation of America (HFA) and supported by the Centers for Disease Control and Prevention (CDC). CHOICE collects information through an online and paper-based survey. This survey collects information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not get care at a federally funded hemophilia treatment center (HTC). De-identified information will be shared

with the CDC to help understand the health status of people with bleeding disorders who do not get care at HTCs.

Anyone with a bleeding disorder is welcome to take the CHOICE survey, whether or not you receive care at a hemophilia treatment center (HTC). The survey is available in English and Spanish and anyone can preview the survey before taking it if they prefer. To take the survey, go to www.hemophiliafed.org/programs/choice or call HFA at (800) 230-9797 and ask for a paper copy.

New gene therapy for hemophilia shows potential as safe treatment

Research showed that bleeding events were drastically decreased in animals with hemophilia B. Using a viral vector to swap out faulty genes proved safe and could be used for the more common hemophilia A.

March 12, 2015

CHAPEL HILL, NC – A multi-year, ongoing study suggests that a new kind of gene therapy for hemophilia B could be safe and effective for human patients. Published in the journal *Science Translational Medicine*, the research showed that a reprogrammed retrovirus could successfully transfer new factor IX (clotting) genes into animals with hemophilia B to dramatically decrease spontaneous bleeding. Thus far, the new therapy has proven safe.

“The result was stunning,” said Timothy Nichols, MD, director of the Francis Owen Blood Research Laboratory at the University of North Carolina School of Medicine and co-senior author of the paper. “Just a small amount of new factor IX necessary for

proper clotting produced a major reduction in bleeding events. It was extraordinarily powerful.”

The idea behind gene therapy is that doctors could give hemophilia patients a one-time dose of new clotting genes instead of a lifetime of multiple injections of recombinant factor IX that until very recently had to be given several times a week. A new FDA-approved hemophilia treatment lasts longer than a few days but patients still require injections at least once or twice a month indefinitely.

This new gene therapy approach, like other gene therapy approaches, would involve a single injection and could potentially

Continued on page 24

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THE CONCENTRATE



23

Spring 2015

New gene therapy for hemophilia *continued*

save money while providing a long-term solution to a life-long condition. A major potential advantage of this new gene therapy approach is that it uses lentiviral vectors, to which most people do not have antibodies that would reject the vectors and make the therapy less effective.

In human clinical studies, approximately 40 percent of the potential participants screened for a different kind of viral vector – called adeno-associated viral vectors – have antibodies that preclude them from entering AAV trials for hemophilia gene therapy treatment. This means that more people could potentially benefit from the lentivirus gene therapy approach.

Hemophilia is a bleeding disorder in which people lack a clotting factor, which means they bleed much more easily than people without the disease. Often, people with hemophilia bleed spontaneously into joints, which can be extremely painful and crippling. Spontaneous bleeds into soft tissues are also common and can be fatal if not treated promptly. Hemophilia A affects about one in 5,000 male births. These patients do not produce enough factor VIII in the liver. This leads to an inability to clot. Hemophilia B affects about one in 35,000 births; these patients lack factor IX.

This new method was spearheaded by Luigi Naldini, PhD, director of the San Raffaele Telethon Institute for Gene Therapy and co-senior author on the Science Translational Medicine paper.

For this study, Naldini and Nichols developed a way to use a lentivirus, which is a large retrovirus, to deliver factor IX genes to the livers of three dogs that have naturally occurring hemophilia. The researchers removed the genes involved in viral replication. “Essentially, this molecular engineering rendered the virus inert,” Nichols said. “It had the ability to get into the body but not cause disease.” This process turned the virus into a vector – simply a vehicle to carry genetic cargo.

Unlike some other viral vectors that have been used for gene therapy experiments, the lentiviral vector is so large that it can carry a lot of payload – namely, the factor IX genes that people with hemophilia B lack. (This approach could also be used for hemophilia A where the FVIII gene is considerably larger.)

These viral vectors were then injected directly into the liver or intravenously. After more than three years, the three dogs in the study experienced zero or one serious bleeding event each year. Before the therapy, the dogs experienced an average of five spontaneous bleeding events that required clinical treatment. Importantly, the researchers detected no harmful effects.

“This safety feature is of paramount importance,” Nichols said. “Prior work elsewhere during the early 2000s used retroviruses for gene therapy to treat people with Severe Combined Immunodeficiency, but some patients in clinical trials developed leukemia.” Newer retroviral vectors, though, have so far proved safe for SCID patients.

To further demonstrate the safety of this new hemophilia treatment, Nichols and Naldini used three different strains of mice that were highly susceptible to developing complications, such as malignancies, when introduced to lentiviruses. But the researchers found no harmful effects in the mice. The researchers think that turning the lentivirus into a lentiviral vector made it safe.

“Considering the mouse model data and the absence of detectible genotoxicity during long-term expression in the hemophilia B dogs, the lentiviral vectors have a very encouraging safety profile in this case,” Nichols said.

More work still needs to be done before this gene therapy approach can be used in human clinical trials. For instance, researchers hope to increase the potency of the therapy to decrease spontaneous bleeding even more while also keeping the therapy safe.

Before the treatment, the hemophilia dogs had no sign of factor IX production. After the treatment, they exhibited between 1 and 3 percent of the production found in normal dogs. This slight increase was enough to substantially decrease bleeding events.

Still, Nichols said it would be best if they could boost factor IX production to between 5 and 10 percent of normal while still remaining safe. This amount of factor IX expression could potentially eliminate spontaneous bleeding events for people with hemophilia B.

Check Science Translational Medicine for a full list of authors. UNC authors include three members of the Department of Pathology and Laboratory Medicine: Dwight Bellinger, DVM, PhD, a professor; Elizabeth Merricks, PhD, a research specialist; and Robin Raymer, BS, the research operations manager at the Francis Owen Blood Research Laboratory. Nichols is a professor in the UNC Division of Cardiology and the Department of Pathology and Laboratory Medicine.

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Source: <http://news.unchealthcare.org/news/2015/march/new-gene-therapy-for-hemophilia-shows-potential-as-safe-treatment>

Credit: Mark Derewicz, UNC School of Medicine



National Hemophilia Foundation's Washington Days

By Terry Stone and Paul Brayshaw

A tradition is a belief or behavior passed down within a group or society with symbolic meaning or special significance with origins in the past. Without a doubt, this IS a perfect way to explain the true essence of NHF's Washington Days. Its roots were planted in the unsettled soil of past challenges this community faced; thanks to strong voices and heart-driven advocacy over many years, the hemophilia community has blossomed into a well-respected leader whose voice continues to drive change. So just like the year before, the Nation's Capital welcomed more than 300 advocates as they came from trains, planes, and automobiles to join this annual advocacy effort from February 26-28th. Armed with their families, their EOBs, and an unwavering dedication, they were ready to ask our nation's legislators to help with several issues of concern.



The gathering site was the Marriott Crystal Gateway Hotel, host to yet another bleeding disorders family reunion and Washington Days event. The first day's meeting helped set the stage for the next day of visits on the hill by orienting attendees to the issues at hand, followed by dinner and time to network across state lines within one room. The next day started with a hearty breakfast, while buses stood at the ready in the falling snow to transport the eager participants into the city.

The legislative agenda this year was three issues that impact the quality and affordability of expert care. The first issue was the request to preserve the current funding level for Federal Hemophilia Programs. Funding through the Health Resources and Services Administration and Child Health Bureau help

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National Hemophilia Foundation's Washington Days *continued*

support our HTC model of care which offers multidisciplinary services like physical therapy assessment, case management, and social worker support. The CDC Division of Blood Disorders offers funding for HTC research, surveillance, and prevention activities. Education and outreach programming so critical to community members are also subsidized thanks to the CDC funding.

Second on the docket is the need for legislation to open the door for better access to skilled nursing facilities for patients with hemophilia. Skilled nursing facilities, (SNFs) are short term facilities where people can go to recover from surgery. Because reimbursement for their services is bundled into an inclusive rate comprising of room and board, nursing, and therapies; SNFs would lose a substantial amount of funds if they accepted a hemophilia patient because the cost of providing that patient with clotting factor would far exceed their daily bundle reimbursement. Medicare allows for certain high cost services to be billed separately outside of the bundled rate. If the law is changed, then more hemophilia patients would be able to access a SNF instead of having to stay in more expensive hospital facilities.

Lastly, support is needed for The Patients' Access to Treatments Act (PATA). There has been a growing concern that some insurance companies are creating a fourth specialty tier in their drug formulary and then moving expensive biological products into this tier. Rather than paying a flat fee copay as with the other tiers, some patients are being asked to pay a percentage of the drug from 25 – 33%. Many of these drugs are very expensive, like clotting factor. With no generic alternative, this can leave a patient in a difficult financial bind. The bill, HR 460 had bipartisan support last year of 142 co-sponsors and is being re-introduced this year. It levels the fairness in out of pocket expenses for all patients whether they use generic drugs or have no alternative but to use biological products for their life-sustaining therapies.

After a long and effective day on the hill, messages were heard and advocates for the bleeding disorder community felt accomplished that they did their part to help. The tradition continues!

Source: Matrix Health Group Newsletter, Spring 2015

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