HNC/HSC Teen Retreat
July 25 - 27
Asheboro, NC

For three days, 22 teen members of Hemophilia of North Carolina and Hemophilia of South Carolina met in Asheboro, NC to share, connect and develop their understanding of advocacy.

Facilitators challenged youth to consider what it means to be an advocate, in various aspects of their lives: politics, peer groups, even with their healthcare providers. Team activities allowed the youth to engage in meaningful conversations and make powerful connections, and much was shared regarding their stay. Below is a small collection of many affirmations that were shared amongst the teens and staff as we reflected on the Retreat:

I made wonderful new friends. I loved the zip lining experience. Being able to bond and have fun was just amazing.

I feel like I made friends with everybody. I feel like I opened up to a lot of people I didn’t think I would.

The zip line brought us all closer. The connections and adrenaline was a really cool feeling.

I am thankful for having friends to talk to. They made my day.

I really enjoyed this Teen Retreat because of all the advisors, especially since they helped us have an enjoyable time.

This weekend I’ve made so many good memories! I will never forget all of these friendly and amazing people! And I am very thankful to have the opportunity to get to come on these trips. Thank you!

I’m a better person thanks to this time with all of you.

All the chaperones/leaders are pretty cool.

Thanks for giving me courage.

Also held at the Retreat were fun outdoor activities – the teens went on a nighttime zip line course, high ropes course, and a dip in the lake that featured a 100 ft. water slide!

Across the board, everyone in attendance took much away from their experience. This experience reinforced HNC, HSC and Palmetto Health staff on how empowered our youth are. We look forward to working with these teens – and our other young adults – to continue strengthening the collective voice of our youth.

Save The Date
HNC Statewide Yard Sale
October 25, 2014

HNC SOAR Retreat
Winston Salem, NC
November 7-9, 2014

HNC Holiday Celebration
Greenville, NC
December 6, 2014

HNC Casino Night
Location TBA
January 2015

HNC Educational Scholarship Dinner
Location TBA
January 2015

NHF Washington Days
Washington, D.C.
February 25 – 27, 2015

HFA Symposium
St. Louis, MO
March 26 – 28, 2015
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.

MISSION STATEMENT
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.

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.

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.

Resource Information
National Hemophilia Foundation
www.hemophilia.org

Hemophilia Federation 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
From the HNC Office

So Long, Summer…

There have been a few times that HNC staff have looked around and said aloud, Where did the summer go? How did we get here so quickly? It seems that between the retreats, meetings, projects, and gearing up for the Hemophilia Walk, time has flown by.

While our plates are full, there’s so much to be excited about. HNC as a community is accomplishing a great deal – our membership is growing, programs are strengthening and we’re moving forward in many aspects. Steadily, HNC is heading towards collective goals and finding new ways to bring supporting programs and services statewide. We are building additional time into our programs in order to hear from members about their visions for the organization and how we can continue to meet the needs of the community as a whole.

As we look toward the future, we hope that you will assist us in our efforts to advance the organization so that we continue to be a voice for the NC bleeding disorders community. Your insights, visions and passions are important to us and are what make us such a distinctive community. It is your skills and passion to make a difference that inspires and motivates us.

We are here for you, for your loved ones, and the community at large. Throughout this newsletter you will find ways that you can support us, but know that we are ultimately here to support you. Call, email or stop by anytime; we appreciate the discussions.

Hope to see you soon,
Charlene and Lakia
HNC Walk Kickoff
August 16
Chapel Hill, NC

It was a Carnival at the HNC Walk Kickoff this year! 60 members arrived to partake in a day’s worth of fun activities, a magic show, snow cones, and plenty of games to play for a chance to win cool prizes!

The Walk Kickoff gets all HNC members and supporters ready for the annual Walk, which takes place this year on Saturday, October 11th. Members receive information about how to organize a team for the Walk, along with resources on raising funds for their team.

If you weren’t able to attend the Kickoff, and want to start your own team, not to worry! HNC staff are here to help. Feel free to contact us here at the office to get you started with a Team Captain packet. It’s never too early to plan for 2015!

Thank you to all of our HNC members, family, friends and sponsors…you work so hard to make the Walk what it is, and we’re truly grateful for your dedication!
Members of the Board of Directors of Hemophilia of North Carolina participated in an energizing and informative all-day retreat in Greensboro on August 2, 2014 that was designed to enhance the Board’s governance and fundraising skills. The retreat was made possible by a grant from the National Hemophilia Foundation.

Facilitated by consultant Dave Sternberg of the Fort Lauderdale firm Loring, Sternberg, & Associates, the retreat agenda covered topics such as the current philanthropic landscape; best practices in board governance; how to secure funding to support the agency’s vision and mission; and strategic planning. Sternberg led board members through a series of exercises to help identify ways in which board practices could be strengthened.

It was generally agreed that the agency needs an updated strategic plan and that the base of financial support should be broadened considerably. A number of board members were surprised to learn that of the $335 billion in charitable dollars donated in the United States in 2013, 72% came from individuals; 15% from foundations; 8% from bequests; and only 5% from corporations. HNC’s fundraising efforts should thus focus on finding and cultivating more individual donors.

Concern was expressed by a number of those in attendance that the agency’s visibility among the general public could be raised, as awareness of HNC’s existence and activities is not optimal. Members also agreed that recruiting and orienting new directors and assessing board performance need improvement. The board is in the process of taking an inventory of current members’ expertise, skills, and demographics in order to pinpoint any gaps that need to be addressed to make a more balanced board, and then orientation and assessment policies will be developed.

Other follow-up steps agreed upon include the initiation of monthly board meetings (both telephonic and face-to-face) and the establishment of time-limited work groups to complete high-priority tasks. The retreat was a terrifically valuable opportunity to step back and take a bird’s-eye view of HNC’s successes and challenges, and board members emerged recharged and with a clearer sense of where HNC needs to go and how to get there.
2014 HNC Family Retreat
August 10 -12
Pine Knoll Shores

Over 70 people arrived to beautiful Pine Knoll Shores for the HNC Family Retreat. At first, thunderstorms were looming in the forecast, but thankfully the skies cleared and all were able to enjoy a great time at the Outer Banks!

The Kickoff Festival, held on the opening night of the Retreat, was a huge success. Families participated in a variety of activities to win prizes, from corn hole, to ring toss, to “Minute to Win It” games. From face-painting to the photo booth, everyone went to bed with a smile. Special thanks to Crystal Coast Photo Booth for providing the fun photo services!

Topics discussed at the Family Retreat included consumer rights, preparing a child for school, and an interactive session where youth were able to work with their parents on talking about the care of their bleeding disorders. The Kids Track featured the famous teddy bear wellness center, and the kids also created and launched their own hot air balloon kites!

On the last night of the Retreat, all attendees were treated to a special talent show. Facilitators from Beyond Recreation, sponsored by Biogen Idec, arrived to teach the basics of circus arts, and there were many adults and kids ready to show off their newfound skills! Who knew the HNC community was filled with so many jugglers, plate spinners, dancers and singers?

Thank you to all who attended, as well as our dedicated volunteers, for making such a memorable Retreat. We hope to see you and many others next year!

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2014 HNC Family Retreat:
Do you know what the color of collected plasma looks like? Or the stages of development beginning from a plasma donation to the development of factor treatment? HNC members had a chance to find the answers to these questions, as HNC partnered with CSL Behring to host a tour at their local Plasma Center in Durham, NC, along with an educational luncheon with guest speakers.

The luncheon was held at the Marriott City Center, featuring speakers Jenifer Wald and Henry Mead, who shared some background on plasma collection and advances in product development. Jenifer, a CSL Plasma Regional Director, provided an overview of the plasma collection process and the CSL Integrated Safety System, the quality assurance processes that CSL uses in the various stages of manufacturing products. Henry Mead, from CSL Behring Medical Affairs, discussed some of the recent innovations in developing recombinant products for the bleeding disorders community and provided a fascinating glimpse into potential future therapies. The presentations were a perfect prelude to visiting the Plasma Donation Center. HNC sincerely appreciates the time that Jenifer and Henry spent with us in Durham.

CSL Behring itself monitors the Plasma Donation Center, as well as the Plasma Protein Therapies Association and regulatory agencies, to ensure appropriate safety measures and practices are maintained. All plasma donations are assessed on a regular basis. The Durham location has space accommodations for over 40 donors at a given time, and CSL Behring is currently in the process of developing another plasma donation center in Winston-Salem.

Attendees left the event with much insight into the initial steps behind creating beneficial therapies. HNC plans to host another plasma donation center tour, so if you weren’t able to attend this event, we hope you can join us in the future!
**Upcoming Events**

**HNC Walk Event**

October 11
Morrisville, NC

The 7th Annual Hemophilia Walk is just around the corner! The largest fundraising event for HNC is taking place on Saturday, October 11th at Lake Crabtree County Park in Morrisville. Registration begins at 9:00am and the walk starts at 10:00am.

Planning is well underway and to date, we’ve raised over $80,000 in local support and our goal this year is $100,000 with 1000 walkers!! We welcome our Walk Chair Team this year, Team Hulk Smash, led by captain Gillian Schultz.

The Hemophilia Walk is the National Hemophilia Foundation’s (NHF) largest event dedicated to finding better treatments and cures for bleeding and clotting disorders, and to preventing the complications of these disorders through awareness, education, advocacy and research. The walk in North Carolina is a collaborative effort between NHF and HNC. The North Carolina chapter is proud to be one of 31 locations around the country participating in this program. 100% of proceeds raised locally will go directly to HNC and help our chapter continue to provide programs and services to our local community.

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 late to get involved, even after the walk – start your walk team today! Visit our webpage at www.hemophilia-nc.org to get information on registering for the Walk and creating a fundraising team. The site features information for sponsors, teams and volunteers.

Sponsorship information 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 Statewide Yard Sale**

October 25
Morrisville, NC

Do you have junk in your trunk? If so, consider joining HNC in hosting a statewide yard sale event! On Saturday, October 25, HNC will host a yard sale in Morrisville, NC, at the Morrisville Chamber of Commerce. Our goal is to have HNC members around the state hosting their own yard sale at the same time, as a collective effort to raise money for HNC.

If you are unable to host a yard sale of your own, and you’re near the area, we’d love to take any donations you may have off your hands! You can donate any items excluding large furniture (sofa, TV, etc) to the HNC office, located at 260 Town Hall Drive in Morrisville. Feel free to contact us with any questions toll-free at 800-990-5557.

**HNC SOAR Retreat**

November 7-9
Winston Salem, NC

Save the date! HNC’s SOAR program is having their annual Retreat on November 7-9 at the beautiful Graylyn Conference Center in Winston Salem. The Retreat will focus on providing content that gives attendees a better understanding of their bleeding disorder, as well as their child’s bleeding disorder. Participants will also learn about the variety of available resources to enrich their lives.

The retreat will be open to women affected by a bleeding disorder, female caregivers of a girl with a bleeding disorder and girls 12 and older diagnosed with a bleeding disorder.

SOAR is a program of HNC, designed to increase the knowledge, awareness and support for girls and women with bleeding disorders. To find out more about SOAR, please contact us at soar@hemophilia-nc.org.

**HNC Holiday Celebration**

December 6
Greenville, NC

The Holiday Celebration will be held Saturday, December 6 this year, so mark your calendar! This year’s theme, The Magic of Community & Giving Back, will hopefully help all of us reflect on and celebrate the connections and memories we’ve collected this year.

The party will be held in Greenville, NC, with gifts for every child in attendance. Enjoy food, fun games, and take a photo with Santa! For special entertainment, we will present a magic show! Magician Joshua Lozoff combines amazing illusions with mental feats that explore the possibilities of the human mind. In one moment, he magically solves a Rubik’s Cube just by tossing it in the air, and in the next he predicts a volunteer’s thoughts even before she knows them herself!

Be sure to visit the HNC website in the coming weeks for more information and to register. We can’t wait to see you there!
Cuidado dental

Las personas con trastornos hemorrágicos no tienen más probabilidades de tener problemas dentales. Sin embargo, quienes no cuidan bien sus dientes tienen un mayor riesgo de tener complicaciones si llegan a tener problemas dentales. Es importante prevenir los problemas dentales y mantener una boca sana para ayudar a conservar la calidad de vida y evitar los riesgos de los procedimientos dentales, particularmente las operaciones quirúrgicas.

Con frecuencia, las personas con trastornos hemorrágicos y sus familias están tan ocupadas con el manejo del trastorno que pueden descuidar el cuidado dental. Sin embargo, debido a que la salud dental afecta la salud en general, es vital tener buenos hábitos y cuidado dental. El cuidado dental idealmente debería empezar cuando su hijo es pequeño, para que se pueda establecer un buen programa preventivo.

Cómo encontrar a un dentista

Para un niño con hemofilia u otro trastorno hemorrágico, es importante encontrar a un dentista con conocimiento de los trastornos hemorrágicos y del plan general del cuidado de su hijo. Cuando encuentre a un dentista con quien tanto usted como su hijo se sientan cómodos, póngalo en contacto con su Centro de Tratamiento de Hemofilia (HTC). Si no puede encontrar a un dentista primario, comuníquese con el HTC. Con frecuencia ellos pueden recomendar a un dentista o pueden tener alguno como parte de su equipo de tratamiento integral.

Ellos pueden desarrollar juntos un plan de tratamiento adecuado y asegurarse de que ciertos procedimientos se realicen de manera segura. Si su hijo tiene una emergencia, un dentista primario debería saber cómo manejar las complicaciones hemorrágicas. Asegúrese de hablar con su dentista sobre el trastorno hemorrágico y las necesidades especiales de su hijo: informe al dentista si su hijo está en terapia profiláctica y cómo trata usted cualquier episodio hemorrágico. Asegúrese de preguntar a su dentista sobre los riesgos de cualquier procedimiento, especialmente si se necesita un anestésico local. Debido a que el anestésico se inyecta algunas veces en un área con vasos sanguíneos mayores, es necesario que entienda con anticipación el riesgo y tenga tiempo de consultarlo con el HTC.

La meta de un buen cuidado dental

Nunca es demasiado temprano para empezar a cuidar bien los dientes de su hijo. Incluso a los recién nacidos hay que limpiarles la boca y encías suavemente con una almohadilla de gaza suave después de cada alimentación.

Las encías (llamadas gingiva), que son tejido suave, cubre los huesos que rodean las raíces de los dientes. Una de las primeras etapas de la enfermedad de las encías (llamada enfermedad periodontal) es la gingivitis, una inflamación de las encías causada por bacterias. Una de las primeras señales de la enfermedad de las encías es sangrado espontáneo.

La enfermedad de las encías es un problema mucho más complicado para las personas con trastornos hemorrágicos debido a que van a sangrar por más tiempo. Tratar la hemorragia con el factor de coagulación o con otras terapias puede detener temporalmente la hemorragia, pero no la enfermedad de las encías que está latente.

Para prevenir la enfermedad de las encías, enseñe a su hijo a cepillarse los dientes y limpiarlos con seda dental con regularidad. Las encías sanas no sangran generalmente, incluso en una persona con un trastorno hemorrágico. Sin embargo, es posible que puedan sangrar un poco si su hijo se cepilla demasiado fuerte. No detenga la rutina de cepillado o limpieza con la seda dental si hay una hemorragia leve. Si la hemorragia dura más de 20 minutos o se detiene y empieza de nuevo, comuníquese con el Centro de Tratamiento de Hemofilia (HTC).

¡La rutina contante de cepillado y uso de seda dental puede ayudar a prevenir la enfermedad de las encías, mantener una sonrisa saludable y proteger los dientes durante toda la vida!

Repasemos la información básica del cuidado dental

Es muy importante cepillarse y usar la seda dental para mantener sanos las encías y los dientes.

Los siguientes son algunas medidas adicionales que puede tomar para asegurar la salud dental:

- Limite la comida y las bebidas azucaradas
- Asista a las citas dentales de rutina
- Hable con su dentista sobre los tratamientos con fluoruro
- Empiece con cuidados dentales preventivos cuando empiecen a salir los dientes del bebé
- No jale los dientes de bebé flojos
- No deje que su hijo corra con algo entre la boca

Tratamiento

- Comuníquese con su Centro de Tratamiento de Hemofilia (HTC) o un hematólogo antes de cualquier procedimiento dental. El HTC y el dentista van a trabajar juntos:
  - Para decidir qué factor de coagulación u otro tratamiento puede ser necesario basado en la gravedad del trastorno hemorrágico y el tipo de procedimientos dentales planificado
  - Para tratar con antibióticos cualquier infección en la boca antes de realizar cualquier procedimiento quirúrgico
  - Para controlar la hemorragia (por ejemplo, enjuagues y procedimientos especiales)
  - Si se necesita medicamentos contra el dolor, no use cualquier medicamento que aumenta la hemorragia, como la aspirina
  - Pregunte al dentista o a su médico sobre alguna dieta especial que pudiera haber para reducir la hemorragia después de los procedimientos dentales, particularmente para la extracción de un diente
  - Siga todos los pasos necesarios descritos por el HTC y el dentista antes de cualquier procedimiento dental, ya sea quirúrgico o no

When considering snacks for your kids, the end of summer doesn’t have to signal the end of healthy eating. Although it is a natural tendency to grab whatever is convenient, prepackaged foods and snacks are usually not the best choice for healthy, growing bodies.

It is especially important to eat healthy if you have a bleeding disorder because healthy nutrients can help you build strong muscle, keep your bones strong and healthy, and help you feel better faster if you have a bleed or get sick.

There are a lot of great tasting, nutritious options for back to school snacks. Sometimes, especially with younger kids, the key is to get creative. Snacks are a great way for kids to get the necessary nutrients their bodies need and meet the recommendations from the USDA’s MyPlate.

**Here are some ideas for back to school snacks:**

- Celery sticks with peanut butter and raisins
- Frozen grapes
- String cheese & whole grain crackers
- Lean turkey or ham & whole grain crackers
- Low-fat cheese
- Apple or apples slices with peanut butter
- Hard-boiled eggs
- Low-fat or Greek yogurt (can add fresh fruit)
- Hummus with various veggies
- Almonds, cashews, peanuts, pumpkin seeds
- Bananas (can add peanut butter & mini chocolate chips)

Continued on page 11
Healthy Back-to-School Snacks
Continued from page 10

- Graham crackers
- Fruit & yogurt smoothies
- Applesauce – save money by making your own (see recipe)
- Various seasonal fresh fruit
- Air popped popcorn
- Various seasonal fresh vegetables with low fat yogurt dip
- Whole grain, low-fat, low sugar granola bars
- Lean meat and cheese roll-ups
- Whole wheat pretzels
- Kale chips

Try to offer fruits and vegetables as snacks first. Most kids do not get the recommended amounts of these foods and generally they offer the most health benefits. Be creative and offer fresh, seasonal fruits and vegetables with low-fat dips or peanut butter. Cutting or making fruit and vegetables into fun shapes can also be a clever way to make fruits and vegetables more appealing to kids.

When considering beverages to offer with snacks, low-fat milk and water are the best options. Try to avoid sugary drinks. An occasional glass of 100% fruit juice will provide a serving of fruit. Avoid juice that is not 100% juice as it is usually high in sugar and offers little or no other nutritional value.

Having a variety of healthy snacks on hand and offering your child a choice will help teach your child what healthy snacks are and give some individuality and ownership to what they choose to eat. Remember to be a good role model and choose to eat healthy too. Stay healthy and strong together.

Homemade Applesauce Recipe (easy)

*This recipe was submitted by a mother of a child with a bleeding disorder. Share your healthy recipe to our FitFactor team at: FitFactor@hemophiliafed.org.

Ingredients:
- 8-10 apples (of your favorite variety), chopped into ½ in pieces (leaving the peel on provides more fiber and vitamins and makes the recipe even easier.)
- ½ tsp of cinnamon (optional)
- ½ C of water

Directions:
Place the apples, water and cinnamon in a pot on the stove. Bring to a boil, cover with a lid and reduce heat to a simmer. Simmer the apples for about 30 minutes, until soft, stirring occasionally.

Remove from heat and mash with a potato masher (applesauce will be chunky). For finer applesauce, mix with a blender (immersion blenders work great) or a food processor.

Sprinkle with cinnamon (if desired). If you prefer a little sweeter applesauce, stir in a small amount of pure maple syrup. Keep prepared applesauce in an airtight container in the refrigerator.

Source:
Hemophilia Federation of America FitFactor, September 2014

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.

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.
Blood Brotherhood Update

By Matt Igelman

The Blood Brotherhood program here in NC has had another exciting and active year. As we close another grant year, we held our educational (and relaxing) beach retreat in Kure Beach, NC. This year’s topic at the beach was nutrition and we had a great presentation on eating healthy and discussion about the impact weight has on our joints. As I reflect back over this year’s programming, there were great presenters, our Blood Brothers learned a lot, and we sure had fun along the way. Meeting other adult men, who share the understanding of living with a bleeding disorder, is a unique experience.

As we look forward to next year with the Blood Brotherhood program, I encourage all adult guys out there to make time to attend our programs. The programs next year will continue to be regionally located throughout the state, so whether we’re close or far, join us when you can.

Meeting dates and locations for 2015 will be posted at www.hemophilia-nc.org when available. As always, thanks to Hemophilia Federation of America for presenting this program and opportunity here in NC and many 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: http://www.hemophiliafed.org/programs/blood-brotherhood/.

For more information on Blood Brotherhood locally, visit the HNC website www.hemophilia-nc.org and join our Blood Brotherhood group at future events!

HOPE Update

HOPE is an HNC program for families with children from birth to twelve diagnosed with a bleeding disorder. Open to any member of HNC, programs are geared towards the unique needs of these families — to educate and support them so that their children can lead fulfilling lives.

HOPE engages in various activities throughout the year, and there are staff and volunteers available to provide resources and information needed for you and your family. You can become a member of HOPE to attend these events and obtain materials. We’re here to help!

For more information, please contact Gillian Schultz, volunteer HOPE Program Coordinator, at gillian.schultz@hemophilia-nc.org or Lakia Poole, HNC Assistant Director at info@hemophilia-nc.org. You can also reach the HNC office at (800) 990-5557.
Walk Team Fundraisers
Some highlights showing the strength of our community for the NC Hemophilia Walk

Helpful Paws —
benefiting Walk team: Wonderfully Made
Helpful Paws is a company that helps charitable organizations and fundraisers receive money through art appreciation. With each purchase of a portrait, half of the proceeds go to an organization/fundraiser featured on the website. HNC’s Hemophilia Walk has been selected this year! Check out their website: www.helpfulpaws.org

Firehouse Subs —
benefiting Walk team: Wonderfully Made
Firehouse Subs in Winston-Salem hosted a Community Commit-ment Night on September 5th where HNC will receive 10% of the proceeds.

Family
Fun Day –
benefiting Walk team: Wonderfully Made
Team Wonder-fully Made hosted a Family Fun Day on Sunday, September 21st in Kernersville, to raise funds for the Hemophilia Walk. The event featured an afternoon of family fun with children’s activities, silent auction and a raffle! Tickets were $8 per individual, $25 for 4. Ticket purchase included lunch and kids’ activities.

Lifting For Luke —
benefiting Walk team: Hemo Hero
In July, Erika Wilson (Team Captain for Hemo Hero) and her team hosted a Lifting for Luke fundraiser at CrossFit in Spring Lake, NC. Attendees participated in a rigorous workout routine, while giving funds for the Walk, through donations and tickets for great raffle prizes. By the last push-up, over $700 were raised! Many thanks to Erika and all the Hemo Heroes who helped make the event such a success.

Hattitude for Hemophilia —
benefiting Walk team: Jaden’s Jewels & Jaden’s Gents
In August, Erica Cook (Team Captain for Jaden’s Jewels & Jaden’s Gents) hosted a Hattitude for Hemophilia fundraiser in Winston-Salem, NC. Attendees were en couraged to wear their favorite hat or other headdress to show off their “hattitude”! They did not disappoint; some hats featured feathers, others had gorgeous bead and sequin adornments. Powerful stories were shared about those who have surrounded Erica’s team to support not only the Walk but the larger bleeding disorders community. Thanks to all the “Jewels” and “Gents” who provide such strength in numbers!

Ice Cream Social & Bake Sale —
benefiting Walk team: Biogen Idec
The Biogen Idec RTP building has continuously been coming up with fun ways to engage their local employees with HNC and the Walk. Thus far, they’ve held an ice cream social and two bake sales, which were both extremely successful in helping to raise funds, provide information, and increase their walkers. They have more events planned and we look forward to seeing what they’ll come up with next.

Bake Sale & Pizza By the Slice —
benefiting Walk team: Miles for Andrew
In September, the Bratton family has been hosting multiple fundraisers include bake sales and a pizza fundraiser at their work. They’ve proven their fundraising skills already by hosting their 2nd Annual Car & Bike show back in March in honor of Hemophilia Awareness Month so we’re confident they’ll have no trouble finding buyers for all the pizza and delicious sweets!

REMEMBER: It’s never too early or too late to fundraise for the NC Walk. This is our largest fundraiser and is a year-round effort of the community!
Advocacy Update

The HNC Advocacy Committee holds conference calls monthly to discuss important legislative matters as they pertain to the bleeding disorder community. Over recent weeks, important legislative developments have taken place, including:

- Mardy Peal, a senior planner for the Department of Health and Human Services who worked as an adviser to the Secretary on Medicaid reform, has resigned from her position. She has taken a new job at WellCare, a health maintenance organization.

- NC House and Senate members approved the state budget in July, with Medicaid as a top concern for many. While large cuts to the Medicaid budget were avoided, what remains is a plan to address the reform of our current Medicaid program. The Budget Conference Report, released on July 30, states the following regarding Medicaid Reform in North Carolina:

  SECTION 12H.1. It is the intent of the General Assembly to continue to work toward the details of Medicaid reform during a special session in November 2014. Until the General Assembly enacts legislation authorizing a plan to reform Medicaid, the Department of Health and Human Services (i) shall continue to consult with stakeholder groups, study, and recommend options for Medicaid reform that will provide greater budget predictability for the Medicaid program and (ii) shall not commit the State to any particular course on Medicaid reform and shall not submit any reform-related State plan amendments, waivers, or grant applications nor enter into any contracts related to implementing Medicaid reform.

- HNC, along with other organizations, continues to advocate for passage in the US Congress of HB 460, which would protect people with expensive chronic medical conditions. HB 460 would set a cap on how much insurance companies could charge for co pays on the most expensive medications, such as clotting factor. We expect discussion on HB 460 to continue when Congress reconvenes in 2015.

If you express an interest in advocacy or updates on these current legislative topics, contact the HNC office for more information.
CDC Six-Year Inhibitor Study Released

New Study Findings: Six-year study shows that all people with hemophilia at risk for developing an inhibitor

The journal Haemophilia has published the results of a six-year study called the Hemophilia Inhibitor Research Study (HIRS) that was designed to test the feasibility of conducting national monitoring for inhibitors among people with hemophilia in the United States. The study collected blood specimens on a regular basis from study participants, which were tested at CDC for the presence of an inhibitor. Data were also collected to learn who was at highest risk for developing an inhibitor. Regular testing for an inhibitor is important because the treatment to get rid of the inhibitor is more successful when an inhibitor is identified early. In the study, investigators from 17 hemophilia treatment centers located across the United States enrolled 1,163 people with hemophilia and followed them for up to 6 years to learn the best way to determine who was at risk for developing an inhibitor. HIRS investigators and CDC researchers found that people with hemophilia of all ages were at risk for developing an inhibitor and that unless people are regularly tested for an inhibitor, they can have one and not know it until it causes a severe bleeding problem.

Main Findings from this Study

- All people with hemophilia are at risk for developing inhibitors
- One-third of newly-developed inhibitors were found in people with non-severe hemophilia
- One-half were over the age 5 years
- One quarter had used infused factor for more than 150 days
- Six out of ten people with hemophilia with an inhibitor had no symptoms
- Regular screening of people with hemophilia for early detection of an inhibitor by the CDC laboratory is feasible, and will inform efforts to measure rates of this complication

Critical Gaps & Future Directions

There is still much to learn about inhibitors and how to prevent and manage health problems associated with them.

- Because there is no effective monitoring system, the actual number of people with hemophilia with an inhibitor in the United States is not known.
- The impact of risk factors (Risk factors are characteristics, conditions, or behaviors that can increase or decrease the risk for developing an inhibitor) on inhibitors is not fully understood.
- An estimated 60% of people with an inhibitor do not have symptoms, but may develop health problems from an undetected inhibitor.
- People with hemophilia receiving care in federally funded hemophilia treatment centers will be tested each year for an inhibitor by the CDC Division of Blood Disorders laboratory as part of the blood monitoring program called Community Counts.

About this Study

Researchers compiled information from 1,163 people with hemophilia over a 6-year period to learn more about how to detect inhibitors and to collect information about what causes them.

CDC Activities

The Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD), Division of Blood Disorders (DBD) considers inhibitors to hemophilia treatment a major public health concern and is committed to monitoring the numbers of people affected by this health problem, raising awareness about the need for inhibitor screening and promoting health education.

More Information

- To learn more about hemophilia, please visit the CDC Hemophilia website: www.cdc.gov/ncbddd/hemophilia/
- To learn more about ongoing research in hemophilia, please visit the CDC Research page on hemophilia: www.cdc.gov/ncbddd/hemophilia/research.html

Paper Reference

ON THE NATIONAL & LEGISLATIVE FRONT

NHF Annual Meeting
September 18 – 203
Washington, DC

Participants from Pittsburgh to Puerto Rico and even Pakistan, no less, made up the nearly 3,000 people who made their way to Washington, DC, September 18-20, for the National Hemophilia Foundation’s (NHF’s) 66th Annual Meeting, Nothing About Us Without Us.

Babies in strollers pushed by parents and grandparents, providers from the network of hemophilia treatment centers (HTCs), pharmacists and researchers, industry partners and chapter staff and volunteers—all made a capital connection this year. Attendees had more than 60 sessions to choose from, including:

- Hepatitis C Updates
- Celebrating 20 Years of Blood Safety and the Ricky Ray Act
- A NEW Teen Track
- A series of roundtable discussion
- Music Therapy for Pain Management
- Fathers and Daughters
- POW! SPLAT! WHAM! Comic Books, Coping and Chronic Illness

The Blood Work art display lined one of the halls, the first such exhibit at an NHF Annual Meeting. Kids and teens in the Childcare Program spent a fascinating day at the Smithsonian National Museum of Natural History. Everyone enjoyed a Night at the Museum—the Final Night Event at the Smithsonian National Air and Space Museum, sponsored by Biogen Idec.

Pull out your smartphone and circle your calendars because NHF’s 67th Annual Meeting is heading out west to the great state of Texas…Dallas, that is. The dates are August 13-15, 2015. See y’all there!

Read more and watch videos from the NHF Annual Meeting at their website: www.hemophilia.org.

Dr. Donna Shalala shares her experience with health issues related to HIV/AIDS while working as HHS Secretary.

Dr. Dana Kuhn speaks at the presentation, Celebrating 20 Years of Blood Safety & the Ricky Ray Act.

Leaving our mark at the Blood Work art exhibit!
When it comes to your factor therapy, you have choices. And at Biogen Idec, we recognize the importance of researching and delivering additional factors to the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

WANT TO KNOW MORE ABOUT YOUR FACTOR OPTIONS?

When it comes to your factor therapy, you have choices. And at Biogen Idec, we recognize the importance of researching and delivering additional factors to the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

TO LEARN MORE ABOUT THESE OPTIONS, CONTACT YOUR CoRe MANAGER:
Nikita Lyons-Murry | Phone: 615.525.1003 | E-mail: Nikita.LyonsMurry@biogenidec.com
While the Affordable Care Act did many great things to provide access to healthcare coverage for the bleeding disorders community, affordability still remains an issue for many. There are some excellent resources to assist our community, whether it is to help cover your private insurance premiums or other out-of-pocket insurance costs, help pay utility bills in an emergency or services that can link you to local resources in your own community.

National Hemophilia Foundation’s (NHF) public policy team gathered and compiled information about these patient assistance programs, including general eligibility criteria and contact information. Eligibility criteria and coverage for these programs frequently change, so we will periodically update the document as we receive information about any changes. Many of these programs have representatives available to answer any questions you may have about your eligibility or to direct you to other resources that may be available.

While these programs are an invaluable resource for our community, there are some situations in which you may not be able to use the assistance. Unfortunately, in the past several months some insurers in a few states (Oregon, Idaho, Montana, Nebraska, Louisiana, and New York) have decided that they will not accept assistance payments from third parties, such as some of the assistance programs listed in this document, for health plans that were purchased in the health insurance marketplaces. Others have recently indicated that they have or are considering changing their policy on accepting manufacturer co-pay cards for plans purchased outside the marketplace, such as employer-sponsored plans. This creates some obvious hardship for our community.

NHF will continue to address this issue with the private insurers that have changed their policies.

NHF Issue Brief
August 2014
http://www.hemophilia.org/Newsroom/Advocacy-Legislative-News

ON THE NATIONAL & LEGISLATIVE FRONT

Find Patient Assistance Programs to Help Cover Your Insurance Costs

Apply for a card and start reducing your out-of-pocket factor costs today:

Grifols Factor Savings Card Programs

AlphaNine® SD
Coagulation Factor IX (Human)

Call
855-355-2574
AlphaNine SD Savings Card Program Help Desk
OR
Visit
www.alphaninecard.com
AlphaNine SD Savings Card Program Website

Alphanate®
Antihemophilic Factor/Iron Willebrand Factor Complex (Human)

Call
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Alphanate Savings Card Program Help Desk
OR
Visit
www.alphanatecard.com
Alphanate Savings Card Program Website

GRIFOLS
www.grifolsusa.com
We may be able to help.

Bayer offers a range of programs that can help you navigate insurance questions about your hemophilia A treatment. If you’re having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call 1-800-288-8374 and press 1 to speak to a trained insurance specialist!

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Donate to HNC

Your support makes it possible for Hemophilia of North Carolina to continue its many programs and services to the bleeding disorders community. It means education for young parents, scholarship opportunities, financial assistance to families in crisis, and much more. Your dollars make a difference.

NAME: 
ADDRESS: 
CITY:    STATE:   ZIP:
HOME PHONE:   CELL PHONE: 
COMMENTS: 
AMOUNT:

Donate to HNC

Please make checks payable to Hemophilia of North Carolina. We are a 501c(3) non-profit organization, so your donation will be tax deductible to the extent allowed by law. We will send you a receipt for tax purposes.

You may also donate online at www.hemophilia-nc.org with your credit card.

Thank you!

To add your cash/check donations to your team’s webpage, follow the instructions below. Remember: when turning in any cash or checks, please identify who is responsible for the donation.

⇒ Go to www.hemophilia.org/walk. Click NC (Raleigh) on the right of the screen
⇒ Sign in with your username & password
⇒ On the left menu, select “Fundraising”. Once the submenu appears, select “Cash/Check”
⇒ Enter your donor’s information (Note: In order for a donor to receive a tax letter, all contact information is required)
Save the Date!

Saturday, October 11, 2014

Lake Crabtree County Park
Morrisville, NC

Check-in begins at 9am, Walk starts at 10am

Face painting
Fun, Games, and Prizes
Dogs are welcome too!

www.hemophilia.org/walk