Save The Date

HNC Blood Brotherhood Event
Morrisville, NC
January 10, 2015

HNC Casino Night
Charlotte, NC
January 24, 2015

HNC SOAR Event
Location TBA
February 2015

NOW Conference
Phoenix, AZ
February 20 – 22, 2015

NHF Washington Days
Washington, D.C.
February 25 – 27, 2014

HNC Blood Brotherhood Event
Chapel Hill, NC
March 14, 2015

HFA Symposium
St. Louis, MO
March 26 – 28, 2014

HNC Annual Meeting
Location TBA
April 2015

2014 with HNC . . .
A Look at Our Year

Hemophilia of North Carolina

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

**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
  htccenter.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

- **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

- **Patent Notification System**
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  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

**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 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

Ch-ch-changes!

What a difference a year makes. 2014 has brought some fantastic experiences to HNC, and we see the impact in our community:

• The hiring of a full-time Assistant Director has significantly helped in the delegation of leadership and program development

• Summer Interns met the need for additional office support during the busy months when HNC retreats, events and conferences took place

• HNC membership, program enrollment and buy-in has grown and continued to increase throughout the year

• Annual events and retreats have been a huge success this year, and attendance is diversifying as more HNC members participate, sometimes for the first time

• Our 2014 Hemophilia Walk exceeded our fundraising goal, with community members, partners and supporters showing up in abundant numbers to invest in the shared vision for HNC

When a new year is around the corner, people get excited about what could be next as well as what changes they’re looking forward to, and we at HNC are no different. We’re dreaming about new and deeper connections with Blood Brothers across the state, as well as more opportunities for them to connect. We envision an increase in advocacy and awareness for the SOAR program, and improved visibility of Latin Union members at HNC events. We’re looking forward to casting a wider net for financial support, to ensure the longevity of this organization. As you can see, there is much that we’re dreaming about and planning for.

So as we gear up for 2015, our sincere hope is that you join us in support of these goals. We’re so grateful for the tireless efforts that all of you make to keep HNC what it is – a powerful, compassionate force within the bleeding disorders community.

Happy Holidays, and we wish you nothing but the best for 2015.

With Gratitude,
Charlene & Lakia
HNC Sets a New Record for the 2014 Walk!

For the 2014 Hemophilia Walk, an unprecedented amount was raised for HNC – $111,000! For exceeding our $100,000 goal, we have HNC members, sponsors, and community partners to thank. Your support and investment is outstanding, and truly appreciated!

HNC held its 7th Annual Walk event in Morrisville on October 11th. Over 600 people were in attendance this year. Early morning clouds soon parted, and beautiful sunshine met the crowd, as everyone enjoyed fun activities. Starbucks coffee, fresh fruit and muffins were provided to attendees as they arrived. Walkers with their four-legged friends were sure to grab a bag of doggie treats, provided again this year by Pet Mania.

The morning featured a great lineup of entertainment – face painting by Ebony Child, a photo booth (complete with fun props!) from MidAtlantic Photo (sponsored by MedPro Rx), an inflatable slide for kids to enjoy, compliments of Interactive Playgrounds, and great music from Performance DJ.

HNC Staff welcomed everyone, introducing our Walk Emcee Heather Waliga of ABC11. Heather’s energetic personality kept the crowd engaged and excited throughout the morning.

Back by popular demand, the dance group Jacoreiography dazzled everyone with another incredible performance. From their suits to their moves, the show was impeccable!

Mike Graham shared a few words on behalf of Grifols, HNC’s Local Presenting Sponsor. Neil Frick, the National Hemophilia Foundation’s VP for Research & Medical Information, also addressed the crowd, congratulating everyone’s hard work towards HNC’s fundraising success, and what this means for the bleeding disorders community. Gillian Schultz, the 2014 Walk Chair, joined the stage with her family to share their story and their involvement with HNC.

Brey Curtis of Baxter International Inc. addressed the crowd and presented team Clot Hoppers with an award for being the top fundraising team.

At each Walk event, special awards are presented to recognize individuals and teams that have displayed outstanding efforts to support the HNC Walk:

- **Hospital Cup** – this award recognizes the staff of the medical group or hemophilia treatment center that has raised the most funds. This year, the UNCTarhealers took home the prize, and remain undefeated for this award.
- **King, Queen & Junior Droplet** – The coveted Droplet award is given to three individuals who have demonstrated extraordinary support for the Walk. Reid Coleman was the winner of the King Droplet award (setting a record by winning the award twice!), Ashley Davis won Queen Droplet, and Luke Wilson took home the Junior Droplet award.
- **Top 3 Fundraising Teams** – Clot Hoppers, Jaden’s Jewels and Jaden’s Gents, Wonderfully Made

With awards given, it was time to begin the actual walk. Heather announced the start of the walk, and the teams took off. Kids were able to participate in a fun scavenger hunt along the trail. When everyone returned, bag lunches, courtesy of Jason’s Deli were distributed to recharge. And thanks to Walgreens, there was plenty of bottled water to quench everyone’s thirst.

A special thank you to all of our sponsors who graciously supported the Walk this year. We are truly appreciative of your continued investment in the work of HNC. A very special thank you to all of our Walk teams and their respective Captains who worked tirelessly to help reach this astounding goal!

Continued
Top 3 Fundraising Teams & Captains
Clot Hoppers – Charles Register
Jaden’s Jewels and Jaden’s Gents – Gwen Stewart & Erica Cook
Wonderfully Made – Erin Otey

Our Teams & Captains
Accredo’s Hemophilia Health Services – Diane Mauldin
Bayer – Tara Lowe
Bennett’s Bro’s – Chris Barnes
Biogen Idec – Nikita Lyons-Murry
Cayton’s Clotters – Shannon Elderdice
Clot Hoppers – Charles Register
CSL Plasma – Damonta Burch
Cullen’s Clan – Lindsey Kissell
CVS Caremark – Wayne Cook
Drugco – Tiffany Holland
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Flowers Plantation – Stefanie Balch
GoodGenes – Kelley Sykes
Grifols – Jeff Bridges
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HPC Bruise Crew – Nicole Bailey
Hulk Smash – Gillian Schultz
I.V. League – Michelle Hodge
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Jeaven – Quinteta McNeill
Latin Angels – Matthew Nunez
M.L.D. – Ashley Davis
Miles for Andrew – Helen Bratton
One Drop – Dawn Smith
Out4Blood – Ashley Emory
Peachtree – Stefanie Balch
SOAR – Heidi Traficanti
South Cows – Charlene Cowell
Taylor Jags – Leroy Taylor
Team Andrews – Scott Andrews
Team B – Brittani Allen
Team Bryan – Troy Schoolcraft
Team Hooker – Tyronna Hooker
Team Liam – Lorin Fentress
The Carolina Warriors – Orson Lovelace
The PoKeMats – Lakia Poole
The Rams – Tashara Young
The Woodge Factor – Sharon Sebolt
UNC TarHealers – Tracy Griles
Von WireWhat?! – Annie Jagger
Wake Forest M’s – Ruth Mastrapa
Wake Walkers – Anita Smith
Wonderfully Made – Erin Otey

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HNC NEWS & INFORMATION

Winter 2015
HNC Adult Retreat
September 26 – 28
Parkton, NC

Gorgeous weather and beautiful tucked away grounds kept HNC members enjoying the Adult Retreat. HNC invited members to spend a weekend to learn, share, connect and relax, and everyone did just that!

The Retreat kicked off with a fun Jeopardy-style trivia game, with categories ranging from Pop Culture to U.S. History. Teams worked together to scramble to find the answers in time, but all in all it was a friendly competition!

Saturday and Sunday brought educational and interactive workshops, presented by American Management Association (AMA) and sponsored by Biogen Idec. Those workshops include Express Yourself and Managing Chaos. This AMA series is designed to present effective life skills for individuals living with a bleeding disorder.

There were also opportunities for attendees to enjoy the Retreat grounds, with a great deal of activities to choose from. Canoeing was quite popular, along with BB gun shooting practice and a high ropes course. And it’s just not a Retreat unless a campfire is involved; Saturday evening was complete with enjoying s’mores by an open flame.

The Adult Retreat is held annually, and welcomes any adult age 18 and older living with a bleeding disorder. One guest is permitted to accompany that attendee. The 2015 Adult Retreat will be held at the Trinity Center at Pine Knoll Shores on August 28-30.

HNC Statewide Yard Sale
October 25

HNC held its first Yard Sale fundraiser in October and it proved to be a success! With over $300 earned, we raised funds and awareness about HNC, and helped a lot of members get rid of items just hanging around their homes!

The Yard Sale began at 8:00am, but arrivals started as early as 7:30 am. There was quite a display of items for sale: electronics, cookware, clothes and shoes, children’s books and so much more. Warm chili (both meat and veggie), along with bottled water and soda were sold to comfort those milling through the Yard Sale on a cool Saturday afternoon.

HNC is so grateful for those who contributed items, time and support to the Yard Sale. Due to the success of this year’s sale, we plan to have another in 2015! If you wish to participate in HNC’s Yard Sale, or host one on your own on the same day, please contact HNC staff toll free at 800-990-8997.
Upcoming Events

**HNC Casino Night**
January 24, 2015
Charlotte, NC

Mark your calendar for our 2015 Casino Night, this time in a new location! Our annual Hearts for Hemophilia Casino Night event will be held at Banquet One in Charlotte, NC in January 2015. With food, a silent auction, music and casino games, this is sure to be an enjoyable event for everyone! To purchase tickets and learn more information, please visit the HNC website.

**NHF Washington Days**
February 25 – 27, 2015
Washington, DC

Join other members of the bleeding disorders community and let your voice be heard. The National Hemophilia Foundation’s (NHF) Washington Days conference is an opportunity to meet face-to-face with lawmakers and staff who shape healthcare policies. Attendees will receive information on issues that are critical to their access to quality healthcare, including effective techniques to advocacy. For more information, please visit the NHF website at www.hemophilia.org. To see if HNC can assist with travel expenses for you to join us in D.C., please contact us at info@hemophilia-nc.org.

Creating a better today and tomorrow for patients

Baxter’s employees are united in a mission to save and sustain lives. We are passionate about applying scientific innovation to meet the needs of the millions of people worldwide who depend on our medically necessary therapies and technologies. We focus on increasing access to healthcare, innovating in crucial areas of unmet need, and pursuing creative collaborations that bring our mission to life for patients every day.
HNC establece Nuevo Record en el 2014 Walk!

Durante el 2014 Hemophilia Walk, se logró recaudar la inesperada cifra de $111,000! excediendo nuestra meta inicial de $100,000. Queremos agradecer a nuestros miembros de HNC, patrocinadores y miembros de la comunidad de Hemophilia. Su participación y apoyo fue verdaderamente excepcional y estamos inmensamente agradecidos.

HNC llevó a cabo el 7th Annual Walk el pasado 11 de Octubre en Morrisville. Alrededor de 500 personas fueron participes de este grandioso evento. Desde muy temprano el cielo se despejó y el resplandor del sol se hizo presente para que las personas se divirtieran con las actividades disfrutando de un hermoso día. A medida que los participantes llegaban, recibían café de Starbucks, fruta fresca y muffins. Los participantes que llevaron a sus amiguitos de 4 patas, recibieron una bolsa con golosinas para perros, proveida por nuestros amigos de Pet Mania.

El día fue hermoso y durante la mañana tuvimos diversas actividades y entretenimiento para todos - Ebony Child se encargo de pintar caritas, MidAtlantic Photo de la cabina de fotos para que pudiéramos capturar los momentos graciosos y divertidos, Interactive Playgrounds de las resbaladillas y juegos inflables para que los niños se divirtieran como nunca y por último, Performance DJ nos hizo bailar con su grandiosa mezcla de música.

El Staff de HNC y la maestra de ceremonias Heather Waliga de ABC11 le dieron la más grata bienvenida a todas las personas que llegaban poco a poco. Gracias al gran carisma y energía de Heather, las personas estuvieron alentadas y motivadas durante toda la mañana.

A petición del público, el grupo de baile Jacoreiography deslumbró a todos con sus increíbles pasos y movimientos dejando a las personas maravilladas con este show.

Mike Graham compartió unas palabras en nombre de Grifols, Patrocinador Oficial de HNC. Neil Frick, Vicepresidente el National Hemophilia Foundation’s for Research & Medical Information, añadió algunas palabras para agradecer a todos aquellos que dieron un gran esfuerzo para llegar a la meta de recaudación y cómo significa esto para la comunidad de Hemophilia. Gillian Schultz, miembro de la mesa directiva 2014, se unió junto con su familia a estos momentos de emotividad compartiendo su historia y como inició formando parte de HNC.

Como es regular, en cada Walk event, se dieron reconocimientos especiales a las personas y equipos cuyo esfuerzo para apoyar el HNC Walk fue excepcional.

• Hospital Cup – Este reconocimiento es para el staff médico o centro de tratamiento de hemofilia que más haya recaudado. Este año el premio se lo llevó UNC TarHealers.

• King, Queen & Junior Droplet – Este reconocimiento se da a las 3 personas que hayan mostrado un extraordinario esfuerzo por apoyar el Walk. Reid Coleman fue el ganador del premio King Droplet (estableciendo récord al ganar por segundo año consecutivo), Ashley Davis ganó el premio Queen Droplet, y Luke Wilson se llevó el Premio Junior Droplet.

• Top 3 Equipos más recaudadores – Clot Hoppers, Jaden’s Jewels y Jaden’s Gents.

Una vez que se dieron los reconocimientos, era tiempo de dar inicio a la caminata (the Walk). Heather anunció el inicio de la caminata y todos los equipos arrancaron. Algunos niños participaron en una divertida búsqueda del tesoro. Cuando todos equipos regresaron, una bolsa con lunch los estaba esperando, cortesía de Jason’s Deli. Y gracias a Walgreens, las botellas de agua nunca faltaron para calmar la sed de los participantes.

Un agradecimiento especial a todos nuestros patrocinadores que apoyaron e hicieron posible este evento. Estamos realmente agradecidos por su continuo esfuerzo. Y por último, queremos agradecer infinitamente a todos aquellos que dieron un gran apoyo y que apoyaron e hicieron posible este evento. Estamos realmente agadecidos por su continüo esfuerzo. Y por último, queremos agradecer infinitamente a todos aquellos que dieron un gran apoyo y que apoyaron e hicieron posible este evento. Estamos realmente

Top 3 Equipos más recaudadores y su capitán

Clot Hoppers – Charles Register
Jaden’s Jewels y Jaden’s Gents – Gwen Stewart & Erica Cook
Wonderfully Fully Made – Erin Otay

Nuestros equipos y sus capitanes

Accredo’s Hemophilia Health Services – Diane Mauldin
Bayer – Tara Lowe
Bennett’s Bros – Chris Barnes
Biogen Idec – Nikita Lyons-Murry
Cayton’s Clotters – Shannon Elderidge
Clot Hoppers – Charles Register
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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.

Womanifesto

A manifesto is a declaration, a speaking of a truth or belief. It defines what you want others to accept or understand about what you feel and/or think. This writing project was presented to the members of HNC’s SOAR program. The SOAR program is designed solely for girls and women, so what is created instead is a womanifesto.

The SOAR members have come together at the 2014 Retreat to declare truths: that girls and women have a voice, and that the SOAR group share a common experience that is to be respected and heard. Each girl/ woman can take time to answer three questions: Who are you? What are things that you believe in? What will you fight for? These questions are not easy ones to address, but the process is just as rewarding as the outcome. The results are carefully crafted writings that ring out with power, hope and strength. Special thanks to Emma, Claire and Sasha for sharing their amazing writing!

I Torin’ell Ingram am willing to fight for ALL things unequal and anyone who is mistreated.

– Emma Ingram

I am a woman of faith, morals, respect, strength, love, determination, and compassion. I believe in the concepts our country was founded on: equality, justice, freedom, and happiness. I will fight long and hard, according to my morals and heart, to help achieve the best possible life for myself and others, whomever they may be. This is my dream, and my identity. I am Marjorie Claire Redfield.

– M. Claire Redfield

I am a young woman who is trying to decide who she is. I believe in equality for everyone. I will fight for the other young girls who do not understand their bleeding disorder. I will also fight for equality. No one should be left out! I am who I am and no one can change that!

– Sasha McCoy
HNC SOAR Retreat

November 7 – 9, 2014
Winston-Salem, NC

Members of SOAR enjoyed a fantastic Retreat this year at the beautiful historic Graylyn Estate in Winston-Salem. The weekend proved to be a great way for members to get away to share, connect, reconnect and, as one member humorously put it, relax!

The Retreat kicked off with a social evening, members dining and chatting excitedly as they caught up with each other’s lives. A Graylyn staff member joined the group during dinner to provide a history of the Graylyn Estate and its founding family. A cocktail hour followed, along with a few fun icebreaker games.

Saturday brought a day of sessions with very relevant and helpful topics: Genetics, Emotional and Social Support, Treatment plans, and The Current State of Health Insurance. The speakers were very engaging with the attendees, allowing so much room for discussion and questions. (If you were not able to attend the Retreat, please note that printed handouts are available for select sessions. Please contact HNC staff for more information).

Sunday held a much-anticipated discussion about the direction of the SOAR program, specifically how SOAR members envision SOAR activities for 2015. There were great ideas for social dinners, mother/daughter art projects, and educational sessions. There was a lot of excitement and energy about getting involved and participating in upcoming activities. We encourage you to join us in 2015.

HNC would like to recognize and thank CSL Behring for their sponsorship for this year’s Retreat, and for their continued support for the SOAR program.
What is a Blood Clot and How to Prevent Them

By: Yvonne Valov-Celso, RVT

Blood clots usually only occur in veins. Veins take the unoxgenated blood back to the heart. In the leg veins the blood must fight gravity to make its way back, and this is done with the help of small one-way valves that push the blood forward, preventing backflow.

In the calf muscles there is a spongey-like tissue called “the soliel sinus” that holds blood and with each step is compressed by the calf muscle that also helps to return the blood back to the heart. Clots occur when there is slow movement of blood flow or sedentary lifestyle. They tend to accumulate at the cusps of the valves and can eventually occlude the entire vein.

New or forming clots are the most dangerous because they can break off and return back to the heart. Once in the heart, they are sent to the lungs for oxygenation. The lungs, like a tree, have many branches and the clot/clots can block these branches. This is called a Pulmonary Embolism or “PE”. This is life threatening and requires immediate hospitalization.

Pulmonary Embolism can occur from extended bed rest from surgery, especially knee replacement or hip replacement surgeries. Care must be taken, especially by the hemophilia community when taking cryo for any surgery, as the tendency for clot growth increases with more clotting factor.

So how do we recognize and prevent blood clots from forming in our legs? The number one sign of a blood clot is pain and swelling in just one leg. If there is swelling in both legs the general consensus is that it is probably just edema. However it is very difficult to ascertain, so this is usually confirmed with a vascular ultrasound study. Occasionally clots are found in both legs with the clot extending into the pelvic area. Another sign is a red line that forms with a cord-like appearance down the leg.

Prevention is the key here. When on long trips, especially when in a sitting position, every 10 minutes or so it is important to flex and/or point the foot. This makes the calf muscle squeeze the soliel sinus and keeps the blood moving. Get up and walk around to keep the blood flowing. Venodynes (compression stockings) should be used after surgery while the patient is bed ridden. Once again, it is important to get up and move to keep the blood flowing.

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.
Mark your calendars... the 2015 Blood Brotherhood schedule of events is now available:

- **Jan 10** – Morrisville, NC
- **March 14** – Chapel Hill, NC
- **May** – Charlotte, NC (specific date TBD)
- **June 13** – Outer Banks
- **Aug 8-9** – Blood Brotherhood Retreat

Detailed information on these events, including topics and registration information, will be provided on the HNC website (www.hemophilia-nc.org) throughout the year as the events near. 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: 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 our 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.
Local Brothers Try to Tame Lifelong Condition

Aaron and Luke Curtiss are trying to maintain normal lifestyles, even though they’re both battling a rare blood condition.

The brothers from Davie County have hemophilia, a bleeding disorder in which the blood doesn’t clot normally. If the boys get a cut, it takes longer than normal for the bleeding to stop. That loss of blood could potentially damage one’s organs and tissues and possibly even be life threatening if untreated. About one in 5,000 males are born with hemophilia each year.

Hemophilia runs in the Curtiss family. Aaron and Luke’s grandfather had dealt with the condition throughout his life. With that in mind, the boys’ parents, Kevin and Alisha, had them tested when each child was born. There are two types of the disorder and it was found that both Aaron and Luke had hemophilia B, which is more rare of the two.

Aaron, now 10 years old and in the fourth grade, had an especially challenging time with the condition during his first few months. When he was a moth old, Aaron suffered a muscle bleed while receiving normal child immunizations. Aaron has battled with several other bleeds that he has been hospitalized for at Brenner Children’s Hospital.

Luke, now seven years old, is in the second grade. Luke has also battled bleeds that had him hospitalized at Brenner. The family is always on alert. Kevin and Alisha spend time educating the boys’ teachers and day care workers about hemophilia, namely what to look for and what to do if an incident occurs.

While there is no known cure for hemophilia, it is a condition that can be managed throughout one’s lifetime. The Curtiss family tires to ensure that Aaron and Luke have a normal life, while not potentially endangering themselves to a serious incident.

Wake Forest Baptist Health has been at the forefront of making sure the boys remain in good health. The family praises nurse practitioner Anita Smith for going above and beyond to achieve that goal.

During school, Aaron and Luke love recess. While home, they enjoy watching PBS Kids programming and playing around with Hot Wheels cars. Both boys love playing outdoors, riding their bikes and playing ball. They’re both big fans of the Carolina Panthers and quarterback Cam Newton. Despite their condition, the boys will occasionally “rough house”. “That’s what brothers do,” says Aaron.

Aaron and Luke Curtiss are excited to be a part of the Dash game against the Carolina Mudcats on Saturday, August 23 as a Home Run for Life honoree. Please join us at the BB&T Ballpark that evening as we celebrate their character, courage and enthusiasm for life.

NCABBD Update

The North Carolina Advisory Board for Bleeding Disorders (NCABBD) meets quarterly, our most recent meeting held in September. Many topics were discussed at the recent meeting, including:

- **Hemophilia Treatment Center (HTC) Updates:** patient population is growing at the ECU treatment center, with busy Friday clinics. Katherine Batt has joined the WFU treatment center staff, serving adult patients. An ongoing discussion of pharmacy utilization of factor brought in by patients (commonly known as “brown bagging”) is taking place at all treatment centers and continues to be a discussion of the committee.

- **HNC Advocacy:** The NC state budget was resolved except for Medicaid reform. The HNC Advocacy Committee prefers the version approved by the House and the Governor for an accountable care model of Medicaid, rather than the version approved by the Senate for managed care and capitation. Medicaid expansion in NC is still a possibility, as many groups, including the Governor and DHHS, now understand the benefits of the expansion.

NCABBD members include staff from North Carolina’s Hemophilia Treatment Centers, as well as representatives from the bleeding disorders community. Hemophilia of North Carolina staff, board members, and volunteers are well represented. Membership is by invitation only, where important information is exchanged to help carry out respective missions.
HNC NEWS & INFORMATION

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Thank You
Traficanti wins award at CLS Behring “Getting in the Game” Golf Tournament

On Saturday, October 18, 2014 Jack Traficanti, represented Hemophilia North Carolina at the CSL Behring “Getting in the Game” Annual golf tournament held at the Sheraton Wild Horse Hotel and Whirlwind Golf Course in Chandler, AZ. Jack may be small in size and young in age at only 7 years old, but he made a big impression on the selection committee by winning the Outstanding Sportsmanship Award. This award was given to the player who best embodied professionalism, good sportsmanship and a positive attitude throughout the tournament!

It was an exciting event from beginning to end as the players arrived on Friday and attended a golf clinic that evening consisting of chipping, putting and driving. Boys and girls from 7 to 17 – and from nearly every state and skill level – demonstrated their talents in front of Perry Parker, CSL Behring’s golf pro in charge of hosting the event. Parker gave an inspirational talk on Friday to get the group motivated (as if they needed much more motivation to play golf), and introduced two former GITG champions from years past. It was exciting to see the kids, all decked out in their golf attire, soaking in every tip Parker delivered on how to make their game better.

The big moment arrived on Saturday morning at 7:30am as the players – all 54 of them – made their way to the course. They would be playing the Devil’s Claw course at Whirlwind Country Club. An ocean of golf carts, each with the player’s name and the name of their assigned caddy, lined the staging area outside the pro shop, while another battalion of carts lay reserved for parents to follow along. Caddies wore the name of their player on the back of their white golf bibs, and after some last minute instructions, the players were off! Follow your child – if you could find them!

Continued on page 16
Navigating Educational Scholarships/Financial Aid Programs Coming Soon!

Is someone in your family pursing higher education and could benefit from a scholarship or financial aid? There are so many educational scholarships available for individuals in the bleeding disorders community, each with different criteria and requirements. It can be overwhelming to search through all the resources available, which is why we will once again this year be partnering with Biogen Idec to host a series of “Navigating the Financial Aid & Scholarship Process” Educational Programs throughout the beginning of 2015. Don’t miss out on an opportunity to hear more!

If you are interested in having a dinner near you, please let us know by email – info@hemophilia-nc.org – and we will do our best to choose locations where there is a need for this information.

Traficanti wins award at CLS Behring “Getting in the Game” Golf Tournament

Continued from page 15

We caught up to Jack on the third hole where he and his caddy, Mike Delaney, were settling in quite well. Mike, an avid golfer himself from the New Jersey area, seemed right at home helping his young super-star determine the distance to hole and selecting the appropriate clubs. By the 6th hole, Jack appeared to be hitting his stride, declaring “I was confident in my swing!” as his ball bounced off the top of a bunker and came to rest against the face of front face of a sand trap. It took four strokes to get out of that predicament. But moments later (and not quite as confident) Jack elected to hit a “junker ball” over the water. He not only cleared the water but barely made it onto the fairway, ending up just in a patch of brush. Fortunately, being left-handed, he had a good enough lie that he could hit up onto the green to make par. And, as if to impress the crowd, Jack managed to nearly sink a 60-foot put on the 8th hole – right in front of Perry Parker! Apparently that was all it took for Parker to later proclaim at the awards ceremony that he “fully expects this boy to come back and win the entire tournament one day.”

Jack shot a 52 for the 9 holes, with the top three scores coming in at 41, 43 and 47. And on the way home, after an exciting weekend of golf, swimming and friend-making, the 7-year old exhausted boy from North Carolina turned to his parents and said, “That was fun. Can we come back next year?”

Thank you to the selection committee at HNC for choosing Jack to represent North Carolina. And thank you to CSL Behring for providing such a wonderful event that allows kids to truly dream, and know that those dreams can someday become reality.

The Traficanti Family (10/24/2014)
FDA Approves Oral HCV Combination Therapy Free of Ribavirin and Interferon

On November 5, 2014, the US Food and Drug Administration (FDA) approved the combination use of two previously approved separate oral therapies, Simeprevir (Olysio™) and sofosbuvir (Sovaldi™), for the treatment of chronic hepatitis C viral (HCV) infection. It is a ribavirin- and interferon-free regimen, both of which were notorious for causing debilitating side effects.

Simeprevir, manufactured by Janssen Therapeutics, is a protease inhibitor that halts the progression of HCV, thus preventing it from reproducing. Sofosbuvir, manufactured by Gilead Sciences, is a daily oral nucleotide analogue inhibitor composed of a small molecule compound that blocks HCV’s ability to replicate. The FDA approval encompasses the combination use of simeprevir/sofosbuvir for both treatment-naïve and treatment-experienced patients. Trial regimens included a 24-week duration for patients with cirrhosis (scarring of the liver) and 12 weeks for those without cirrhosis, both of which excluded the use of either ribavirin or interferon.

The new FDA approval is based on results of the COSMOS study, a phase II trial that included patients with HCV genotype 1. Rates of sustained virologic response (SVR, meaning they no longer had detectable virus in their blood) measured 12 weeks after treatment ended were 93% among those treated with the combination for 12 weeks, and 97% among those treated for 24 weeks. The most common adverse reactions reported by more than 10% of treated patients during 12 weeks of combination treatment were fatigue in 25%, headache (21%), nausea (21%), insomnia (14%), itching (11%), rash (11%), and sensitivity to light (7%). Dizziness (16%) and diarrhea (16%) were the most commonly reported among those patients treated for 24 weeks.

**ON THE NATIONAL & LEGISLATIVE FRONT**

**FDA Holds Novel Patient-Focused Meeting on Bleeding Disorders**

On September 22nd, the US Food and Drug Administration (FDA) held a meeting devoted to hearing directly from people with bleeding disorders about their lives and treatment needs. The meeting was part of the FDA’s Patient-Focused Drug Development Initiative, a series of 20 disease-specific meetings providing the FDA with input from people affected by a condition and also their caregivers. FDA wants to better understand how people affected by a condition think about the risks and benefits of potential treatments and cures.

At the meeting, people affected by hemophilia, von Willebrand disease (VWD) and rare bleeding disorders told their own stories and explained how their daily lives are affected by having a bleeding disorder, how their disorder and treatments have changed over time, and what they desire from the ideal treatment. Participants told powerful stories of fear of developing inhibitors (antibodies to infused factor product), living with chronic pain, and dealing with depression and anxiety. There were also hopeful stories of the freedom that has come from home treatment, prophylaxis and the new longer-lasting products. There was a discussion of what “normal” is and should be for people with bleeding disorders.

The good news is that there’s still time for you to share your input. The FDA accepted written comments on the questions discussed at the meeting until November 28, 2014. Further, the National Hemophilia Foundation (NHF) is finalizing a survey on the same questions, which will be distributed to the community. The meeting was recorded and will be posted on the FDA website shortly. To learn more please visit www.fda.gov. To submit electronic comments, please visit www.regulations.gov. You can submit written comments to the Division of Dockets Management (HFA-305), Food and Drug Administration, 5630 Fishers Lane, Rm. 1061, Rockville, MD 20852.

Source: www.hemophilia.org, Advocacy and Legislative News

Editor’s Note: this article’s last paragraph was changed to reflect the end of the data collection.

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