

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SPRING 2017

44th HNC Annual Meeting: Taking Care of YOU, Bleeding Disorders and Mental Health

March 4, 2017
Cary, NC

The 2017 Hemophilia of North Carolina (HNC) Annual Meeting was an enlightening and engaging educational program for members. The event took place on March 4 at the Embassy Suites Raleigh-Durham Research Triangle in Cary. The meeting started on the right note with the introduction of the first general session speaker, Tim Ringgold, MT-BC, and his program *Music Therapy for Stress Management*. Tim provided wonderful and entertaining insight and tools members can use to cope with stress related to managing your or your loved ones bleeding disorder.



Continuing with the theme, HNC members were privileged to be able to participate in two additional programs related to mental health and chronic illness. Dr. Charles Burnett, a psychologist who specializes in the treatment of individuals with chronic illnesses, led the afternoon general session with a program called *Minding your Moods: Managing Mental Health and Chronic Illness*. In the meantime, teens were engaged in a program called *Stress Management and Bleeding Disorders* led by Joe Torrey and Myles Ganley of Gut Monkey.

In addition to the helpful information provided to members through these programs and speakers, attendees were fortunate to have Dr. Alice D. Ma, a Professor of Medicine and the fellowship director in the Division of Hematology-Oncology at the University of North Carolina School of Medicine in Chapel Hill, conduct two important sessions. Dr. Ma began with a morning breakout session about inhibitors. The second presentation was a popular general session for all. Dr. Ma's presentation on *Treatment Options and Emerging Therapies*

provided valuable information for people with all bleeding disorders that will help them

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HNC Members enjoy Dinner and Bowling after the Annual Meeting in Cary

Save The Date

World Hemophilia Day
April 17

Family Festival & 5K Walk
Charlotte, NC
April 22

NOW Conference
Phoenix, AZ
April 28-30

NC Legislative Day
Raleigh, NC
May 2

SOAR Dinner
Charlotte, NC
May 17

Latin Union Zoo Event
Asheboro, NC
May 20

**HOPE & Blood
Brotherhood Paired Event**
Charlotte, NC
May 13

HOPE Steps for Living
Morrisville, NC
July 1

HNC/HSC Teen Retreat
Rock Hill, SC
July 6-9

Men's Retreat
Pine Knoll Shores, NC
July 28-30

Adult Retreat
Wilmington, NC
August 12-13

Family Fun Day
Clemmons, NC
August 19

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North Carolina*

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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
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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

St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital Hematology & Oncology Clinic

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

UNC Treatment Center

UNC Hemophilia and Thrombosis Center
170 Manning Drive
3rd Floor Physicians Office Building
Campus Box 7016
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

Resource Information

National Hemophilia Foundation
www.hemophilia.org

Hemophilia Foundation of America
www.hemophiliafed.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

Coalition for Hemophilia B
1-212-520-8272
www.coalitionforhemophiliab.org

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

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www.inalex.com

LA Kelley Communications
1-978-352-7657
www.kelley.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.

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, a member of the NC Center for Nonprofits.



Novant Health St. Jude Affiliate Clinic: now an official Hemophilia Treatment Center

Submitted by: St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital

The first federally funded pediatric Hemophilia Treatment Center (HTC) has arrived in Charlotte. This means that all children with bleeding disorders will have a new specialty medical home for treatment, education and supportive services in Charlotte. The St. Jude Affiliate Clinic HTC provides access to specialty trained physicians, nurses, physical therapists and social workers who have extensive training in taking care of children with these rare complex disorders.

Hemophilia Treatment Centers provide treatment that adheres to national standards while offering innovative therapies and a national network of consultants for this unique patient population. According to the Centers for Disease Control and Prevention, a study of 3,000 people with hemophilia showed that those who used an HTC were 40 percent less likely to die of a hemophilia-related complication compared to those who did not receive care at a treatment center.

“Since moving to Charlotte in 2005 one of my dreams has been to see a pediatric hemophilia treatment center grow and flourish in our community,” said Dr. Paulette Bryant, a pediatrician at the center. “I could not be more grateful for our patients who have been pushing us to establish an HTC locally and for all of the HTCs in North Carolina who were supportive of us through the process.”

The St. Jude Affiliate Clinic HTC, located at 301 Hawthorne Lane, will allow patients to participate in a national hemophilia registry and other research opportunities currently not available in Charlotte. Parents and young adults will have a voice in directing their care through the newly planned parent advisory board. These patients will now be able to participate locally avoiding the travel to Wake Forest, Chapel Hill and East Carolina for comprehensive hemophilia care.

The 2017 Hemophilia of North Carolina Family Festival & 5K Walk for bleeding disorders will be held on Saturday, April 22 at 9 a.m. on Mint Street at Third Street and Martin Luther King Boulevard. Participants are encouraged to either make a donation, raise funds on their own, or both. Physicians and families are encouraged to come participate in friendly competition to raise funds for Hemophilia of North Carolina.

The center is welcoming referrals from all providers including, pediatrics, neonatology, family practice, gynecology, maternal fetal medicine, urgent care and emergency rooms. “We are incredibly excited and very thankful to be able to provide these services as a hemophilia treatment center,” said Bryant. “If you have pediatric patients with any bleeding concerns, we look forward to seeing them at the St. Jude Affiliate Clinic HTC.”

For more information or to make a referral, call 704-384-1900.

Why I Serve

By: Arlette Whitaker, Member of HNC Board of Directors



I was first introduced to the hemophilia community about 4 years ago. When I was first introduced, I didn't know a thing about hemophilia. I knew it was a bleeding disorder and I was afraid, honestly. I heard all the myths of hemophilia and not the truth. As I began to learn about the hemophilia community, I began to fall in love with the community. There was so much more beneath the surface. There were other bleeding and thrombosis disorders that I had never heard of. Little by little these myths that I had “known” were proven to not be true. How many more are misled? How many more patients have the disorder but have no idea? How many have died in the past and they did not have to? I felt compelled and a sense of responsibility to educate, bring awareness and serve. The more I learned, the greater my passion grew and the greater my hopes grew thinking that I can make a difference.

My patients have taught me more than I could ever learn from a book. Everyday I see the bravery, the determination, the adaptation, and the strength to conquer and win. I see them building the strength in one another, sharing tips, secrets, and warnings of not treating. The amount of love shown in the hemophilia community is real. Close-knit bonds across millions in the world are instant and unbreakable. Who would not want to be a part of that? So let's formally meet. I am Arlette Whitaker, I am here to serve you and your community and bring education and awareness to the hemophilia and bleeding disorder community. Together we can.

Arlette is a pediatric and adult hemophilia nurse at the East Carolina University Hemophilia Treatment Center

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understand current therapies available as well as new treatments on the horizon for their specific bleeding disorder.

As a tradition of the Annual Meeting, the HNC Business Meeting was held. Members were provided an update about programs and services delivered during the past year as well as a review of the sound financial position of the organization. An election was held to elect new board members and re-elect current board members seeking a new term. Following the business meeting, a wonderful buffet lunch was served before starting the afternoon sessions.

Breakout sessions were held for different HNC programs. Morning sessions included: Advocacy, Latin Union Program (designed for Spanish-speaking individuals), von Willebrand's Disease and Inhibitors. The afternoon sessions provided time for meetings of the groups: SOAR (women & girls), Blood Brotherhood (adult men), Spouses/Partners, and HOPE (for families of young children). Thank you to our speakers: SOAR Speaker, Karla White (CSL Behring); Blood Brotherhood, Tim Ringgold MT-BC; Partners & Spouses, Lauren Neybert (HFA); VWD, Virginia Kraus (Grifols); Latin Union, Miriam Pimentel (Shire); HOPE, Gillian Schultz (HNC); and for the Advocacy session, NC House Representative Nelson Dollar. Representative Dollar was kind enough to join us and discuss how to communicate with your legislator and provide insight for those interested in learning more about how to tell their story.

As promised, there was something for everyone and that meant kids too. Children and teens were kept busy with a full day of fun-filled activities and programs targeted toward the different age groups present. Children ages 4-12 participated in programs including *Mad Science*; *Biobuddies*; and *Cold Blooded Encounters* along with time in a game truck and other games, movies and crafts. The teens began with a program called *Being a Teen Living with*

Hemophilia and spent the rest of the day participating in a Leading Edge program where they developed skills around personal motivation, taking positive risks, goal setting, embracing change when it is difficult, and expanding their comfort zones through a fully interactive program.

Another big "thank-you" goes out to all the presenters of our kids' and teens' programs: Joe Torrey and Myles Ganley of Gut Monkey; Daysi Fardales of Pfizer Hemophilia and Chris Barnes of Diplomat Specialty Infusion Group for providing these fun learning opportunities to HNC's younger members. Childcare was also offered for infant children so adults could benefit from the programming worry-free. We appreciated all of the help from Peak City Sitters in making that possible!

After a full day of learning together and connecting with other members, some chose to participate in a social activity after the meeting at Buffaloe Lanes in Cary for bowling and dinner. Though

Continued next page



Tim Ringgold shows members how music can help with managing pain



Dr. Alice Ma explains emerging therapies to the general membership



NC House Representative Nelson Dollar leading the Advocacy breakout session



Amy Shair, Board President, along with board members in attendance holding the business meeting

Meet HNC's New Board Member



George McCoy,
Newly Elected to the
HNC Board of Directors

HNC would like to welcome a newly elected member to the Board of Directors. Elections took place at the 44th Annual HNC Annual Meeting in Cary on March 4. All current members were successful in seeking re-election.

The board's commitment to HNC and its members is greatly appreciated. Please take a moment to read about and get to know our newest board member, George McCoy, and to thank all board members for their dedication and service to the bleeding disorders community.

George McCoy was born in 1947 with severe hemophilia A, and is a veteran of the HIV and HCV wars as well. Retired from state government, George is ready to step up his existing commitment to HNC by serving on the Board of Directors. George helped organize HNC in the 1970s, and remained actively involved until the mid 1980s. At that point, juggling work and health demanded his full attention. Since retirement in 2005, George has volunteered in various activities for HNC, from public speaking to advocacy to stuffing envelopes. He has enjoyed building friendships through the Blood Brotherhood as well. George holds a Master's Degree in Education from UNC-CH. He worked for 31 years in the NC

Department of Health and Human Services in programs serving people with disabilities, ending his career serving as State Director for the NC Division of Vocational Rehabilitation Services. His career was recognized with the bestowal of the Order of the Long Leaf Pine, one of the highest civilian honors granted by the Governor of NC. George lives in Raleigh with his husband, Phil Poovey. He is not employed by any industry vending goods or services to the bleeding disorders community.

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2017 HNC Annual Meeting:

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- HPC Specialty Pharmacy • Matrix Health Group
- Option Care

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some had just met that day for the first time, they left as friends looking forward to coming together again at a future HNC event.

Finally, thank you to all the volunteers and members who contributed and helped make HNC's 44th Annual Meeting a complete success.



Teens learning how to use Gut.Monkey's infamous "rings"

HNC Casino Night: All In Fun

January 28, 2017
Charlotte, NC



Hemophilia of North Carolina (HNC) hosted the 10th annual “Hearts for Hemophilia” Casino Night event in Charlotte on Saturday, January 28 at the Big Chill in Charlotte. The room and guests sparkled as they enjoyed the live music, fine food, casino games and, of course, the exciting live and silent auctions. Guests received \$10,000 worth of “fun money” to get things started. The games included blackjack, craps, texas hold’em poker, and roulette; so whether you won big or lost all your chips, it was great fun for a great cause.



Casino Night guests having fun, win or lose

decide where to place their bet that evening. A sure thing for everyone was the chance to catch up with friendly faces and get to know some new ones as people gathered together to support Hemophilia of North Carolina at this important fundraising event. The silent auction table was filled with a variety of gifts including: a Wine Class at Total Wine, College Basketball Tickets, Museum Tickets, NC Symphony and Charlotte Ballet Tickets, a day at the NC Zoo, White Water Rafting, Rock Climbing, Handmade Jewelry, Weekend Getaways and more.

With the help of Auctioneer John Palinkas, the highlight of the evening was the live auction, which offered some fantastic items for some very lucky winners. The bidding began for the football autographed by Carolina Panthers’ Ted Ginn Jr., and continued with two fabulous getaway packages to Sea



Silent Auction Prizes await a lucky winner

Trail Resort in Sunset Beach, NC, and Port-O-Call in Ocean City, NJ, and ended with the auction of four Disney Park Hopper Passes. Of course, the most meaningful part of the live auction was the opportunity to make a bid of financial contribution to the emergency financial assistance program, an important part of HNC’s mission to support the bleeding disorders community.

Even if guests didn’t win at the auction, there were other opportunities to win with raffle prizes and a chance to win on the lottery board drawing. If your luck ran out, you still didn’t go home empty-handed as each attendee received a souvenir cup and a deck of cards as a thank you for supporting HNC. HNC raised over \$45,000 at this year’s “Hearts for Hemophilia” Casino Night and all proceeds will help to continue the goal of improving the quality of life for those affected by a bleeding disorder. Through fundraising events such as this, HNC is able to continue providing critical programs and services to the community we serve.

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 the entire list of sponsors and individuals for continuing the casino night tradition!



Casino Night Auctioneer John Palinkas

Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for HNC’s 2017 “Hearts for Hemophilia” Casino Night:

King of Hearts



Queen of Hearts



Jack of Hearts



2017 Volunteer and Special Guest Dinner

March 3, 2017
Cary, NC

HNC hosted its annual Volunteer and Special Guest Dinner as traditionally held the evening before the Annual Meeting. This year's celebration of HNC's volunteers and special guests took place on Friday, March 3, at the Embassy Suites Raleigh-Durham Research Triangle in Cary. Guests included both members and non-members, who over the course of the past year have dedicated their time and talent to HNC's overall mission of improving the quality of life of persons affected by bleeding disorders.

The dinner featured an inspirational presentation from music therapist Tim Ringgold, MT-BC, about *Overcoming Obstacles*. Tim shared the challenges he and his family faced at the diagnosis and loss of his daughter to a rare disease in order to help guests learn valuable tools they can use as they face their own obstacles. Tim was able to add a level of humor and warmth to his thought-provoking and interactive presentation. Everyone who attended

left the dinner having a greater understanding of how to face an unexpected challenge.

HNC members face unexpected challenges every day. It was fitting that those who offer such overwhelming support to HNC and its members should be provided with an inspiring message to help renew and energize them to continue their vital work for the community. This dinner is a small way to show them how grateful HNC is for their continued support.

There are many ways people around the state can become a volunteer or contribute their talents to help HNC promote advocacy, education, promotion of research, and delivery of supportive programs and services. If you would like to find out more about these opportunities, please call the HNC office (800) 990-5557 or email info@hemophilia-nc.org for additional information.



Volunteer Dinner attendees enjoying the evening meal and presentation by Tim Ringgold, MT-BC

HOPE Educational Dinners: Spotlight on Unaffected Siblings

January 17, 2017
Charlotte, NC

February 9, 2017
Durham, NC

Families gathered together on January 17 at Firebirds Woodfired Grill in Charlotte and February 9 at Maggiano's Little Italy in Durham for the first HOPE Educational Dinners of 2017. After everyone arrived and had some time to catch up, they were treated to an enjoyable dinner and presentation entitled *Spotlight on Unaffected Siblings* led by Tanya Stephenson, CORE Manager with Bioverativ. Families learned how having a child with a bleeding disorder affects the entire family, including unaffected siblings. Whether acting out, feeling jealous, worried, or a variety of other emotions, families gained tools to help unaffected siblings cope. These included spending special one-on-one time with the unaffected child, devoting family time for special activities including cooking, watching a movie, finding constellations or anything the family desires. Thank you to Bioverativ for sponsoring the educational dinners. Keep your eyes on the HNC website, Facebook page, and your email for details on upcoming HOPE Program events this spring.

NC Nurses Learn about Bleeding Disorders

February 16, 2017
Raleigh, NC



It was a very welcome call from the North Carolina Nurses Association (NCNA), asking whether HNC could provide a speaker on February 16 to educate local nurses about bleeding

disorders. Brenda Nielsen, RN, MSN, Nurse Consultant, at UNC's Hemophilia Treatment Center (HTC) was quick to respond that she would happily speak at the meeting.

The event was well-attended with at least 20 nurses from all around the state. As Brenda presented, one could see the pens moving swiftly as attendees took key notes about the information provided. In less than an hour and a half, Brenda had successfully highlighted the symptoms and treatment for those with bleeding disorders. During and after the presentation there were a number of excellent questions raised by nurses, who were absorbing a lot of new knowledge that they could take back to their practices.

It was a remarkable opportunity for HNC to help spread awareness of bleeding disorders. Thank you to the NCNA for providing a platform to make this possible, and to Brenda for always jumping at any chance to raise awareness in the greater community.

Mentoring Lunch 'n Learn Events

February 18, 2017 March 25, 2017
Morrisville, NC Concord, NC

Members of the new HOPE Mentoring Program joined together on Saturday, February 18 from 11:00am-1:30pm at the HNC Office in Morrisville. After providing some time for everyone to chat and get to know each other, attendees heard a presentation from Jennifer (Jen) Newman, UNC-CH Physical Therapist. Jen provided an overview of bleeding patterns, signs that children of different ages may exhibit when experiencing a bleed, and transitioning back to activity following a bleed. It was an interactive conversation with people sharing information about their own experiences and asking questions. The children had the opportunity to watch a movie and play games so their parents could focus completely on the presentation. Following the educational session everyone enjoyed a delicious lunch from Salsa Fresh.

The next Mentoring Lunch 'n Learn will be on March 25 at Dave & Buster's in Concord.

The HOPE Mentoring Program for Parents/Caregivers is a new initiative of HNC, which started in the summer of 2016. There are a number of mentors who have been trained in techniques and methods of listening and supporting others. They are all caregivers of a child with a bleeding disorder. If you are looking for additional support in caring for your child with a bleeding disorder, please contact Gillian Schultz, HNC Program Manager about joining the Mentoring Program and getting support from other parents who have "been there/done that." Our mentors are all excited to be able to provide their support to a young family.



Children take a break at the Mentoring Lunch 'n Learn

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Celebrate World Hemophilia Day

April 17, 2017

World Hemophilia Day is a special opportunity for everyone in our community to come together and support those with hemophilia and other inherited bleeding disorders. On April 17, the tradition of “lighting it up red” will continue and people in cities around the world will light up major landmarks in red to show support for the global bleeding disorders community. There is a dual purpose for this event. Lighting up red shows support for the global bleeding disorders community campaign and creates visibility for people living with a bleeding disorder so they know that the World Federation of Hemophilia (WFH) is there for them. Another benefit to lighting up red is to bring awareness to the general public about World Hemophilia Day and inherited bleeding disorders.

To show support and help raise awareness for hemophilia, landmarks across the nation will be lit red in honor of World Hemophilia Day. We are pleased to announce that the Wells Fargo Duke Energy Building in Charlotte will be lit red on the evening of Monday, April 17th. HNC is asking members to change your front porch light to red for April 17. Be sure to share on social media and tell your neighbors why you’re doing it. Another way to spread awareness is by asking your local schools to add to their morning announcements on April 17 that it’s World Hemophilia Day. Some important points to provide your networks, neighbors or local schools to help them better understand are:

What is a bleeding disorder?

Bleeding disorder is the general term used to describe a range of rare, hereditary conditions, which can lead to poor blood clotting and uncontrolled bleeding. The most well-known bleeding disorder is Hemophilia. Von Willebrand Disease (VWD) is the most common bleeding disorder.

How common is hemophilia?

Hemophilia is quite rare. About 1 in 10,000 people is born with hemophilia A. About 1 in 50,000 people is born with hemophilia B.

How common is VWD?

It is estimated that up to 1% of the world’s population suffers from VWD (that’s almost 75 million people!), but because many people have only very mild symptoms, only a small number of them know they have it. Research has shown that as many as 9 out of 10 people with VWD have not been diagnosed.

Are there other types of bleeding disorders?

Yes, there are a number of inherited platelet disorders and several other factor deficiencies that also cause abnormal bleeding. These include deficiencies in factors I, II, V, VII, X, XI, XIII. The most severe forms of these deficiencies are even rarer than hemophilia A and B.

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USBS/MG159/16-0029a(1)



HNC Legislative Day: Call to Action

May 1-2, 2017
Raleigh, NC

This is a time of change. The Bleeding Disorders Community is diverse in many respects including political views. One thing all have in common is the need to stand as watchdogs for you as an individual, our families, and our community on topics that may have an impact on those living with bleeding disorders.

Represent your State Legislative District at the HNC Legislative Day in Raleigh this year on Tuesday, May 2. One continuing focus of the annual HNC Legislative Day is to continue building awareness and relationships among our North Carolina State Representatives and the bleeding disorders community throughout the state. Politics can be fluid, so as we get closer to the date, the HNC Advocacy Committee will determine what specific issues may impact people affected by bleeding disorders in NC. HNC's Legislative Day is a perfect opportunity to address it with the state House and Senate members and the community needs YOUR voice and YOUR story.

There will be a training session and dinner the evening of Monday, May 1, with hotel accommodations available upon request through April 10 for attendees traveling over 30 miles who will also attend the training on Monday night.



2016 HNC Legislative Day

HOPE & Blood Brotherhood Event

May 13, 2017
NASCAR Hall of Fame, Charlotte, NC

Join HNC's HOPE Program for families and Blood Brotherhood for adult men with bleeding disorders for an opportunity to get together and form lasting bonds at the first-ever joint event between the HOPE and Blood Brotherhood groups.

On May 13, attendees will be visiting the NASCAR Hall of Fame for lunch, an educational session on physical therapy led by HNC member Erin Otey, PT, DPT and a tour of the NASCAR Hall of Fame. The tour will include fun activities like the Pit Stop Challenge and Race Simulator. Information will be posted soon on the HNC website, Facebook page, and by email.

Teen Retreat: Carolina Crew Meets Again in July 2017!

July 6-9, 2017
Camp Canaan, Rock Hill, SC

Attention Teens (ages 13-18)! Save the date, July 6-9, 2017 for the next joint Teen Retreat with HNC and HSC, also known as the Carolina Crew (coined by teens back in 2013). Teens will head back to Camp Canaan in Rock Hill, SC, to enjoy a great weekend of fun and educational programming. Gut Monkey will also return to entertain and educate teens in their Leading Edge program. Find out more about it at www.gutmonkey.com and while you are there you can check out their website's gallery for pictures of the HNC/HSC 2016 Teen Retreat.

As always, this is a fun, educational weekend designed especially for teens in the community. Whether it's you or another family member who has a bleeding disorder, the entire family is affected and all teens have an opportunity to benefit from this awesome weekend event. If



2016's Carolina Crew at Camp Canaan

you've never been to one of HNC's Teen Retreats, please check out the HNC Facebook page for photos. The Retreat is a remarkable opportunity to make new friends, share laughs, challenge yourself and prepare for your future.

HNC will provide busing from certain parts of the state, locations TBD based on registrations. 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. This will help HNC staff to ensure we select the most popular pick-up locations for busing.

Get Excited for the Charlotte and Raleigh Family Festivals & 5K Walks!

Charlotte Family Festival & 5K Walk

April 22, 2017

Mint Street at 3rd St. & MLK Blvd., Charlotte, NC

Raleigh Family Festival & 5K Walk

October 14, 2017

Lake Crabtree County Park, Morrisville, NC

Registration is now open for both the Charlotte and Raleigh Family Festivals & 5K Walks for Bleeding Disorders! Hopefully by now you have read, seen, and heard about the name change for one of our largest events. Instead of the Hemophilia Walk, you will now hear about the Family Festival & 5K Walk, with the first event in Charlotte only about a month away on April 22! You can expect the same entertaining fundraising event, filled with a half day of food, fun, and activities. Kevin McVerry from Performance DJ will be back spinning some energizing tunes to keep the crowd motivated. Jecoreiography will be entertaining everyone with some talented dance moves. There will be plenty of other entertainment for people of all ages, so bring your friends, family, co-workers, and 4-legged friends for a great day of fun, festivities and a 5K walk!

As in the past, the Festival's success depends on the support of Walk teams and sponsors in order to reach our fundraising

goals. All money raised stays right here in North Carolina. As HNC's largest fundraiser, the Family Festivals & 5K Walks in Charlotte and Raleigh benefit you by providing critical programs and services to the bleeding disorders community. There are a number of ways you can help HNC reach this goal:

- Register to participate in this year's Festival & Walk.
- Promote your walk team and ask for family, friends and coworkers to join your team or donate.
- Set up your own fundraising event at your home, office, school, place of worship or neighborhood.
- Contact local restaurants and businesses about hosting a fundraising event.
- Contact potential corporate supporters like car dealerships, doctor's offices, banks, insurance companies, or any business that you think could be interested. Not sure about asking? We're happy to assist!
- Need some fundraising ideas? Contact the HNC office or look on the website for suggestions.

Be sure to visit the HNC website for more information about the HNC Family Festivals & 5K Walks and for directions on how to register and set up your team. When registering, be sure you select the option to create a fundraising page if you plan to collect any donations or doing any type of fundraising. Please note there are some changes to the registration process as First Giving is now being used to host the registration and fundraising webpages. Contact the HNC Office at (800) 990-5557 or email festival@hemophilia-nc.org if you have any questions or want additional information about these exciting events.



Team Diego having fun at the 2016 event

NHF Annual Meeting: Registration Now Open

The National Hemophilia Foundation's (NHF) 69th Annual Meeting, Exploring the New Frontier, will be held in Chicago, Illinois, August 24-26, 2017. It will be at the Hyatt Regency Chicago, including three days full of educational sessions, networking opportunities, and access to the exhibit hall. Childcare will be available for children under 12 years old.

For more details and information about registration, visit www.hemophilia.org, use the "Events & Educational Programs" tab and click "NHF's 69th Annual Meeting".

HNC realizes that attending this conference is a substantial commitment of time and money. **HNC has grants available for members to attend these events**, so call the HNC office at (800) 990-5557 if you're interested in attending! Grant applications are available on the Programs & Services page of the HNC Website.

Noticias en UNION LATINA

El pasado 4 de Marzo, en la Reunión Anual de HNC, los miembros de Unión Latina participaron en una dinámica de integración “Comparte tu historia” realizado por Patricia Espinosa Thomson y Miriam Pimentel. Esta presentación dio oportunidad a los participantes a compartir sus historias personales sobre cómo han enfrentado en su día a día los trastornos hemorrágicos. A esta dinámica se le conoce como “Discurso de elevador” ya que la historia se debe contar en el mismo tiempo que toma entrar y salir de un elevador. En ocasiones es el tiempo que una persona tendrá para compartir sus experiencias sin embargo este tiempo puede resultar muy provechoso para aquellos que escuchan la historia.

Aparta la fecha para los siguientes eventos:

- 20 De Mayo. El programa Unión Latina inicia con el programa *Sin sudor: Activo y Sano con trastornos hemorrágicos*. Aprende como incorporar actividad física en tu vida teniendo un trastorno hemorrágico. El evento se llevara a cabo en el Zoológico de Asheboro en el que además daremos un tour y disfrutaremos del lunch.
- 17 de Junio. En Charlotte, aprenderemos como mantener un estilo de vida saludable con la adecuada nutrición a través de la presentación *Alimento para el pensamiento: Elecciones saludables para aquellos con trastornos hemorrágicos*.
- 24 de septiembre. En Greensboro.

- 2 de Diciembre. En Greenville, después de la celebración navideña.

El programa Unión Latina es un programa de HNC que busca apoyar a educar a la comunidad Latina en Carolina del Norte que tiene trastornos hemorrágicos. Los programas son en español y son posibles gracias a la farmacéutica Shire. Para más información, visita nuestro sitio web www.hemophilia-nc.org. Si estas interesado en ser voluntario y eres bilingüe, actualmente buscamos voluntarios que nos apoyen a traducir información y a realizar llamadas en español. Si conoces a alguien que esté interesado en esta oportunidad, te pedimos te comuniquemos a nuestras oficinas al (800) 990 5557.



Reunión Anual NHF: Inscripciones disponibles

La 69° Reunión Anual de NHF Explorando nuevas fronteras, se llevara a cabo en Chicago, Illinois, del 24 al 26 de Agosto 2017. Se realizara en el Hyatt Regency Chicago, en el que incluirá 3 días de sesiones educativas, oportunidad de conectar con muchas personas y acceso a nuestras salas de exhibición. Habrá servicio de cuidado infantil para niños menores a 12 años.

Para más detalles e información sobre el registro, visita nuestro sitio web www.hemophilia.org, en el apartado “Events & Educational programs” dando clic en “NHF’s 69th Annual Meeting”.

Asistir a este evento implica un compromiso monetario y de tiempo. **HNC tiene espacios disponibles para asistir a este evento.** Si estas interesado en aplicar, llama a nuestras oficinas y/o ingresa a nuestro sitio web en el apartado “Programs & Services”.

44° Reunión Anual: CUIDANDO DE TI, Trastornos hemorrágicos y salud mental

4 de Marzo 2017
Cary, NC

La Reunión Anual 2017 de Hemofilia de Carolina del Norte (HNC) ha sido un programa muy atractivo y educativo para los miembros de la comunidad HNC. EL evento se realizó el pasado 4 de marzo en el Embassy Suites Raleigh-Durham Research Triangle en Cary, NC.



Miembros de la Unión Latina que participan en la sesión anual de la Reunión Anual para miembros de habla hispana

La reunión inicio con la participación de Tim Ringgold MT-BC y su programa “Terapia con muisca para el control del estrés”. Tim mostro una visión bastante entretenida del programa y además compartió herramientas a los miembros para

saber cómo lidiar con el estrés relacionado al control de los trastornos hemorrágicos de nuestros seres queridos.

Más adelante, los miembros tuvieron el privilegio de poder participar en 2 programas adicionales relacionados a la salud mental y enfermedades crónicas. El Dr Charles Burnett, psicólogo especializado en tratamiento de enfermedades crónicas, llevo a cabo la sesión general junto con el programa “Al cuidado del estado de ánimo”: Manejo de la salud mental y enfermedades crónicas. Durante ese tiempo, los adolescentes atendieron al programa “Manejo del estrés y trastornos hemorrágicos” dirigido por Joe Torrey y Myles Ganley de Gut Monkey.

Además de la información proporcionada a través de estas conferencias, los miembros tuvieron la suerte de contar con la presencia de la Dra. Alice D. Ma, profesora de medicina y directora de la División de Hematología y Oncología de la Escuela de Medicina de UNC Chapel Hill, llevo a cabo 2 sesiones muy importantes. La primera conferencia fue sobre los inhibidores y la segunda fue una sesión informativa general. La presentación “Diferentes tratamientos y terapias emergentes” proporcionó información valiosa para la comunidad de HNC que ayudara a entender sobre las diferentes terapias disponibles así como los nuevos tratamientos para el control de los trastornos hemorrágicos.

Como es tradición de la Reunión Anual, se realizó la Reunión de Negocios de HNC. Los miembros recibieron actualizaciones sobre los programas y eventos realizados durante el año

pasado así como una revisión sobre la posición financiera de la organización. Hubo una elección general para elegir a los nuevos miembros de la junta directiva y reelegir a los miembros actuales. Después de la reunión negocios se sirvió un delicioso buffet para el lunch.

Otras dos sesiones se realizaron como parte del programa de HNC. La sesión matutina fue enfocada al Programa Unión Latina (con conferencistas de habla hispana) la cual se habló sobre la enfermedad von Willebrand e inhibidores. Para las sesiones vespertinas, se dio espacio para los programas SOAR (mujeres), Blood Brotherhood (hombres), Spouses/Partners y HOPE (familias y niños). Nuestros conferencistas fueron los siguientes. Conferencista de SOAR, Karla White (CSL Behring); Blood Brotherhood, Tim Ringgold MT-BC; Partners & Spouses, Lauren Neybert (HFA); VWD, Virginia Kraus (Grifols); Union Latina, Miriam Pimentel (Shire); y para la sesión de defensa, NC House Representative Nelson Dollar. Un agradecimiento especial para Nelson Dollar que amablemente acepto ser parte de este evento y compartió valiosa información.

Los jóvenes no se quedaron atrás y disfrutaron de actividades durante todo el día. Hubo diferentes actividades para las diferentes edades. Los chicos de 4 a 12 años participaron en actividades y dinámicas muy divertidas, así como jugar en un camión lleno de juguetes y ver películas entretenidas. Los adolescentes participaron en el programa “jóvenes con hemofilia” y en una dinámica para desarrollar habilidades para la automotivación, toma de riesgos positivos, establecimiento de metas, como enfrentar cambios y como expandir su zona de confort a través de un programa interactivo.

Otro agradecimiento especial para todos presentadores de los programas para jóvenes: Joe Torrey y Myles Ganley de Gut Monkey; Daysi Fardakes de Pfizer y Chris Barnes del Grupo Diplomático de Infusión Especial. El servicio de cuidado de niños estuvo disponible sin costo alguno para que los padres aprovecharan al máximo las sesiones. Agradecemos a Peak City Sitters por haber hecho esto posible.

Después de un día en el que los miembros convivieron y aprendieron, muchos decidieron ir a tener un poco de diversión jugando boliche en Buffaloe Lanes en Cary. Para muchos, fue la primera reunión en la que participaron y el resultado fue muy positivo ya que esperan con ansias los próximos eventos de HNC.

Para concluir, muchas gracias a todos nuestros voluntarios y miembros que hicieron posible que la 44° Reunión Anual fuera un éxito.

SOAR Program Update

The women of HNC's SOAR Program have been off to a busy start, following the first SOAR dinner of 2017 and breakout session at the 44th HNC Annual Meeting in March. You can read about both events in this newsletter.

As the year continues, SOAR will be exhibiting at the North Carolina Nurse's Association (NCNA) 2017 Nurse Practitioner Spring Symposium from March 26-28 in Asheville. This exhibit provides the opportunity to share information about bleeding disorders, especially among women since they often go undiagnosed for many years, with those who are on the front lines and have the most contact with patients.

Using the feedback from the first few events of 2017, HNC staff will be planning the next SOAR opportunity for late

spring so stay tuned to the HNC website, Facebook page, and your email for information.

SOAR is an HNC Program for women and girls with bleeding disorders. The mission is to improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential. Sessions are planned to support women with von Willebrand Disease, platelet disorders, and factor deficiencies including symptomatic hemophilia carriers and women affected with hemophilia.

For more information, or if you have an idea for an event, contact Gillian Schultz, HNC Program Manager at soar@hemophilia-nc.org or call the HNC office, (800) 990-5557.

SOAR Advocacy Dinner for Women

February 15, 2017
Cary, NC

Twelve women gathered at Bocci Trattoria & Pizzeria on February 15 to discuss the importance of advocacy. It was a lively roundtable, filled with many examples of what it means to be an advocate. Whether talking with medical providers, schools, legislators or your neighbor, one can practice advocacy in a variety of settings and may not even realize it.

The conversation flowed nicely between the different types of advocacy. Karla White, Director, State Government Affairs at CSL Behring, helped to facilitate the discussion. Attendees bounced suggestions and ideas off one another, leading to a lot of great suggestions for future SOAR events and initiatives. The support felt throughout the room was truly encouraging.

After a delicious dinner and shared laughs, it was time for dessert. Attendees completed a SOAR Needs Assessment. The feedback received will help HNC staff to design future SOAR programming. The evening flew by. By the time the event wrapped up, the restaurant was already closed. Everyone traded hugs and then it was time to head home until the next event.



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
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.*

An HNC Program for Girls and Women with Bleeding Disorders

A Growing Network of Support

NHF develops two websites just for women.

By: Leslie Pepper | 07.15.2016

Originally Published July 2016

Symptoms of a bleeding disorder can feel frightening and isolating. The National Hemophilia Foundation (NHF) intends to change that experience by providing two websites for women. With them, NHF will raise awareness for bleeding disorders and give women a place to connect with others.

Obstacles and opportunities

Women can face several challenges on the road to a diagnosis. Because bleeding disorders often run in families, many women don't even recognize something is off. "We've heard many times, 'Well, I didn't know that a super heavy period that lasted eight days wasn't normal, because my mom had that, too,'" says Corinne Koenig, MA, NHF manager of education and training.

Even if they do suspect a problem, women often find diagnosis can be difficult. That's because the tests for von Willebrand disease, for example, can be skewed by stress, exercise and whether you have an active infection or inflammation. Some tests may have to be repeated. Further, the tests have to be conducted by a specialized lab.

But an accurate and timely diagnosis is crucial. "Women with bleeding disorders are at risk for bleeding with childbirth or surgical procedures," says Chris Guelcher, MS, APRN, PPCNP-BC, a member of the NHF Women with Bleeding Disorders working group and a pediatric nurse practitioner. Both of those require foreknowledge of the specific bleeding disorder and a treatment plan, she adds.

There are also important quality-of-life issues. For example, iron deficiency from blood loss, which can lead to anemia, can inhibit your ability to participate in activities. "If you're constantly exhausted, having headaches and dizziness, you're going to be less productive," says Guelcher.

NEW: Better You Know Website

NHF's new site, betteryouknow.org, targets individuals who are symptomatic but haven't yet been diagnosed. It uses a screening tool initially developed by Claire S. Philipp, MD, and Ambarina Faiz, MD, at the University of Medicine and Dentistry of New Jersey in Newark. The tool has been validated through a study on women with menorrhagia (heavy menstrual bleeding) conducted in conjunction with six US medical centers and the US Centers for Disease Control and Prevention.

After users answer a series of questions, the screening tool tells them if they may be at risk for a bleeding disorder. The

website also offers information on how to find the right healthcare provider and how to best prepare for a healthcare appointment. Further, there is general information on bleeding disorders and how to manage symptoms.

Material on the site can serve as a good starting point for talking with your doctor. "This site will fill in the gap for women who have symptoms but aren't getting the information, diagnosis or care they need," says Kate Nammacher, MPH, NHF director of education.

RENEWED: Victory for Women Website

The journey to getting a diagnosis can be long and frustrating. Afterward, questions may abound, such as: How will this condition affect my life? What do I do? How do I cope? To help answer those questions, NHF has refurbished and relaunched its Victory for Women website, victoryforwomen.org.

Previously, Victory for Women existed as an informational site. But anecdotal feedback from women in the community and from a 2015 NHF survey revealed that women wanted a resource that lets them connect with others. "NHF already had a lot of other women's information resources on hemophilia.org and stepsforliving.hemophilia.org, but nowhere on our sites to connect," says Nammacher.

Results from the survey and guidance from women with bleeding disorders helped establish the content on the refreshed website. It will now feature users' stories, poems, artwork and photography. NHF will also launch a podcast series. Each quarter, the site will highlight a woman who has made a contribution to the community. In addition, an "Ask the Expert" section allows women to post questions, which NHF will direct to experts, who will then post the answers.

Women can upload pictures of their art, podcasts, stories and videos, connecting with other women in the bleeding disorders community. "We want this to be a place where women feel they're connected to others who know what they're going through, whether they have a chapter right down the street or 10 hours away," says Koenig.

"It's going to be a space for women to be creative, to tell their stories and to share life's fun moments," says Nammacher.

Both sites offer reliable information and a supportive network to help you on your own path to victory.

Reprinted from hemaware.org from www.hemophilia.org.

Our Young Voices

Spring 2017

Kids and Teens at HNC's 44th Annual Meeting

The Annual Meeting had something for everyone, including kids and teens. Here are some favorite moments from the day.



Our story about Washington Days

By: Zack Hargett, age 5



Zack explains how he uses his port to infuse factor

On March 8th – 10th we went to Washington D.C. and we advocated for bleeding disorders. I had a blast. We met with Tyler from the 13th district. This is the newest district in NC, held by congressman Ted Budd. They were very nice and gave us passes to visit the crypt and Supreme Court that was used in the 1810 to 1860s. We also got tickets to the gallery to watch the House debate the new health care reform proposal. We saw statues of famous people like Abraham Lincoln, Robert E. Lee, and Thomas Jefferson. We learned that when Billy Graham passes away, he will get a statue and replace the one of Charles B. Aycock to represent NC.

I met with 4 different offices, two Congress people and both NC Senators. I brought an album of pictures that showed me with my medicine and times when I had a bleed. They asked how I get my medicine so I showed them the port in my chest.

We hung out with the whole group from NC and met new people from other states. I can't wait until next year!



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Hemophilia Federation of America presents Project Calls

Across the country, the Hemophilia Federation of America (HFA) has heard of many cases of patients and their families facing limitations and restrictions from their insurance services. In an effort to respond to these challenges, HFA created [Project CALLS](http://www.ProjectCALLS.org). HFA's goal for Project CALLS is to identify trends in health insurance that create barriers to accessing care and treatment by collecting stories from the bleeding disorders community across the country. The more data we collect, the more information we will have to educate policymakers, insurance companies, pharmacies, and other providers to build a case for change. **Learn how to share your story by visiting www.ProjectCALLS.org or calling 202.836.2530.**

*Have you had trouble with your insurance?
Have you had trouble getting access to care or medication?*

PROJECT CALLS

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www.ProjectCALLS.org

2017 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2017.

We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

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HOPE Program Update

- Help
- Opportunity
- Partnership
- Empowerment

The HNC HOPE Program, designed for families with young children affected by bleeding disorders, is off to a strong start in 2017. Between January and February, HNC hosted two educational

dinner in partnership with Biogen, now Bioverativ. The Mentoring Program is up and running with several families benefitting from the partnerships and the first lunch 'n learn of the year was held. As HNC looks forward into the spring and summer, the HOPE Program has some very exciting events coming up.

On May 13, the HOPE Program will partner with HNC's Blood Brotherhood Program for a joint event where children affected with bleeding disorders will have the opportunity to spend time with some of the adult men in our community living with bleeding disorders, and hopefully form some special bonds. Members of these groups will be visiting the NASCAR Hall of Fame in Charlotte for an educational session on physical therapy, lunch, and then a guided tour of the museum including the Pit Stop Challenge and Race Simulator. Stay tuned to the HNC website, your email, and Facebook for more information on this unique event. And although fall seems so far away, save the date for the Family Retreat on September 15-17. The Family

Retreat will be moving back to the beach this year at the Sea Trail Resort in Sunset Beach, NC.

HOPE stands for *Help, Opportunity, Partnership, Empowerment*. The mission of HOPE is to improve the quality of life for families of the newly diagnosed through the age of twelve with bleeding disorders, so that they may HOPE to lead a fulfilling life. Together, with a community of other parents, we can support each other. Open to any member of HNC, HOPE programs are geared specifically towards parents with young children. For more information about the HOPE Program, if you have ideas for events or are looking for an event near you, or would like more information about the Mentoring Program, please contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or the HNC office at (800) 990-5557. You may also check the HNC webpage, Facebook page, and your email for updates on upcoming programs and events.

Latin Union Program Update

On March 4, at the HNC Annual Meeting, Latin Union members participated in a HELLO TALK, *Sharing Your Story*, facilitated by Patricia Espinosa Thomson and Miriam Pimentel from Shire. This interactive presentation gave participants the opportunity to share their own stories by determining what they want people to know and how they would say it when advocating for themselves or their child with a bleeding disorder. Sometimes this is called an "elevator speech" because it is learning how to tell your story to someone in the amount of time that it takes to get on and off an elevator. Sometimes that is all the time that a person will have to share their experiences about bleeding disorders but it can be very powerful and memorable to those hearing it!

Save the date for upcoming events:

- On May 20, the Latin Union program will be returning the N.C. Zoo in Asheboro for a HELLO TALK *No Sweat: Staying Active and Healthy with a Bleeding Disorder*. Learn about how being physically active benefits people with bleeding disorders and how to incorporate physical activity into daily life. Enjoy lunch and a visit to the zoo.
- On June 17 in Charlotte, learn about maintaining a healthy lifestyle with proper nutrition in the HELLO TALK, *Food for Thought: Healthy Choices for Those with a Bleeding Disorder*.
- September 24 in Greensboro
- December 2 in Greenville following the Holiday Celebration

The Latin Union is an HNC Program designed to support and educate Latino individuals and families in North Carolina who are affected by bleeding disorders. Programming is provided in Spanish and is possible thanks to a grant from Shire. For more information please visit the HNC website. We are currently looking for bilingual Spanish/English speaking volunteers to help with translating information into Spanish and making phone calls. If you or someone you know is interested in this opportunity, please call the HNC office directly at (800) 990-5557.

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— 2017 —

May 6 – Greenville

May 13 – Charlotte

July 28-30 – Pine Knoll Shores

September 9 – Winston-Salem

October 20-22 – Blowing Rock



Blood Brotherhood

A national program for adult men living with hemophilia or von Willebrand disease.

It is a multi-avenue outreach designed to provide education and support, promote good health, and establish a sense of community for adult men. If you are an adult male with a bleeding disorder, you are a part of Blood Brotherhood!

*In addition to these meetings
join us throughout the year at
community.bloodbrotherhood.org
a members-only online
discussion forum.*



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There are three camps in NC! Please call the HNC office for more information or look at the Winter newsletter edition, where HNC highlights camp dates and registration deadlines.

Camps have many benefits for children living with a bleeding disorder. They can help a child become more independent, learn more about bleeding disorders, and learn how to take control of his or her life (rather than the bleeding disorder controlling the child's life). Camp is a chance for children to be with and learn from others who face similar challenges.

The majority of summer camps for young people with bleeding disorders have a common goal—to provide the children with a typical camp experience—a place where everybody is treated the same and where possibilities, not limitations, are emphasized. However, they differ in how they accomplish that goal. Some focus on health education and advocacy; others have the let kids be kids philosophy and do not broach the topics of infusion, self-sufficiency, or weightier issues, such as preparing for a career and obtaining health insurance.

Finding the Right Camp for Your Child

Here are some tips to help you choose a camp:

- Know what to look for in a camp:
 - o Look for a coeducational camp that includes siblings; remember, bleeding disorders affect the entire family.
 - o Check that Hemophilia Treatment Center (HTC) staff participate fully in camp life.
 - o Pick a camp that offers not only recreation but also opportunities to build self-esteem and teach successful strategies for living with a bleeding disorder.

Camp: How to Prepare

Throughout North America many camps are designed to serve young people and their families who are affected by bleeding disorders. Preparing your child and yourself for his or her going away to camp starts long before you place your child on the bus to camp.

If you and your child are new to the camp experience, it's important that you discuss and understand what will happen during your child's time at camp. Both you and your child need to know how long you'll be separated from each other, that your child will be the responsibility of another person, and that your child will have to follow the rules of the camp and the directions of the counselors.

Discussing these and other aspects of camp life early will help you and your child prepare for a great camp experience!

The majority of the camps for people with bleeding disorders are organized by a Hemophilia Treatment Center (HTC) and a local bleeding disorders organization. Discuss any questions or concerns you may have with those organizers, or if you know the camp that your child will be attending, talk to the camp director.

Preparing for Camp

The camp's website probably has valuable information you can look at during your search. If you're unable to visit in person, you and your child will get to see photographs of the camp and, perhaps, the camp counselors.

Some basic questions you should have answered (check the camp's website for answers, if available):

- What are the rules and responsibilities of the children attending?
- What sports, games, and activities does the camp offer?
- What should children bring—or not bring—to camp?
- What is the camp's general daily schedule?

The camp and the medical staff will provide you with a list of what to bring to the camp. Be sure that you follow that list closely. Needed items and supplies may not be available if your child doesn't pack them. The list will include items ranging from clothing to all medications.

Before your child attends camp, you will need to fill out a registration or application form. Complete the forms honestly, especially the health form. The camp organizers need this information to help ensure a safe and fun camp experience.

To help make your child's camp experience go smoothly, here are some considerations you might keep in mind:

- Campers who enjoy their time at camp the most have spent time away from home previously.
 - o Consider how your child might handle being away from home for a few days, a week, several weeks, or more.
- You should follow the rules and regulations regarding contacting your child at camp; most camps allow communication via e-mail or snail mail.
- You should label absolutely everything with your child's name.
- Homesickness is a real emotion your child may experience while being away.
 - o Before going to camp, have an honest discussion about the feelings they may experience.

What a Bleeding Disorder Camp Offers

A large focus of bleeding disorder camps is to give children age-appropriate independence so that they can learn to be accountable for their own lives.

Some ways that camps accomplish this is by:

- Teaching self-infusion
- Teaching life skills, such as leadership and teamwork
- Meeting other children with bleeding disorders
- Creating a feeling of belonging
- Helping develop the child's self-esteem

You may wish to prepare your child for this by introducing these concepts at home well before your child goes to camp.

While camps may vary slightly, the camp staff is there to create an unforgettable, positive camping experience for your child. They have put tremendous effort and years of experience into developing activities to promote group bonding, friendships, and personal growth.

Some activities that might be provided at your camp:

- | | |
|--|--|
| • Swimming | • Games |
| • Sailing | • Medical programs, including bleeding disorder education and self-infusion training |
| • Canoeing/kayaking | • Arts and crafts |
| • Fishing | • Challenge courses |
| • Nature study | • ...And much, much, more! |
| • Specially designed athletic activities | |
| • Campfires | |

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A Service Dog for our Son

By: Russell Williams, Retired Behavioral Specialist

In a conversation with a psychologist friend, I began to understand some deeper benefits of a service dog. Our son came to live with us as a foster child 12 years ago. Only after he came to our home was he diagnosed with a rare and severe form of hemophilia. He had come from a troubling past and had no idea that some of the physical pain he had suffered was from untreated bleeds. He had lived that way for the first 14 years of his life. My wife and I knew nothing about hemophilia, except that it was a bleeding disorder. We have since received an education to say the least.

Some time ago, we began to sense that some of our son's bleeds were self-inflicted. During periods of frustration, anxiety, stress and anger bleeds occurred more often. Past events that were so troubling would play over and over in our son's mind. There was no changing of what happened in the past, no better outcome this time through. The past was the past. There would be no resolve, no resolution, no reconciliation. This mental replaying of past events caused a constricting tunnel vision resulting in more bleeding episodes. It was damaging his life and there seemed to be little that could be done to prevent this reoccurring cycle. Then Yoder arrived to our home.

Yoder was to be my retirement dog, however she imprinted on our son and over time, he attracted to her, the bond was made. Our efforts to diffuse situations that could cause our son to harm himself often made matters worse. Yoder came to his rescue. She would jump on his lap or on his leg, sometimes barking until he would pick her up. She would then try to bury herself into him. It was like watching an F-5 tornado vanishing into nothing. After awhile we didn't have to say anything to our son for Yoder to react. She seemed to know instinctively. It's believed that our son when in distress, puts out a pheromone (a slight odor) that Yoder picks up on and reacts. I trained Yoder for almost a year to be our son's service dog. In April 2016 I began training our son as the handler. Both train together regularly and are seldom apart.



I have a friend who told me a story about when he was a Court Psychologist. "A woman stood before a Judge, accused of stealing. The Judge for some reason referred her to him before hearing her case. The Court Psychologist asked her, what did you steal? I stole candles, she replied. Why Candles? Stretching forth her arm, she said I use the candles to burn myself. There were severe burns the length of her arm. Why would you do such a thing? The lady responded, the pain from the burns is severe and it's the only relief I get from the pain of my past". My psychologist friend said that the mental anguish from adverse memories of long ago can be more severe and longer lasting than the burns from a candle. The burns to her arm, if severe enough, provided a brief distraction from her terror of long ago. The burns from the candle, are harm. Self-inflicting bleeds, are harm. Yoder, as our son's service dog, has replaced harm with healing.

Yoder gives our son unconditional love, loyalty, wanted responsibility, protection, and joy. Yoder is consistent. Our son reflects these attributes not only to Yoder, but also to everyone he meets. With Yoder at our son's side, it's been nearly a year without a bleed. The boy has become a man and the man is finding peace.

Yoder Facts:

- Hemophilia Service Dog: University of North Carolina, Hematology and Thrombosis Center
- Psychiatric Service Dog (PSD) Designation in American Disabilities Act (ADA) Carolina Health Care System, North East Psychiatric
- Medical Service Dog: Novant Health, Granite Quarry Internal Medicine and Pediatrics
- Medic Alert:
 - Registered as Hemophilia/Psychiatric Service Dog to the Handler
 - Yoder carries Handler's Emergency Treatment Plan, Medical Information and Emergency Contacts
 - Handler and Service Dog are on the same ID Tags worn by Handler and Service Dog
- North Carolina Department of Health and Human Services (DHHS) Vocational Rehabilitation Holds Service Dog letters from Medical Institutions Registered North Carolina Service Animal with ID and Tag.
- Yoder goes everywhere with her handler.

My Life, Our Future Research Repository Offering Free Genotyping

Submitted by the National Hemophilia Foundation

Recently, Rare Disease Day marked the opening of the *My Life, Our Future* Research Repository to scientists. Thanks to your participation, our community has created the world's largest genetic hemophilia repository, a collection of samples and data from more than 5,000 participants, enabling researchers to further understanding about the disorder. Together, we are one step closer to scientific breakthroughs for our community that will impact generations to come. You can read more about this exciting announcement by scanning the QR Code.

My Life, Our Future is a nationwide campaign for progress in hemophilia. Leaders in our community, including the American Thrombosis and Hemostasis Network, Bloodworks Northwest, the National



Confirmed and potential carriers can enroll and participate through the end of 2017. Contact your local HTC if interested.

Hemophilia Foundation, and Bioverativ (formerly Biogen), have come together to offer free genotyping, so that participants may gain a deeper understanding of their hemophilia today, while helping to advance the breakthrough treatments of tomorrow.

We will continue to keep you informed about program milestones, and encourage you to visit NHF's website and MyLifeOurFuture.org for updates on research progress. In the meantime, if you haven't already participated, *My Life, Our Future* is still enrolling participants through the end of 2017 – this includes confirmed and potential carriers, too! Contact your local HTC to learn how you and your family can get involved. With every yes, progress!

Spark Therapeutics Announces Initiation of Phase 1/2 Trial

February 23, 2017

Spark Therapeutics, Inc. has announced the initiation of a phase 1/2 trial of SPK-8011, the company's investigational gene transfer candidate for hemophilia A.

The therapy entails a one-time intravenous infusion of SPK-8011, designed to trigger the production of therapeutic levels of factor VIII, a protein that is normally deficient in individuals with hemophilia A. Spark Therapeutics' proprietary bioengineered adeno-associated viruses (AAVs) act as delivery vehicles, or vectors, to carry the genetic codes that prompt the FVIII production. The approach being tested in this trial uses a modified novel AAV vector to deliver the corrected FVIII gene into liver cells where the protein is normally made.

In collaboration with Pfizer, Spark Therapeutics has been conducting an ongoing AAV-based gene therapy for hemophilia B

known as SPK-9001. In December 2016, Spark Therapeutics and Pfizer announced updated preliminary data from the first nine participants in its ongoing phase 1/2 clinical trial of SPK-9001. These data were presented at the 58th American Society of Hematology Annual Meeting in San Diego, CA, on December 4, 2016.

While the SPK-8011 study for hemophilia A is currently only open for recruitment at the Children's Hospital of Philadelphia, there are plans for additional trial sites to open in the upcoming months. To learn more about this study or for specific inclusion/exclusion criteria go to clinicaltrials.gov and search by trial ID#: NCT03003533.

Source: Spark Therapeutics, Inc.

Reprinted with permission from www.hemophilia.org

There are always new clinical trials and studies that might benefit those diagnosed with a bleeding disorder. This is just one of many. To find out more, check with your doctor and visit

<https://www.hemophilia.org/Newsroom/Industry-News>

for additional information.



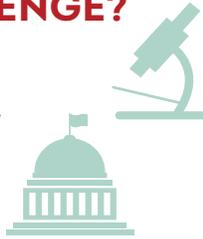
THE 2017 RED TIE CHALLENGE™

NHF | REDTIECHALLENGE.ORG

HOW DO YOU "RED TIE"?

WHAT IS THE RED TIE CHALLENGE?

NHF's Red Tie Challenge aims to advance the fight against inheritable bleeding disorders by **raising funds for its research, education and advocacy initiatives.**



TAKE THE RED TIE CHALLENGE IN 3 EASY STEPS!

1 MAKE A DONATION at redtiechallenge.org.

2 Get a **red tie**, then record & share your best red tie style with **#RedTieChallenge**.



3 Challenge your friends to join you in the **fight against bleeding disorders**.



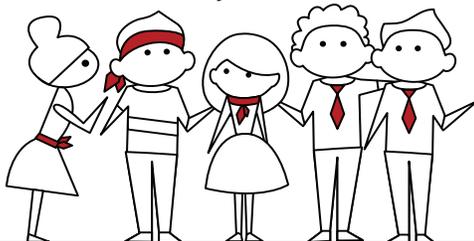
THANK YOU FOR YOUR SUPPORT!

WHAT ARE INHERITABLE BLEEDING DISORDERS?

More than three million Americans have either hemophilia, von Willebrand disease or rare factor deficiencies, all of which: prevent the blood from clotting normally; can result in extended bleeding after injury, surgery or trauma; and can be fatal if not treated effectively.

WHY THE RED TIE?

The red tie symbolizes the **blood ties** that bind our community.



SHOW YOUR SUPPORT FOR BLEEDING DISORDERS AWARENESS MONTH EACH MARCH!



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

NHF is a 501(c)(3) nonprofit organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. NHF has 54 chapters throughout the U.S. Learn more at www.hemophilia.org.

7 Pennsylvania Plaza #1204, New York, NY 10001 | T (212) 328-3700 | redtiechallenge@hemophilia.org



National Hemophilia Foundation's (NHF) Washington Days

March 8-10, 2017

Washington, DC

HNC members attend NHF's Washington Days. For a detailed account of the time spent in Washington, DC, please read Zack Hargett's article on Page 17 in the Our Young Voices section and Matt Igelman's Advocacy Update on page 26.



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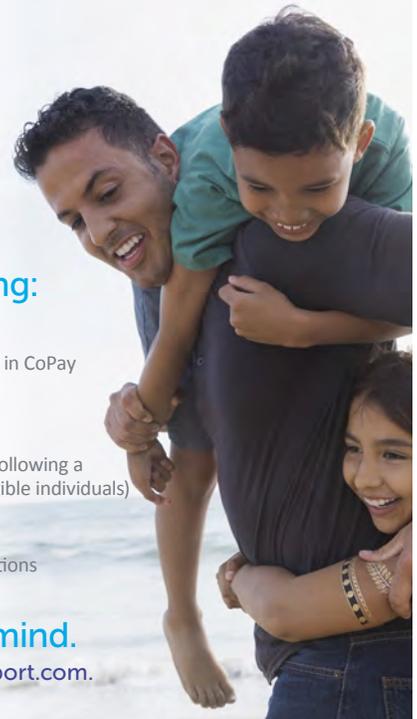


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S28369 02/17



Advocacy Update

By: Matt Igelman, HNC Advocacy Chair

Change is a constant, and 2017 will be no different with looming changes to our state Medicaid and changes across the country in the health insurance market on the horizon. NC Medicaid has a new secretary, appointed by Governor Roy Cooper, and the state awaits approval of a Section 1115 Medicaid Reform Waiver as well as proposed changes to clotting factor reimbursement. Health insurers around the country are expecting changes to the Affordable Care Act and our national organizations are advocating in Washington for protections for the bleeding disorders community.



Rep. Nelson Dollar with Advocacy Committee Chair, Matt Igelman, and Advocacy Committee Member, George McCoy

HNC has hit the ground running in terms of advocacy in anticipation of a year full of changes. We have hosted our monthly advocacy calls and encourage advocates here in NC to join us by telephone the first Tuesday of each month. The committee has already hosted a stakeholder meeting to discuss Medicaid changes in this state. In addition, HNC proudly hosted the Honorable Nelson Dollar at our Annual Meeting. Representative Dollar spoke to our advocates on the issue of Medicaid reform here in NC and showed us all just how easy it is to become an advocate and speak to your local legislator.



Rep. Nelson Dollar with Advocacy Committee Members at the Annual Meeting Advocacy breakout session

In March, advocates from NC joined NHF's Washington Days, helping to set a new record attendance for the event. As Congress tries to nail down the changes to the Affordable Care Act (ACA), the bleeding disorders community advocated for the protections in the new healthcare law that are most important to us. With the cherry blossoms ringing in an early spring, pollen and change were in the air. Participants from NC enjoyed seeing the democratic process of our country hard at work and listening to the issues of the bleeding disorders community.

Please join us here at HNC in advocating for what's important to you! We are hosting our annual HNC Legislative Day on Tuesday, May 2nd. We start Monday evening, May 1, with an optional training and dinner, so even a first time attendee will be prepared to tell their story and make a difference. Then we meet with legislators throughout the day on Tuesday. As a rare community we need each and every voice we have! Please register online or contact the office at (800) 990-5557 to have your voice heard in Raleigh. Accommodations are available upon request through April 10 for attendees traveling over 30 miles who will also attend the training on Monday night.

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HNC Members at NHF's Washington Days



Hemophilia of North Carolina 2017 Calendar of Events Highlights



April 17, 2017	World Hemophilia Day
April 22, 2017	HNC Family Festival & 5K Walk for Bleeding Disorders – Charlotte, NC
April 28-30, 2017	NOW Conference – Phoenix, AZ
May 2, 2017	HNC Legislative Day – Raleigh, NC
May 13, 2017	HOPE & Blood Brotherhood paired event – Charlotte, NC
May 17, 2017	SOAR Dinner – Charlotte, NC
May 20, 2017	Latin Union Zoo Event – NC Zoo, Asheboro, NC
June 17, 2017	Latin Union Event – Charlotte, NC
July 1, 2017	HOPE Steps for Living – HNC Office, Morrisville, NC
July 6-9, 2017	HNC/HSC Teen Retreat – Camp Canaan, Rock Hill, SC
July 28-30, 2017	HNC Men's Retreat – Trinity Center, Pine Knoll Shores, NC
August 12-13, 2017	HNC Adult Retreat – Wilmington, NC
August 19, 2017	Family Fun Day – Tanglewood Park, Clemmons, NC
August 24-26, 2017	NHF 69th Annual Meeting – Chicago, IL
September 15-17, 2017	HNC Family Retreat – Sea Trail Resort, Sunset Beach, NC
September 24, 2017	Latin Union Event – Greensboro, NC
October 14, 2017	HNC Family Festival & 5K Walk for Bleeding Disorders – Morrisville, NC
October 21, 2017	HNC Yard Sale Fundraiser – HNC Office, Morrisville, NC
October 20-22, 2017	Blood Brotherhood Retreat – Blowing Rock, NC
December 2, 2017	HNC Holiday Celebration – Greenville, NC
December 2, 2017	Latin Union post-Holiday Event – Greenville, NC



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we'll help find an answer—
call Pfizer Hemophilia Connect



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Community Resources

Learn about support programs like HemMobile™, Patient Affairs Liaisons, scholarship assistance, and the educational speaker series.

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If you have any questions about the use of the Pfizer Factor Savings Card, please call 1.888.240.9040 or send questions to: Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 200, Morrisville, NC 27560. For more information, please visit www.HemophiliaVillage.com.

†The Pfizer RxPathways Savings Card is not health insurance. For a complete list of participating pharmacies, visit PfizerRxPathways.com or call the toll-free number 1.877.744.5675.

There are no membership fees to participate in this service. Estimated savings is 36% and depends on such factors as the particular drug purchased, amount purchased, and the pharmacy where purchased. Pfizer RxPathways is a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation™.

*Terms and conditions apply. You must be currently covered by a private (commercial) insurance plan. For questions about the Pfizer Hemophilia Trial Prescription Program, please call 1.800.710.1379 or write us at Pfizer Hemophilia Trial Prescription Program Administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736. You may also find help accessing Pfizer medicines by contacting the Pfizer RxPathways Program.





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Hemophilia of
North Carolina

FAMILY '17 FESTIVAL

& 5K Walk for Bleeding Disorders

CHARLOTTE – Sat., April 22, 2017

Mint Street at 3rd St. & MLK Blvd.
Uptown Charlotte, NC

RALEIGH – Sat., October 14, 2017

Lake Crabtree County Park
1400 Aviation Parkway
Morrisville, NC

Check-ins begin at 9:00am 5K / 3.1 Miles or
Walks begin at 10:00am 2.4K / 1.5 Miles
(short route)

save the date

START YOUR WALK TEAM TODAY!

Join Hemophilia of North Carolina (HNC) for its annual Family Festival and 5K Walk, fundraisers dedicated to preventing the complications of bleeding disorders.

All proceeds help us continue our education, advocacy, and peer support programs and services to our North Carolina community. Your support and participation ensures that the enthusiasm and impact of Hemophilia of North Carolina will make a difference across the state!

For more information please visit:

www.hemophilia-nc.org/festival or contact:

Charlene Cowell, HNC Executive Director

at festival@hemophilia-nc.org

or call **(800) 990-5557**.

www.hemophilia-nc.org/festival