

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

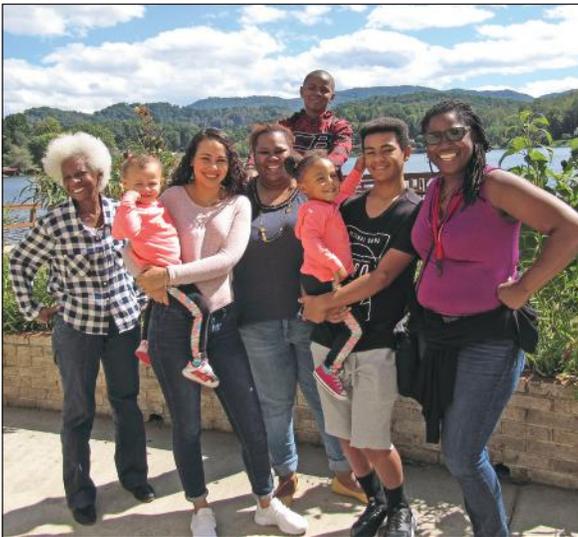
SUMMER 2017

Family Retreat is Back at the Beach

September 15-17, 2017
Sunset Beach, NC



Mark your calendars for the 2017 Family Retreat on September 15-17. This year's retreat will be moving back east to the Sea Trail Resort and Conference Center in Sunset Beach, NC. We'll only be a few minutes from the beach while at Sea Trail!



Families Enjoying the 2016 Family Retreat

The weekend will be full of fun and educational activities for families who have a child affected by a bleeding disorder. There will be sessions for adults and children, and childcare will be provided for younger children. The current sessions are being finalized, but expect to hear about camp opportunities, parenting a child with bleeding disorders, and roundtables. Other sessions that we have had in the past include emotional wellness, advocacy, basics of bleeding disorders, preparing for school, staying active and more. Children's activities may include sessions for unaffected siblings, learning about bleeding disorders, and other fun sessions from animal encounters to science experiments. There will be social activities and plenty of time to mingle, network, and get to

know other families who also have a child with a bleeding disorder.

Priority will be given to families who have a child age 12 and under with a bleeding disorder as the programming is geared towards this age range. This opportunity, including accommodations and meals, is offered free to HNC members thanks to the support of our sponsors. More information and registration will be available soon, so save the date!



Tending to his "patient" at the Family Retreat Teddy Bear Clinic

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Save The Date

HOPE Family Education Program
Morrisville, NC
July 1

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

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

HNC Adult Retreat
Wilmington, NC
August 12-13

Family Day Out
Clemmons, NC
August 19

NHF Annual Meeting
Chicago, IL
August 24-26

Blood Brotherhood Event
Winston-Salem, NC
September 9

HNC Family Retreat
Sunset Beach, NC
September 15-17

Latin Union Event
Greensboro, NC
September 24

HNC Family Festival & 5K Walk
Morrisville, NC
October 14

Blood Brotherhood Retreat
Blowing Rock, NC
October 20-22

HNC Yard Sale
Morrisville, NC
October 21



Hemophilia of North Carolina

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

MISSION STATEMENT

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

Contact Numbers

Hemophilia of North Carolina

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

National Hemophilia Foundation

(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

Community Health Charities of NC

(919) 554-3272 (Collect)
www.healthcharities.org

About This Publication

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

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

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

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

Hemophilia Treatment Centers

East Carolina University Brody School of Medicine

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

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

Inalex Communications
201-493-1399
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.



From the HNC Office: A note about mailings



As we look back on the first half of 2017, we are pleased to report that HNC has offered more than two dozen opportunities for members to participate in events geared toward education, support and community awareness. We hope you and your family members were able to benefit from at least one of these opportunities.

As we continue to improve our communication efforts and in order to reach out to our members in all areas of the state, you may have noticed that we have begun to provide event invitations both by mail and email. HNC understands the great diversity of our membership and is always trying to provide information in a manner that suits the needs of each family.

Wherever possible, we will try to combine multiple event invites in one envelope in order to reduce costs. When you receive mail from us, please be sure to look at all the inserts enclosed so you don't miss an announcement that might be interesting to you.

As you can imagine, with this effort to mail invitations to each member's home, there has been an increased cost to HNC. If this is the best way to reach you, we will gladly continue to mail event materials to your home. However, if you wish to opt out of paper mailings and receive only email announcements of upcoming events and programs, please email us at info@hemophilia-nc.org to let us know your preference. Those who opt out of event mailings will be placed on our "Newsletter-only" mailing list.

Thank you for helping us in our efforts to support HNC members. As always, we are interested in hearing from you about what topics might be relevant to you as we continue to plan educational events and dinners throughout the state.

Feel free to contact us at the office by emailing info@hemophilia-nc.org or calling (800) 990-5557.

Sincerely,

Charlene, Gillian and Karyn

An Open Letter to the HNC Board of Directors and All Members



As you know I was recently elected to the HNC Board of Directors, for a term beginning July, 2017. It is with sadness and regret that I am writing to announce my resignation from this important post, effective immediately.

After a period of ill health, I have just been diagnosed with pancreatic cancer. In the coming months Phil and I will be concentrating on the various challenges this diagnosis brings. We will continue to support HNC as best we can, but for now our focus will be elsewhere.

It has been a great honor and privilege to serve as a volunteer for HNC. I have met wonderful people through the Advocacy Committee, the Blood Brotherhood, and various ad hoc activities. I was looking forward to working with and learning from the Board of Directors.

My best wishes to you all. I hope you realize what a jewel you have in HNC, and will continue to deepen your commitment to the organization. HNC will become more important than ever against the background of shifts in health care insurance law and policy.

Thank you for the opportunity to serve!

George D. McCoy

HNC Family Festival and 5K Walk for Bleeding Disorders in Charlotte: A Great Success!

April 22, 2017
Charlotte, NC

Despite a threat of rain in the forecast, the day turned out to be just right for a morning walk around Uptown Charlotte for the 3rd Annual Charlotte Family Festival & 5K Walk for Bleeding Disorders. The Staff and Board of Directors of Hemophilia of North Carolina (HNC) would like to thank everyone who participated in making this event a success. To all the members, volunteers, sponsors, donors and contributors that gave their time and effort to this event and for all of your continued dedication to events throughout the year, thank you.

Over 340 people attended this year's Family Festival & Walk. We continued to spread awareness through Uptown Charlotte as people from the neighborhood and local community came over to learn what the crowds of people and upbeat music were all about. We exceeded our fundraising goal of \$50,000 by raising a total of \$56,204! With your support we can continue to sustain and develop programs and services that meet the various needs of our community.

The first volunteers of the day arrived before sunrise to set up the event space on Mint Street. As the sun came up, more and more volunteers arrived to put the finishing touches in place to transform the street into a festival for walkers to enjoy. Participants enjoyed entertainment and activities for the entire family, giveaways and raffles, coffee from Starbucks, various breakfast goodies, lunch from Will's Dogg'n it Deli and Dogs, doggie bags from Carolina Pet Pantry, cotton candy, ice cream from Freddy's in Concord, and so much more! A special thanks goes to the activity and prize sponsors that helped make all of the fun possible: Accredo (cotton candy), Drugco Health (balloon artist), Grifols (face painter), HPC Specialty Pharmacy (photo booth), and Grand Prize Sponsor Cottrill's Specialty Pharmacy for their donation of a 128 GB iPad with Wi-Fi and cellular capabilities that went to a lucky passport raffle prize winner.



To get things started, Larry Sprinkle from Charlotte's WCNC returned this year as the emcee. The Carolina Panthers' Sir Purr mascot was there too, along with



Continued next page

Charlotte Festival Sponsors

Presenting Sponsor

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Bronze Sponsors



In-kind Sponsors



Blood Brotherhood and HOPE Program Educational Event

May 13, 2017
Charlotte, NC



Members of all ages enjoyed the HOPE Blood Brotherhood NASCAR Event

Forty HNC members attended the first joint Blood Brotherhood and HOPE Program Educational Event at the NASCAR Hall of Fame in Charlotte on May 13, 2017. Designed to provide families who have children with a bleeding disorder an opportunity to talk and network with adult men with bleeding disorders, everyone got to know each other during lunch. A presentation on joint health was given by HNC member and mom of two young boys with hemophilia, Erin Otey, PT, DPT.

Following lunch, participants were divided into three groups to tour the museum and take part in the exhilarating Race Car Simulator and Pit Stop Challenge. The Race Car Simulator provided the opportunity to sit in a racecar and safely compete against each other. The Pit Stop Challenge had teams competing to change tires and fill the gas tank in

the shortest amount of time. After the tour was over, people had the time to talk a little more before heading home. Attendees are already asking when the next joint event will be. What an exciting event and a unique opportunity for the Blood Brotherhood and HOPE Programs!

HNC Family Festival and 5K Walk for Bleeding Disorders in Charlotte: A Great Success!

continued from previous page



Performance DJ and Jecoreography who motivated the crowd before the walk began. Jecorei Lyons from Jecoreography spoke on the benefits of staying active with a bleeding disorder. Throughout the morning, those passing by the Festival site and route stopped and asked questions about bleeding disorders and about the event which provided HNC members a chance to spread awareness to the greater community.



As the morning continued, some HNC members and supporters received special recognition for their efforts in making this event a day to remember! Congratulations to Team Gman, top team fundraiser, and Erin Otey, top individual fundraiser. Also, a special thanks to the extraordinary efforts of our 2017 Droplet Award Winners: King Tommy Odom, Queen Carla Barbee and Junior Droplet Charlie Stotz. Finally, HNC would like to recognize the second annual Charlotte Hospital Cup winner, St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital.

To see pictures and video clips of the event, please visit HNC's Facebook page. If you aren't already following HNC on Facebook, simply search for Hemophilia of North Carolina and "like" the page to see HNC news, events and pictures throughout the year.



Save the date for the 10th Annual Raleigh Family Festival & 5K Walk for Bleeding Disorders on October 14, 2017 at Lake Crabtree Park in Morrisville. The 4th Annual Charlotte Family Festival & Walk will take place on April 14, 2018.



Mentoring Lunch ‘n Learn

March 25, 2017
Concord, NC

Members of the HOPE Mentoring Program got together on Saturday, March 25, at Dave & Buster’s in Concord for a fun Lunch ‘n Learn event. Families spent time catching up while children participated in crafts and games. Afterwards, everyone enjoyed lunch and listened to an educational presentation on *Emergency Preparedness* led by Anita Smith, CPNP, and coordinator for the Wake Forest University Comprehensive Hemophilia and Thrombosis Diagnostic and Treatment Center. Families learned about the importance of being prepared for a variety of emergencies including, but not limited to, hurricanes, tornadoes, and fires. They learned what an emergency kit should have in it and additional items that are necessary when dealing with a bleeding disorder. Participants also learned about a great resource on the Emergency Preparedness and Response page of the CDC, <https://emergency.cdc.gov>.

Following the presentation and after saying their goodbyes, families were provided with game cards to go play in the Dave &



Anita Smith discusses *Emergency Preparedness* with Mentoring Program members

Buster’s arcade. This was a big hit, especially for the kids!

Mentoring Lunch ‘n Learns are scheduled regularly throughout the year. For more information about the Lunch ‘n Learn events and the Mentoring Program, please contact Gillian Schultz, Program Manager at gillian.schultz@hemophilia-nc.org.



DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.



Working for you—From the Sunshine State to the Carolinas

Name: Daysi Fardales

Home state: Florida

Dessert of choice: Dulce de leche

Favorite show: My family loves watching reality talent shows together.

What motivates you as a liaison? I've always had a passion for educating. My 20+ years as a nurse have given me additional insight and skills to educate and guide the hemophilia community.



To get in touch with Daysi, call Pfizer Hemophilia Connect 1.844.989.HEMO(4366)

What we do:

- ✓ Provide helpful information about Pfizer Hemophilia programs and services
- ✓ Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- ✓ Serve as a primary point-of-contact for local advocacy groups
- ✓ Participate in local and national events and programs
- ✓ Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

“IT’S GREAT TO EDUCATE AND HELP THE COMMUNITY TO BE AWARE OF PFIZER HEMOPHILIA’S SUPPORT SERVICES.”

—Daysi Fardales



Educational Dinners: Sharing Your Story

April 3, 2017 April 4, 2017
Raleigh, NC Charlotte, NC



HNC Members learn more about advocacy at the SharingYour Story Educational Dinner in Raleigh

left feeling a little more comfortable with what to include in their story, how to make it meaningful, and some attendees were ready to advocate for the bleeding disorders community in Raleigh on May 2.

On Monday, April 3, and Tuesday, April 4, HNC partnered with Shire for two educational dinners in Raleigh and Charlotte. The topic of the Hello Talk was *Sharing Your Story* presented by Patricia Espinosa-Thomson.

Between the two evenings, twenty-one people enjoyed dinner and learned about the importance of their 30 second “elevator speech” when advocating for themselves or family members with bleeding disorders. Although being able to share your story is important when going to the doctor or expressing needs at school or work, the focus of this session was specific to legislative advocacy to prepare for the HNC Legislative Day on May 2.

Following an interesting and interactive presentation, people

SOAR Women’s Dinner

May 17, 2017
Charlotte, NC

Hemophilia of North Carolina held a SOAR Dinner for women with bleeding disorders and moms of girls with bleeding disorders. The women gathered at Firebirds Wood Fired Grill in Charlotte for an evening of



Women gather to share their experiences at SOAR Women’s Dinner

community, support, and education. Chelsea Frimpong from the National Hemophilia Foundation presented the program *Advocating for Yourself as a Woman*.

Everyone talked for hours, learning about different situations where it’s important to advocate for themselves and ideas about how to be a self-advocate. From emergencies to the different situations girls may encounter in school, there was a wealth of information shared among the group. After a delicious dinner, everyone left feeling full, including a new feeling of belonging to a supportive community of women with bleeding disorders.

Latin Union Program Takes to the Zoo

May 20, 2017
Asheboro, NC

With 27 people in attendance it was a packed house in the Hippo Beach shelter at the NC Zoo on May 20. Members of the HNC Unión Latino Program gathered for an afternoon of learning and fun. Each family introduced themselves and shared a little about what brought them to the zoo. Some had known each other for a long time through the program and enjoyed reconnecting. Others were excited at the chance to meet new people from the community. The picnic-style food was also a delicious start to the afternoon.

Patricia Espinosa-Thomson from Shire presented *No Sweat: Staying Active and Healthy with a Bleeding Condition*. Everyone gained new knowledge, whether it was about the amount of time that is suggested for physical activity or the benefits that this activity has on your mind and body. Even those who do not live with a bleeding disorder found that this information is useful to anyone who wants to stay healthy. As soon as the presentation was done, it was time to put these lessons into action as everyone headed into the zoo. There was no shortage of physical activity opportunities once participants entered the huge park to visit with all of the animals!

HNC Educational Dinner: Understanding von Willebrand Disease

March 14, 2017
Hickory, NC

Several HNC members joined together at Bistro 127 in Hickory for an educational dinner and HELLO TALK presentation, *Understanding von Willebrand Disease* presented by Shire Senior Clinical Specialist, Nancy Roy, MSN, FNP. After some time of getting to know one another, learning about the bleeding disorder that each person was affected by, and grabbing dinner from the buffet, Nancy led an informative and educational session. The presentation provided an overview of von Willebrand Disease (VWD), including just what von Willebrand

factor is and what it does, the different types of VWD, and how it is passed on through genetics. The graphics and illustrations were very helpful in explaining how the various types of VWD are different from each other and how von Willebrand factor is so essential in the clotting process, including its connections to platelets, factor 8, and collagen. Following the presentation, everyone had a better understanding of von Willebrand Disease. HNC would like to thank Shire for partnering with us for this HELLO TALK.

HFA Symposium

April 6-9, 2017
Providence, Rhode Island

Nearly 1,300 community members of the bleeding disorders community came together April 6-9, 2017 in Providence, R.I. for the Hemophilia Federation of America (HFA) 2017 Symposium to collectively create an unforgettable weekend. Attendees had opportunities for networking, education, and support through sessions and social time. Sessions included information about HFA's policy and advocacy efforts, with topics for adult men and women with bleeding disorders and families. Specialized tracks for von Willebrand disease, inhibitors and Spanish speaking families were offered, as well as bleeding disorders education for children and teens. It was an incredible weekend of creating new relationships and cementing old ones as a bleeding disorders family.

The theme of HFA's 2017 Symposium was "Hope Ignites," representing both the state of Rhode Island, "Hope," and a period of emerging treatment. "Ignites" was inspired by a signature fixture in downtown Providence, an art sculpture along the city's waterfront known as "WaterFire," which has been described as the city's "most popular work of art created in the capital city's 371-year history." The Final Night Event featured a WaterFire event showcasing HFA's 44 member organizations and the bleeding disorders community to the entire city, igniting awareness of our community to a wider audience.

Teen Group Make An Impact For Homeless in Providence

The teens at Symposium 2017 were busy working to help the homeless of Providence. Over the course of the weekend, the teens contributed by collecting, sorting, bagging, and donating thousands of individual toiletries to donate to the local homeless shelter. In addition to donating to the homeless shelter, the teens made and decorated clay pots to donate. The teens also canvassed the streets of downtown Providence making the community at large aware of bleeding disorders by sharing posters and awareness cards with local businesses.

Symposium 2018 Will Be In...

Symposium 2018 will be in Cleveland, Ohio from April 26-29, 2018! HFA looks forward to being in the Great Lakes region!



HNC staff members, Charlene and Gillian, represent North Carolina at the HFA Symposium

World Hemophilia Day Lights up the World Red

April 17, 2017

Worldwide



Members light up their homes red in honor of World Hemophilia Day

The World Federation of Hemophilia (WFH) presented World Hemophilia Day (WHD) this year on April 17 with a focus on bringing attention to the women and girls in the community who are affected by bleeding disorders. Visit www.worldhemophiliaday.org to learn more about the event and hear the stories shared by women and girls from throughout the community and around the world.

As a way to commemorate the event, WFH expanded their “Light it up Red” campaign to show support for WHD with nearly 70 landmarks lit up red in 18 different countries all around the world. This included one in North Carolina as the Wells Fargo Duke Energy Building in Charlotte lit up the skyline red to honor those affected by bleeding disorders worldwide.

HNC members celebrated this awareness building occasion by attending viewing parties in Charlotte or, for those outside the Charlotte area, lighting it up red on their own. Thanks to those who supported WHD near and far.



Members gather at a viewing party to see the Charlotte skyline light up red

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Novoeight® patient ambassadors are ready to connect with you. Each team member shares their history, their diagnosis, and their unique stories that can inspire you and your caregivers.

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novoeight®
Antihemophilic Factor
(Recombinant)

THE CONCENTRATE



Summer 2017

NHF Annual Meeting

August 24-26, 2017
Chicago, IL

This year's National Hemophilia Foundation (NHF) Annual Meeting will be held at the Hyatt Regency in Chicago and is themed Exploring the New Frontier. For three days, the NHF will provide multiple educational sessions, workshops, networking opportunities and access to their exhibit hall. There's something for everyone including kids and teens programs. Registration is now open and includes entrance to the Opening Session, Awards Luncheon and Final Night Event. Childcare is available for children under age 12. At this time, HNC is no longer accepting applications for travel grants to the NHF Annual Meeting but would encourage all members who are able to do so to make the effort to be part of this exciting opportunity.

Carolina Crew at the HNC/ HSC Teen Retreat

July 6-9, 2017
Rock Hill, SC

This July, the Hemophilia of North Carolina and Hemophilia of South Carolina teens (aka, The Carolina Crew) will gather again for a weekend retreat at Camp Canaan in Rock Hill, South Carolina. They will participate in a range of fun and educational activities designed to promote both physical and emotional wellness. You will be able to read more about it in the fall newsletter.



2016 Teen Retreat

HNC's 2nd Annual Family Day Out

August 19, 2017
Clemmons, NC

Enjoy a day of fun & games, food & friends and an afternoon at the Tanglewood Aquatic Center on Saturday, August 19.

Lunch will be provided in the picnic shelter, followed by games and activities the whole family can enjoy. HNC members will also have an opportunity to learn more about HNC programs before spending the remainder of the day at the Tanglewood Aquatic Center.

The Aquatic Center amenities include a winding tubing river, water slides, a splash pad with fun water features and lots of deck space to sit in the sun and relax! There is also a children's pool area with spraying fountains for kids to play in the water and a lap pool with diving boards for those who want to perfect their swimming strokes!

Tanglewood Park is a 1,100 acre park in Clemmons, NC, just 20 minutes outside of Winston-Salem. Registration is available on the HNC website or call the HNC office to register.



Tanglewood Park Aquatic Center

HNC Men's Retreat

July 28-30, 2017

Pine Knoll Shores, NC

Are you an adult male 18 and over living with a bleeding disorder or a dad of a child with a bleeding disorder? If so, save the date for the 3rd Annual Men's Retreat, taking place July 28-30, 2017 at the Trinity Center in Pine Knoll Shores, NC. For those who haven't been to the Trinity Center, the retreat center is walking distance to the beach. There will be programming from Inalex Communications, sessions to support men in the community through mentoring and common connections, and free time to explore the beach and the nearby area. This is a great opportunity for dads and their adult sons to pair up and share the



HNC Members at the 2016 Men's Retreat

experience, each from their own perspective. Several fathers and sons have joined this group in past years, and it has been a great experience for them. Each person must register separately, but no other special arrangements are necessary. Please contact the HNC office if you have any questions. Registration is available on the HNC website or call the HNC office to register.



Bioverativ is committed to making a meaningful impact in the lives of people with hemophilia and other rare blood disorders by:

- Striving for progress when and where people need it most
- Advancing innovative programs to address serious unmet needs
- Challenging the status quo at every step with focus, urgency, and integrity
- Carrying on Biogen's hemophilia treatments with a continued focus on quality, safety, manufacturing, and product accessibility

Visit Bioverativ.com to find out more

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HNC Adult Retreat is Back!

August 12-13, 2017
Wilmington, NC

Hemophilia of North Carolina (HNC) is pleased to announce the return of the Adult Retreat in 2017. If you are an adult affected by a bleeding disorder, spouse/partner, or parent of a child with a bleeding disorder, this weekend is for you. Join HNC at the Hilton Riverside in Wilmington from August 12-13, 2017. There will be educational sessions on Saturday and Sunday as well as free time, and optional activities. All accommodations, meals, refreshments, and activities will be provided free to HNC members through the generous support of our sponsors. Registration is available on the HNC website or call the HNC office to register.



HNC Adult Retreat returning to Wilmington, NC

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.

General Donations

Richard Atwood
Gay Boggess
Janice Crawford
Irene Cowell
Mr. & Mrs. W. Allen Heafner
Steve Humes
Laura & Dean Shumway

In Honor of World Hemophilia Day

Diane Johnston

For the Red Tie Challenge

Chau Tran

In Memory of Ruby B. Smith

Deborah & Peter Bliss
Joe & Kathy Borrelli
Sandra Hamilton
Diane Lumpkin Peery
Louis & Betsy Santospago
Karl-Heinz Schneider
Gail Brinn Wilkins

Thank You 

In Memory of Andrew AJ Hill

Jeff & Andrea Bridges

support • outreach • advocacy • resources
for girls & women with bleeding disorders

SOAR Program Update

The SOAR Program is continuing to expand through 2017. A dinner was held in Charlotte in partnership with the National Hemophilia Foundation's (NHF) Victory for Women program. On June 10, many women of SOAR will have gathered together for a day of camaraderie and learning at the Graylyn International Conference Center in Winston-Salem. You will be able to read more about this event in the fall newsletter.

There are still a few dinners being planned for the second half of 2017 along with a fundraising event that will help HNC to provide more programming and events for SOAR members. If you are interested in a particular topic or activity, please let us know so that we can try to meet your

needs. You do not need to be alone as a woman or mom of a girl with a bleeding disorder. Our events are designed to bring people together who share a common bond.

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 Education Day

June 10, 2017
 Winston-Salem, NC

On June 10, HNC held the SOAR Women's Educational Day at the Graylyn International Conference Center in Winston-Salem. The day included educational, fitness, and team building sessions. Thank you to CSL Behring for helping to make this opportunity possible. You will be able to read more about it in the fall newsletter.



HNC SOAR Members gathering at the Graylyn Conference Center



It's not too soon to start making tutus to raise awareness for women with bleeding disorders for the HNC Family Festival & 5K Walk for Bleeding Disorders in Morrisville in October 14.

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

HNC Actualización del Programa Union Latina

El Programa Union Latina de Hemophilia de Carolina del Norte (HNC) ha estado muy activo! El pasado Marzo tuvieron una sesión durante la Reunion Annual. Miembros de la Union Latina visitaron el Zoológico de NC y participaron en una charla de como mantenerse activos y sanos y luego tuvieron la oportunidad de visitar el zoológico.

El 17 de Junio, la Union Latina realizo un evento en el estudio de cocina para niños, Flour Power Kids Cooking, en Charlotte en donde prepararon piza vegetariana y

zapallitos fritos, mientras recibían información acerca de opciones para comer saludable. Después de un receso de verano, la Union Latinoamericana retomara sus programas nuevamente en el otoño.

El programa Union Latinoamericana del HNC ha sido designado para apoyar y educar individuos y familias Latinas en Carolina del Norte, quienes sufren de desordenes hemorrágicos. El programa es ofrecido en Español y es posible gracias a financiamiento de Shire. Para más información, visite el sitio internet de HNC.

El Programa Union Latina Se Toma el Zoológico

20 de Mayo, 2017
Asheboro, NC

Recibimos a 27 personas y con eso llenamos el Hippo Beach del Zoológico de NC, el 20 de Mayo. Miembros del programa Union Latina del HNC se reunieron en una tarde de aprendizaje y entretenimiento.

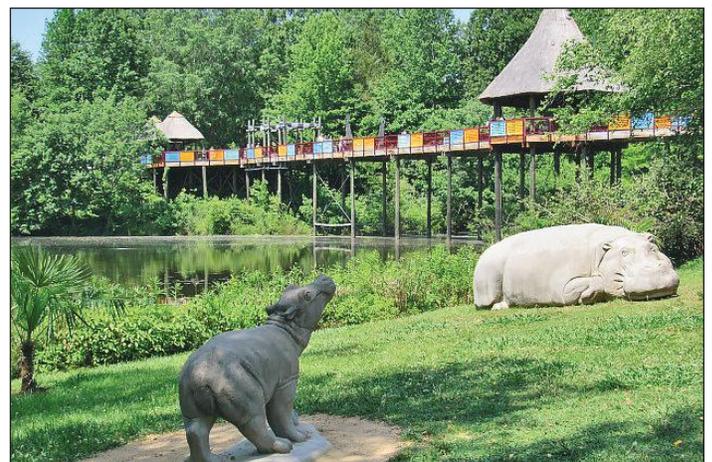
Cada familia hizo una introducción de ellos y la razón por la cual estaban presentes en este evento en el zoológico. Algunos miembros son ya antiguos conocidos del programa y disfrutaron la oportunidad de poder reconectarse, mientras otros estaban contentos con el hecho de conocer nuevas caras de la comunidad. La deliciosa comida fue estilo picnic y una estupenda manera de comenzar la tarde.

Patricia Espinosa-Thomson, representante de Shire presentó No Sweat: Staying Active and Healthy with a Bleeding Condition (No Sude: Siga Activo y Saludable con una Enfermedad Hemorrágica). La audiencia aprendió cual es la cantidad de tiempo aconsejable para realizar actividad física y los beneficios que estas actividades brindan a la mente y el cuerpo. Aun los participantes sanos consideraron esta información valiosa y aplicable a quien quiera mantenerse sano.

Tan pronto la presentación terminó, se pusieron en práctica las lecciones recibidas ya que todos se dirigieron al zoológico. Hubieron variadas oportunidades de realizar actividades físicas al tiempo que recorrían el gran parque y visitaban a los animales!



Miembros de la Union Latina en el zoológico



Family Retreat Regresa en la Playa

15 al 17 de Septiembre, 2017
Sunset Beach, NC

Marquen sus calendarios para el proximo Family Retreat, del 15 al 17 de Septiembre. Este ano el Retreat volver al Este, al Sea Trail Resort and Conference Center en Sunset Beach, NC. Estaremos a solo unos minutos de manejo entre Sea Trail y la playa!

El fin de semana estara lleno de entretenidas actividades educacionales orientadas a las familias con ninos afectados por desordenes hemorragicos. Habran sesiones para adultos y ninos. Como tambien cuidado para ninos menores. Las sesiones estan siendo finalizadas en este momento, pero pronto recibiran informacion acerca de oportunidades de campamentos, tambien para padres con hijos con desordenes hemorragicos y mesas redondas. Otras sesiones previas han icluido bienestar emocional, dedicacion, informacion basica acerca de enfermedades hemorragicas, preparacion para la escuela, manteniendose

activos y mucho mas. Las actividades infantiles podrian incluir algunas para hermanos sanos, informacion acerca las enfermedades hemorragicas, y otras amenas actividades desde encuentros con animales hasta experimentos cientificos. Habran tambien actividades sociales y suficiente tiempo para socializar e interactuar con otras familias que tambien tienen hijos con desordenes hemorragicos.

Se le dara prioridad a las familias con hijos menores de 12 anos con desordenes hemorragicos, ya que el programa esta basicamente orientado a este rango de edad.

Esta oportunidad, que incluye comidas y alojamiento, se ofrece de manera gratuita a los miembros de HNC gracias a la generosa ayuda y respaldo de nuestros auspiciadores. Mas detalles e inscripcion estaran disponible pronto. Esten atentos y mientras tanto reserven la fecha.



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References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. 2. Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. 3. King MW. Introduction to blood coagulation. <http://themedicalbiochemistrypage.org/blood-coagulation.php>. Last modified January 2, 2017. Accessed November 21, 2016.

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Never Too Young To Volunteer!

By: Kaylah Brathwaite

Hi, my name is Kaylah Brathwaite and I'm fifteen years old. I've volunteered for both of the walks that took place in Uptown Charlotte. There are many things that made me come back to this awesome organization. The love that the community has for each other is so overwhelming (in a good way, of course) that it spreads to complete strangers. Every time I volunteer for the HNC I learn something new. I talk about my findings to my mom (a nurse) and friends who have personal experiences with hemophilia. The first time I volunteered in 2016, I arrived before the sun rose to help set up the event. It was in those early hours that I met many of the other volunteers. Later in the day, I met many of you. This year, it was an incredible experience seeing everyone again. I think that raising community awareness of hemophilia and funding is important and getting to be apart of this amazing community that does that is so special to me.



Kaylah Brathwaite at the 2017 Family Festival & 5 KWalk in Charlotte



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[†]The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future KOVALTRY[®] or KOGENATE[®] FS purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

[‡]People with private, commercial health insurance may receive KOVALTRY[®] or KOGENATE[®] FS co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

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Blood Brotherhood Update

Blood Brotherhood members continue to enjoy the events of 2017!

On May 6th HNC hosted the popular Kinesio Taping event down east in Greenville, NC. Guys gathered to learn the benefits of the tape for acute muscle or joint bleeds, and to decrease pain and/or swelling in chronically affected joints. Jennifer Newman, Physical Therapist at UNC-Chapel Hill, presented the program.



Blood Brothers enjoying the NASCAR Event

Blood Brothers also enjoyed the opportunity to connect with younger families pairing with the HNC Hope program on May 13th in Charlotte, NC. Folks enjoyed the Joint Health program presented by Erin Otey, PT, DPT, and the time spent at the NASCAR Hall of Fame. You can read about this event in more detail on page 5.

The Blood Brotherhood program hosts events throughout the state, so regardless of which corner you live in members should have a chance to join in an event in your area.

Upcoming for the Blood Brotherhood program for the rest of 2017 includes:

July 28-30 – HNC Men’s Retreat – Pine Knoll Shores

September 9th – Aging Presentation – Winston-Salem

October 20-22 – HNC BB Retreat – Blowing Rock

If you can’t make an event, consider connecting with adult men with bleeding disorders from the comfort of your own home on the new and improved Blood Brotherhood private online forum! Go to www.hemophiliafed.org to register.

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HNC Latin Union Program Update

Hemophilia of North Carolina’s (HNC) Latin Union Program has been busy! In March, they held a breakout session at the Annual Meeting. In May, 27 Latin Union members visited the N.C. Zoo for an educational program on staying active and healthy and then had the opportunity to visit the zoo. On June 17, the Latin Union held an event at Flour Power Kids Cooking Studio in Charlotte where they made healthy veggie pizza and zucchini fries while learning about healthy eating options. Following a break over the summer, the Latin Union will resume programming again in the fall.

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, visit the HNC website.





HOPE Update

- *Help*
- *Opportunity*
- *Partnership*
- *Empowerment*

Hemophilia of North Carolina strives to support persons in all walks of life affected by bleeding disorders. For families who have young children with a bleeding disorder, the support provided to help educate and encourage them can be invaluable. Through educational and supportive programs and events, the HOPE Program is intended specifically to help families with young children affected by bleeding disorders.

On May 13, the HOPE Program partnered with the Blood Brotherhood for a fun and educational day at the NASCAR Hall of Fame in Charlotte. It was a wonderful opportunity for families to connect with a greater part of the bleeding disorders community here in North Carolina.

There will be a HOPE session on July 1 at the HNC Office in Morrisville, NC led by HNC Program Manager Gillian Schultz. On August 19, HNC will be returning to Tanglewood Park in Clemmons, NC for the Family Day Out which includes a picnic lunch, activities, and a visit to the aquatic center. Plans are being finalized for the Family Retreat taking place this year September 15-17 in Sunset Beach, NC.

The Mentoring Program for Parents/Caregivers is another option for those who need more individualized support. The mentors are parents who have “been there, done that” and have experience raising a child with a bleeding disorder. Through monthly meetings, over the phone or in person, those in need of a shoulder to lean on can find that support through the Mentoring Program. In addition, sessions geared for those in the Mentoring Program, called Lunch ‘n Learns are held every few months. The most recent Lunch ‘n Learn on June 3 helped members to learn more about organizations and programs, in addition to HNC, that can help and support them. If you feel that you might benefit from having more individualized support through a mentor or are interested in learning more about the Mentoring Program, contact Gillian Schultz, HNC Program Manager.

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. Open to any member of HNC, HOPE programs are geared specifically towards parents with children twelve and under. 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.



HOPE program members having fun at NASCAR Hall of Fame

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What's in a Number?

By: Cazandra Campos-MacDonald

Numbers, numbers, numbers. Our society is flooded with numbers. From Social Security numbers to birthdays, PINs, passcodes and checking our weight, we can hardly get through a day without numbers. When you are living with a bleeding disorder, you monitor the assays of your factor, track the number of bleeds per month, check how many doses of product are on hand, and measure the circumference of a swollen knee. But when you live with an inhibitor, there's another number that can become the focus of treatment: the Bethesda unit (BU).

The Bethesda inhibitor assay is a test that measures the titer (strength) of the inhibitor, described in Bethesda units. Inhibitor titers may range from less than 1 BU to thousands of BU. Knowing this number will help determine how bleeds are treated. If the inhibitor registers as low titer (less than or equal to 5 BU), bleeds may be treated with high doses of standard factor concentrate. If the inhibitor registers as high titer (greater than 5 BU), standard factor concentrates are ineffective and special factor concentrates called bypassing agents are used instead. Attempting to treat bleeds in the presence of inhibitors is less effective than treating bleeds without inhibitors—so the goal is to eradicate the inhibitor. If the inhibitor registers as less than 10 BU, this is when many providers will have patients begin immune tolerance therapy (ITT), also called immune tolerance induction (ITI), a treatment protocol designed to eliminate the inhibitor.¹ Knowing your BU is crucial in order to take the next step in working toward that goal.

It's easy to put your faith completely in the numbers. Knowing your current BU is important, but know first that every individual is unique and there are several different ITT protocols. Each person does not react to ITT in the same way. One body may accept ITT easily, and his BU will come down in a short time. Others on the protocol may take years to get the same results. Numbers do not dictate that the treatment for one person will be the same as for another. For example, two brothers, both with severe hemophilia and inhibitors and with the same parents, can live very different lives with an inhibitor. My older son, Julian, was one year old when he was diagnosed with a low-titer inhibitor; it never rose above 5 BU. He immediately had a port inserted, and he started ITT for two and a half years. He tolerized, meaning his inhibitor dropped to zero, and he has never had an inhibitor resurface.

My younger son, Caeleb, was 11 months old when diagnosed with a high-titer inhibitor that registered over 2,200 BU. His titer dropped to 0 BU at one point after ITT, but now he is living with a low-titer inhibitor, and he receives factor daily to maintain his tolerance. My sons both reached 0 BU after ITT, but they had different outcomes.

The numbers can be promising and sometimes disappointing. But ultimately, the numbers are a key component to treatment.

Everyone who tracks his BU has an ultimate goal in mind: to lower the titer to zero. If your titer is 323 BU, your goal may first be 299 BU, then 250 BU.² Another person may be hoping to get to double digits, and another to single digits. Of course, when you're tracking your BU, you want to get to zero and stay there. When you reach 0 BU, you may think that the inhibitor is now a thing of the past—but not necessarily. Once 0 BU is attained, the next step is to monitor the half-life of the factor. To be successfully considered tolerized (this is also called complete tolerance), the following must be maintained:

- The inhibitor titer can no longer be measured.
- Factor recovery is greater than 66% of normal.
- The half-life of factor VIII is greater than six hours.³

But someone may live with 0 BU for many years without these three characteristics. This is called partial tolerance. For example, if your child has 0 BU and a three-hour half-life of factor in his body, he will probably continue with the same ITT therapy, which may be daily infusions. ITT is not always successful: an ITT attempt in which inhibitor titers fail to decrease at least 20% over three to six months, or remain over 5 BU after three to five years, is considered a failure. This example shows that not only is BU important, but monitoring the number of hours for the half-life is critical to treatment. So how does a family live with the numbers?

“Lab work disappointment” is a phrase Kari Atkinson's family used when the numbers were not what they had expected for their son. “We had so much hope that the inhibitor would go away.” But now, says Kari, “we are not as concerned about the number because we can tell when [the BU is] up and down by how our son bleeds.” How an individual's body reacts to treatment is the

Continued next page



What's in a Number? *continued from previous page*

ultimate measure of success. If you're living a full life with few bleeds and an active inhibitor, the important thing is that you are healthy, happy, and thriving. Eric Frey's son, age seven, has lived with an inhibitor for over five years. "After time, we learned two things: First, we already knew what the results [BU] were going to show by the way our son was bleeding, bruising, and behaving. Second, the Bethesda number is far less important than how our son was bleeding, bruising, and behaving."

Despite living full, healthy lives with an inhibitor, many families still worry about the numbers. "Making peace" with the inhibitor is something that most people don't want to do. It can feel as if you're giving in and accepting that the inhibitor will always be present. In order to live a life where hemophilia is not the center of everything, making peace is crucial. "We have had enough experience that we know if the inhibitor is under 7 BU, we are living pretty good," says Kari. Her family is not focusing on 0 BU, but for now, they know that anything under 7 BU is acceptable. "It's really hard to not focus on the numbers, especially when you have the active inhibitor and either you need to get below 10 BU to start ITT, or you are doing ITT and trying to get down to zero," says Eric. "We understand how hard that is. Focus on health. Focus on wellness."

Numbers are essential for people living with inhibitors. Keep track of bleeding episodes because this is a significant tool to see if your treatment is appropriate. Continue your regular blood draws according to your provider's recommendations. Even if you're not a slave to the BU, it's vital to monitor the progress of your inhibitor. The key is to enjoy life. Savor every moment. When things aren't going well, try to remember that life will get better. And when life is good, soak it in.

1. ITT is a proven treatment toward eradicating inhibitors. Larger-than-normal doses of factor are given in the hope of overriding the inhibitor. ITT protocols can differ in frequency of infusing, depending on the physician's and individual's needs.

2. Once you achieve 10 BU, it doesn't matter if the BU gets lower, because all infused factor is inactivated in minutes. Even so, families living with an inhibitor will find emotional relief when the numbers get closer to zero.

3. D. M. DiMichele, W. K. Hoots, S. W. Pipe, G. E. Rivard, and E. Santagostino, "International Workshop on Immune Tolerance Induction: Consensus Recommendations," *Haemophilia* 13(2007): 1-22.

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Cazandra Campos-MacDonald is a motivational speaker, educator, and patient advocate for families with bleeding disorders. She writes a blog chronicling the journey of her two sons with severe hemophilia and inhibitors, and has written articles and blog posts for other publications. Cazandra's older brother, Ronaldo Julian Campos, died of complications from hemophilia as an infant. Cazandra lives with her family, Rev. Joe MacDonald, Julian (20), and Caeleb (11), in Rio Rancho, New Mexico.



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HFA's "Dateline" Special Issue: Navigating Patient Assistance Programs

The 2017 Special Issue of HFA's "Dateline" contains a lot of helpful information to assist those with bleeding disorders navigate the high cost of treatment. With articles that include the following titles, this will be a great resource for every individual trying to manage bleeding disorders and related illnesses.

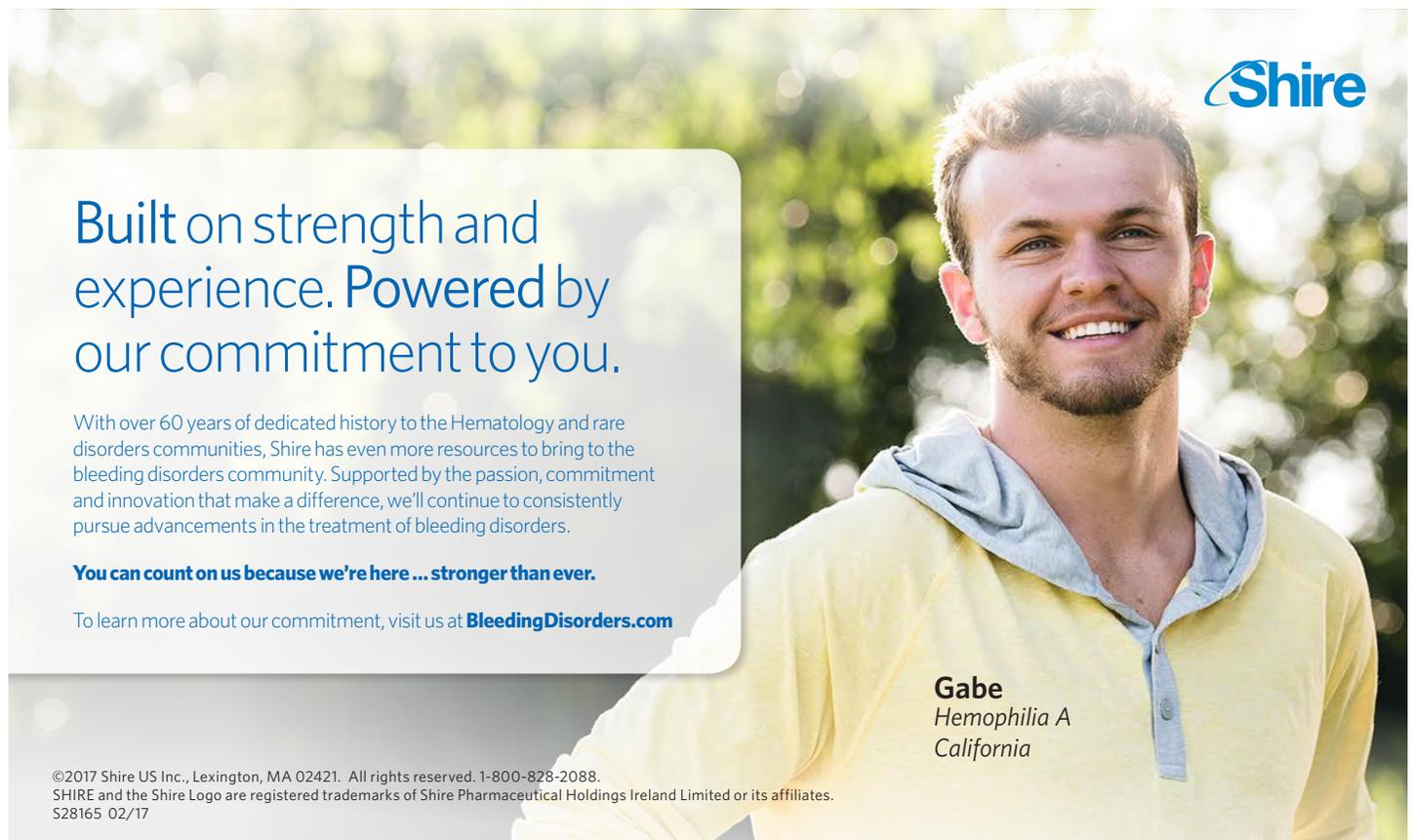
- Affording to Bleed
- The Policy of Patient Assistance
- Navigating Patient Assistance Programs
- Manufacturer Co-pay Programs
- Manufacturer Product Assistance Programs
- Hepatitis C Virus Co-pay & Patient Assistance Programs



Scan this QR code for direct access to this Special Issue of HFA's "Dateline"

As stated in the article Navigating Patient Assistance Programs, "Co-payments and out-of-pocket expenses can be devastating on a family's budget". This magazine will provide an overview of various co-pay and assistance programs as well as many additional resources that can help patients and caregivers find help when they need it. There is more to consider than the cost of medication and direct medical expenses paid to doctors and medical professionals. Families must also factor in the indirect expenses of living with a chronic condition such as travel to appointments, missed work due to medical appointments, and more. Finding resources to help is an important step in advocating for yourself and your family, and this issue of HFA's "Dateline" can help you find those resources.

Go to http://www.hemophiliafed.org/uploads/HFA_Dateline_Special-IssueG.pdf (type into your browser or scan the QR code provided) to view the magazine online, or contact the HNC Office at 800-990-5557 and we will mail a copy to your home.



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HNC Heads to DC Again

The National Hemophilia Foundation (NHF) made a Call to Action for 22 state organizations to come to Washington DC on June 7-8 and HNC answered the call. In response to the American Health Care Act (AHCA) passage in the House, NHF found themselves shifting advocacy related to the repeal and replacement of the Affordable Care Act (ACA) to the Senate as that branch works on their draft of a proposed healthcare bill. The main focus of the day was to ensure that the harmful provisions in the AHCA that would jeopardize access to quality, comprehensive health insurance for the bleeding disorders community are not enacted. The talking points included:

1. Reject the AHCA policy that allows states to define essential health benefits (EHBs). States must continue to require a comprehensive set of EHBs to maintain the ban of lifetime and annual caps.
2. Reject the AHCA policy that allows state waivers of community rating so that pre-existing condition protections aren't meaningful.
3. High risk pools are not a solution to eliminating ACA patient protections. The Patient and State Stability Fund should be used for reinsurance and directly lowering out-of-pocket costs for individuals.
4. Do not repeal the ACA's Medicaid expansion; maintain categorical eligibility for childless men and women and enhanced federal funding for the expansion population.

* Approximately 30% of the bleeding disorders community is currently enrolled in Medicaid.

Charlene Cowell, HNC Executive Director, and Luke Waller, HNC Board Vice President, spent the day with a fellow advocate and community member from Tennessee to visit four senate offices. These meetings allowed NHF, HNC and all other bleeding disorder organizations to tell the stories behind these talking points. Real-life situations helped illustrate to legislators the serious impact that this could have for our community and many others dealing with pre-existing and chronic conditions. If you are interested in getting involved in advocacy efforts, or would like more information on these talking points and potential effects on the community, please contact the HNC office.



A Rare Disorder Gets a Rare Opportunity

For years, people with hemophilia have waited for life-changing advancements to help manage their rare disorder. Though much progress has been made, research is the key to a brighter tomorrow. That day is here.

My Life, Our Future has opened the world's largest genetic hemophilia repository to scientists. This invaluable resource, a collection of data and samples from more than 5,000 people with the disorder, will allow researchers to advance scientific understanding of hemophilia that may improve care and treatment.

Learn more by visiting www.MyLifeOurFuture.org.






My Life, Our Future is a partnership between four leaders in the bleeding disorders community. The program offers free genetic testing to people affected by hemophilia, while also building a research repository to advance scientific study.

HNC Advocacy Update

HNC continues its great work advocating for people with bleeding disorders here in NC and nationally. Most recently, members participated in HNC Legislative Day in Raleigh where participants had an opportunity to meet with state representatives and tell them their story about obstacles and challenges related to living with a bleeding disorder. This event began with a training and dinner on Monday, May 1, with visits to legislators scheduled on Tuesday, May 2. Hotel accommodations were provided for members traveling from a distance. HNC would like to thank Nathan Schaefer from National Hemophilia Foundation and Sarah Shinkman of Hemophilia Federation of America for joining HNC and their continued support of this importance initiative. In addition, HNC would like to express appreciation to Patient Services, Inc., for making appointments with state legislators on behalf of HNC member. For a detailed account of one member's experience at Legislative Day, please read the article titled, My Legislative Day Experience, on page 25 of this issue.

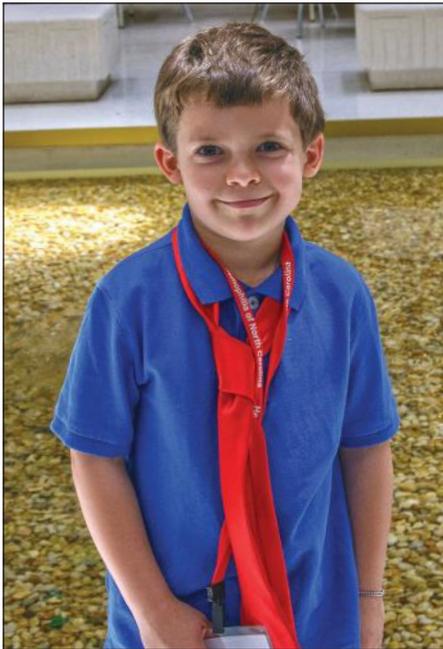
Additionally HNC is proud to work with our national organizations on a host of advocacy needs impacting everyone in our country living with a bleeding disorder. The Advocacy Committee will continue to alert members when action is required to reach out to our government officials on behalf of the bleeding disorders community about pending legislation or proposed changes to existing policies, so be on the lookout for emails related to these calls to action.

To join HNC advocacy efforts we encourage you to be proactive and participate on our monthly advocacy committee calls, register for our advocacy committee email list for continued updates, and contact HNC to get involved!



My Legislative Day Experience

By: Gillian Schultz, HNC Program Manager



Participating in HNC events is not new to me. Having joined HNC in 2010 shortly after Noah was diagnosed, I have been going to educational and support events ever since. I even took part (though very passively) in the monthly Advocacy Committee calls for a short time while Noah was still a toddler, but I dropped out of the calls when I first went back to teaching. When I came on staff with HNC in 2015, I figured it was time I take a more active role in advocacy, participating more in the Advocacy Committee and going to the Legislative Day in Raleigh. My first Legislative Day experience was in 2016.

For the 2017 Legislative Day, I brought along Noah who is now 6 years old. We attended the training dinner on Monday evening and shared details about our experiences. Noah even shared details on what hemophilia means to him and things he may tell the Representatives and Senators the following day. Since we weren't advocating for any particular bill this year, the purpose of the Legislative Day was to build awareness about bleeding disorders and build relationships with the Senators and Representatives who were elected to our districts by sharing our personal stories with them.

On Tuesday, we were scheduled for 6 appointments. Wearing our red ties, we visited the offices of several Representatives and Senators. Unfortunately, it was a slow day at the Capitol and most were not in, so we shared our stories with the legislative staff. Noah did get a little shy, not wanting to share any of his story although he did show his veins where he gets his factor.

I have learned over the past several years that as a mom, I am always advocating for my children and the bleeding disorders community. Whether it is advocating for proper treatment in the Emergency Room, following a plan at school to make sure that Noah's needs are met but he is not discriminated against at the same time, to sharing our story with friends, family, or people in the general public, advocacy is not so hard. Thinking about it like that makes going to the state capitol a little less scary. It's also never too young to start teaching our children that they can be advocates for themselves and the community. I don't know how much Noah got from his experience this year, but as he continues to grow up I will continue to bring him to the Legislative Day so that he can learn that he has a voice and by participating in Legislative Day he can make a difference.

The 2017 Legislative Days took place on May 1-2 in Raleigh



How Can YOU Support HNC? Let Us Count the Ways!

- If you shop online, consider using AmazonSmile. AmazonSmile works just like Amazon, but in addition they donate 0.5% of your purchase to the organization of your choice! Consider HNC when making your next purchase!



- Host a garage sale – you can clean out those unused items, and help HNC at the same time!
- Ask for a company match – many companies will work with their employees to match their donations to a charitable organization.
- Serve a meal fundraiser at your local church or community center
- Talk to a local school or business about hosting a raffle



History made!

Chris Bombardier: first with hemophilia to summit Everest!

History was made on Monday, May 22, at 9:59am in Nepal when our board member and hemophilia mountaineer, Chris Bombardier, reached the top of the world...Mount Everest! Chris spent weeks in the Himalayas preparing for this ascent to 29,029 feet. This is his sixth summit in his quest to climb the highest peak on each continent...and definitely the feather in his cap!

Chris wrote this message after his achievement, when he returned to the Everest base camp:

“No longer can anyone say that someone with hemophilia can’t climb Everest with proper treatment, training and medical care. By standing there I hope to show what we should be striving for. Not that everyone should climb mountains (although I do believe the outdoors are for everyone) but that everyone should be able to shoot for their dreams.

I hope by holding that banner we can show the world only 25% of people living with hemophilia even have access to adequate treatment to chase dreams. Those that do have access fight stereotypes of being told they’re fragile and that they can’t, or aren’t allowed to participate like others. Together we can equalize the care all people with hemophilia receive. We can use this platform to fight for change. We can lobby governments to buy factor and show that if people with hemophilia get treatment the sky is the limit.”

In honor of Chris’ historic climb, 71 children have been sponsored and over \$12,000 has been raised to help families of the Nepal Hemophilia Society. Join the many who have cheered Chris on!

To read more about Chris’ experience or show YOUR support to sponsor or donate, visit www.saveonelife.net .

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At 9:59am on May 22 Chris Bombardier has just made history by becoming the first person with severe hemophilia to summit Mount Everest, at 29,029 feet, the tallest mountain in the world.

Hemophilia of North Carolina 2017 Calendar of Events Highlights



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 Day Out – Tanglewood Park, Clemmons, NC
August 24-26, 2017	NHF 69th Annual Meeting – Chicago, IL
September 9, 2017	Blood Brotherhood Event – Greensboro, NC
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
January 27, 2018	Hearts for Hemophilia Casino Night – Raleigh, NC
March 9-10, 2018	HNC Annual Meeting, Winston-Salem, NC
April 14, 2018	HNC Family Festival & 5K Walk for Bleeding Disorders – Charlotte, NC



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Saturday, October 14, 2017

Lake Crabtree County Park
1400 Aviation Parkway
Morrisville, NC

Check-ins begin at 9:00am
Walks begin at 10:00am

5K / 3.1 Miles or
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