

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2018

2019 HNC Annual Meeting in Charlotte

March 2, 2019
Charlotte, NC

Hemophilia of North Carolina (HNC) will host its 46th Annual Meeting on March 2, 2019, in Charlotte. The Annual Meeting is HNC's largest one-day educational event with sessions geared towards all ages, backgrounds, bleeding disorders, and relationships within the community. Attendees will find opportunities to network with fellow community members, find support, learn, and hear from expert speakers about important news and information related to bleeding disorders.

While details of the agenda are still being finalized, HNC is excited to welcome Dr. Steven Pipe, MD, pediatric hematologist and medical director of the Hemophilia Treatment Center at the University of Michigan. He will be speaking on new and emerging therapies in bleeding disorders.

As in past years, there will be a First-Time Attendees Session just prior to the start of the meeting where HNC members who have never been to an Annual Meeting can learn about what to

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HNC members participating in activities at the 2018 HNC Annual Meeting



Join in the fun at the Annual "Hearts for Hemophilia" Casino Night

HNC Casino Night: Hit Big in Durham

January 26, 2019
Durham, NC

Back in Durham, the 12th Annual "Hearts for Hemophilia" Casino Night Fundraiser will be held once again in the Grand Ballroom at the Durham Convention Center. This elegant evening out makes a wonderful date night, a night out with friends, or thank you to some of

your outstanding employees. Each ticket includes dinner, two bar tickets, \$10,000 in "fun money" for the casino gaming tables, a chance at raffle prizes, music, and more! Whether you're there for the casino games, the live and silent auctions, or to enjoy the fun atmosphere and great food, it's

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Save The Date

Volunteer Event

January 12
Morrisville, NC

"Hearts for Hemophilia" Casino Night

January 26
Durham, NC

Factor 7 Round Table

February 2
Morrisville, NC

Legislative Day

February 12
Raleigh, NC

Annual Meeting

March 2
Charlotte, NC

Coalition for Hemophilia B Symposium

March 14-17
Orlando, FL

NHF Washington Days

March 27-29
Washington, DC

HFA Symposium

April 4-7
San Diego, CA

World Hemophilia Day

April 17
Charlotte, NC

Family Festival & Walk for Bleeding Disorders

April 27
Charlotte, NC



Hemophilia of North Carolina

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

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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 delivery of 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 Moyer Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676

Hemophilia Treatment Center of Levine Cancer Center and Levine Children's Hospital

1021 Morehead Medical Drive, Suite 5300
Charlotte, NC 28204
Phone: (980) 442-4363

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

Wake Forest University School of Medicine

The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone: (336) 716-4324

Additional Medical Resources

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.kelleycom.com

Patient Notification System

The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.
1-888-UPDATE-U
www.patientnotificationssystem.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 member organization of the Hemophilia Federation of America, a member agency of Community Health Charities, a member of the NC Center for Nonprofits.



FROM HNC'S BOARD OF DIRECTORS

Calling for Nominations to the 2019-2020 Board of Directors

Hemophilia of North Carolina (HNC) is looking forward to welcoming new board members in 2019. The Board of Directors has been working hard for all of our members and we want your help in finding new people to be elected to the Board of Directors. Board positions will be elected by the membership at the Annual Meeting March 2, 2019. Changes have been made to how nominations will be handled (see article below), so names of candidates for nomination are requested to be submitted no later than **January 16, 2019**.

Board positions are open to both HNC members and qualified individuals outside our affected community. Suggestions of where to find potential candidates include: professionals in your local sphere of influence, friends, alumni from local colleges and universities, retired individuals, and NC small business owners.

HNC seeks support from individuals who represent the diverse demographics of our community including individuals with the following experience or talents:

- Fundraising/ Networking
- Accounting/ Finance
- Public Relations/ Communications
- Law
- Medical
- Computer/software/web design
- Event Planning
- Human Resources (HR)

CALL TO ACTION: If you know of anyone that might be a good candidate for nomination to our Board of Directors, please email nominations@hemophilia-nc.org or contact Charlene Cowell by phone at (800) 990-5557.

FROM HNC'S BOARD OF DIRECTORS

HNC Board Adopts Elections Policy: A Notice from HNC's Board of Directors

The Hemophilia of North Carolina (HNC) Board of Directors has recently taken two important actions that will affect future elections of HNC officers and board. These include a new elections policy (adopted at the September 22 meeting), and a new bylaw (Article VI, Section 5, adopted at the October 9 meeting). Together, these actions are intended to bring HNC's election process up to widely accepted standards for present-day nonprofit organizations. It is important for the HNC community to be aware of this as we prepare to elect the 2019-2020 HNC Board of Directors at our next Annual Meeting on March 2, 2019.

The new policy has two main purposes that go hand in hand. First, it will help us identify potential board members who have both the talents and the time needed to support HNC's mission. Second, and equally important, it creates a thoughtful process for potential candidates to get a realistic understanding of the commitment and time sacrifice that is expected of every HNC board member. Finally, the policy provides a schedule that will allow the board

and staff sufficient time to make preparations necessary to run an open and smooth-functioning election.

If you would like to submit a candidate for nomination to the board, send his or her name and contact information by email to nominations@hemophilia-nc.org – or contact the HNC office – by January 16, 2019 (that's 45 days before the Annual Meeting). The board's Governance Committee will then arrange a "getting to know each other" meeting with the candidate. This can be either in person or by telephone. It's important to do this well in advance of the Annual Meeting date. In special cases the Governance Committee can accept late nominations, but not later than five days before the election.

We encourage everyone to review the complete Bylaws of HNC and the full Board Member Nomination Policy on the HNC website at www.hemophilia-nc.org/board. Printed copies are available on request from the HNC office by calling (800) 990-5557.

Phillip Poovey: HNC 2018 Volunteer of the Year



Hemophilia of North Carolina (HNC) is delighted to announce the 2018 Volunteer of the Year is Phil Poovey. A native of North Carolina, Phil joined the HNC community approximately 15 years ago in support of his late husband and former HNC board member, George McCoy. While always a devoted member of HNC, since George's passing in 2017, Phil has continually gone above and beyond when it comes to supporting HNC with his time and talents. From labeling and stuffing envelopes to helping Santa wrap kids' presents for the Holiday Celebration, or whatever the call to action may be, Phil cheerfully assists. In addition to his work at the HNC office, Phil helped to create and sits on the committee for HNC's George D. McCoy Scholarship Fund which will begin issuing scholarships for higher education in 2019.

On behalf of all HNC Members, the staff and board of directors would like to thank Phil for his service to this community and congratulate him on this well-deserved and long overdue honor.

HNC Volunteer of the Year, Phil Poovey, with Charlene Cowell, HNC Executive Director

March is Bleeding Disorders Awareness Month

March is the time for the community to come together and spread awareness about bleeding disorders. There are various ways you can participate.

Hemophilia Federation of America (HFA) will begin a fact-a-day social media campaign on Facebook and Twitter which member can share on their own profiles. Members can also update profile images with HFA's support ribbon or use downloadable images for their cover photos or profile pictures. These and other ideas for spreading awareness throughout the month of March can be found on the HFA website in the Bleeding Disorders Awareness Month section.

National Hemophilia Foundation (NHF) will once again be spearheading the Red Tie Campaign raising funds and awareness to find better treatments and cures for bleeding disorders. Visit redtiecampaign.org more information on how to participate in the 2019 campaign.

If you would like to share your ideas on how to spread awareness and promote March as Bleeding Disorders Awareness Month here in North Carolina, please contact the HNC office.

2019 HNC Annual Meeting in Charlotte *continued from page one*

expect throughout the day. Other sessions will include breakouts for men, women, parents, partners/spouses, Unión Latina, rare bleeding disorders, and von Willebrand disease. There will be childcare for all ages, including a specialized teen track. The HNC Annual Meeting is also the time for members to let their voice be heard as those who attend the Business Meeting will have the opportunity to vote for the Board of Director nominees.

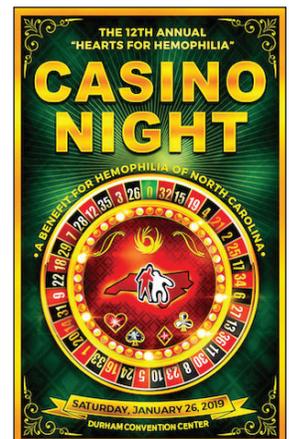
The HNC Annual Meeting, including lunch, snack breaks, and childcare, is provided free to HNC members thanks to the generous support of our sponsors.

More information about the agenda, as well as invitations and registration will be available this winter. Check your email and mailboxes in January, or contact the HNC office for more information.

HNC Casino Night: Hit Big in Durham *continued from page one*

sure to be a night to remember right in the heart of Downtown Durham's City Center District.

If you or someone you know would like to support the event by donating an auction or raffle item, please contact the HNC office. In addition, HNC is continually looking for new opportunities to broaden its outreach by looking for new partnerships with businesses interested in sponsoring Casino Night. To purchase tickets and learn more about sponsorship opportunities, please visit the HNC website or call the office!



World Hemophilia Day

April 17, 2019



April 17 will mark the 29th World Hemophilia Day! The World Federation of Hemophilia will be announcing the theme for 2019's World Hemophilia Day soon.

For more information, please visit: www.wfh.org/en/whd

Stay tuned to find out what HNC has in store for World Hemophilia Day in 2019!

Registration Opens January 1 for the 2019 Charlotte Family Festival & Walk

April 27, 2019
Charlotte, NC

Save the Date for the 5th Annual HNC Family Festival & Walk for Bleeding Disorders in Uptown Charlotte!

Be a part of the fun by registering on January 1. As in past years, the Charlotte Family Festival is being held in uptown Charlotte in front of BB&T Ballpark and Romare Bearden Park. This is the perfect setting for members and supporters of HNC to gather for a morning of fun, entertainment, and of course a Walk around Bank of America Stadium and BB&T Ballpark. Start a team or register as an individual. Bring your family, friends, coworkers, and 4-legged friends as you raise money and awareness in support of HNC. The more people who participate, the more money that is raised to support HNC's programs and services, so help get the word out in your local communities.

Attention Team Captains: Get your teams registered to be included in a team captain meeting early next year in the Charlotte area. Specific date, time, and location will be announced soon.



Top three teams from the 2018 Charlotte Family Festival & Walk

70th NHF Bleeding Disorders Conference

October 11-13, 2018
Orlando, FL

It was an important year for the National Hemophilia Foundation (NHF) as they celebrated their 70th meeting, and the first year with its new name, *Bleeding Disorders Conference*. The event is a must for anyone with a bleeding disorder and Hemophilia of North Carolina (HNC) is fortunate to be able to send community members each year. This year, there were tracks for the various disciplines including sessions for people with bleeding disorders, Chapters (like HNC), social workers, physical therapists, pharmacists, and more. Within the tracks for people with bleeding disorders, NHF has a pre-conference meeting for those with the rarest forms of bleeding disorders like Factor X. Charlene Cowell sat on a panel discussion for the *Blood Otherhood* session, which was open to anyone and discussed the many challenges for people that may feel like an "other" in the community at times. Hearing from spouses, siblings, non-affected supporters, and more, the session provided affirmation that everyone belongs and brings their own unique story. The panelists also offered ways to help get more involved on the local level in order to support "others" that may be feeling the same way so that everyone feels the sense of belonging.



HNC Members gather at the 70th NHF Annual Bleeding Disorders Conference

Throughout the conference, there were many reminders about the significance of this meeting, including a ceremony that included a handful of community members speaking to the crowd as they put their hopes and dreams on paper and into a time capsule. That was a special moment for everyone in the room as you could feel the inspiration beaming from the stage. For those that haven't been to a national meeting, make sure to look for travel grants from the NHF and HNC for next year's conference, being held from October 3-5, 2019 in Anaheim, CA.

Continued next page

70th NHF Bleeding Disorders Conference

continued from previous page

FROM HNC MEMBERS IN ATTENDANCE:

By: Donna Blair-Paynter

Our family recently got a chance to attend the 2018 NHF Bleeding Disorders Conference for the first time in Orlando, Florida in October. It was an amazing experience. There were educational tracks for the whole family. My husband and I were able to attend an array of lectures on subjects from advances in treatment and gene therapy to current and upcoming legislative issues that impact the bleeding disorders community. We were able to attend the screening of the documentary *Bombardier Blood* which is truly an inspiring story and a must see for everyone affected by a bleeding disorder. Our son, Riley, attended the teen track which was just the right mix of education and fun. The teen program kept the kids engaged and entertained throughout the meeting. We especially liked the talk *Going Solo* which discussed the transitioning to adulthood and their first visit with an adult hematologist. We attended the 2018 Teen Impact Awards where Riley was honored for his achievements in academics. It was wonderful to get a chance to see the different honorees doing great things in academics, sports, and service to their communities. Each evening there were family events that were fun and allowed us to mingle, meet other families, and catch up with old friends and HTC staff. The NHF meeting was truly a wonderful experience for our family and one we will long remember.

By: Tera Griffith

Our family recently had the privilege of attending the NHF Annual Meeting. This was a great learning opportunity for us. We were able to attend sessions to learn about the newest treatments and factor available. We learned about infusing and tricks for successful sticks. We met lots of other families and were able to connect with them. Through everything that we go through on a daily basis of the worrying, infusions, and insurance stress, it was very nice for our son to see an opportunity that Hemophilia gave him. He was able to have fun at the meetings and dinners while learning so much about his condition. He was the most excited about even longer lasting factor and subcutaneous sticks! We hope to attend another annual meeting in the future.



Riley at the Teen Impact Awards



Gavin gets to meet NY Giant, Otis Anderson at the NHF Annual Conference

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Serious Fun, Serious Purpose with a “Hattitude”

Winston-Salem, NC

October 13, 2018

By: Kathy Register, HNC Board Member



St. Stephen Missionary Baptist Church in Winston-Salem was the venue for a delightful, spirit-rousing celebration that included a powerful message and no small sum of money for our community. The October 13 event was “Hattitude”, which has become an annual event at the church to raise funds for Family Festival and Walk team *Jaden’s Jewels and Gents* and for Hemophilia of North Carolina.

The celebration began with introductions, scripture, prayers, and a charming video of Jaden as a

youngster, along with her family. Jaden has von Willebrand disease, a bleeding disorder that affects up to 1% of the population and knows no age, gender, or ethnic boundaries.

Despite lifelong severe bleeding episodes, and through the love and care of her family and community, Jaden has blossomed into a beautiful 13-year-old. She was the day’s star guest.



Over the last several years, “Team Jaden” has consistently fielded the largest non-industry team at our Family Festival and Walk, with around 55 pink-clad members each year. Since its establishment, *Jaden’s Jewels and Gents* has raised \$35,000.00 for HNC.

Now—back to “Hattitude.” What a festive happening! Church members, their families and guests arrived in formal coordinated suits, casual wear, Sunday-go-to-church outfits, and evening-wear featuring every bright color of the rainbow. The common denominator: HATS. Easter hats, cloches, turbans, ascots, fedoras, roadsters, top hats, buckets, sun hats, pill-boxes and lots and lots of bows and feathers. All present were treated to a moving performance by the beautifully costumed GEMS (SSMBC’s dance troupe) and



by Praise Team 1, a gospel choir led with lovely vocals accompanied by haunting, piercing close-harmony.

During lunch, tables competed for attention with colorful wares and a dessert centerpiece. The entire room meandered about, sampling and sharing one another’s feasts. Desserts were everything from red velvet cake to pecan pie and

Moravian sugar cake.



As if dessert weren’t enough, we were treated finally to an inspiring presentation by Dr. Penni Sweetenburg-Lee, Senior Pastor of Richmond’s On Kingdom Business Ministries. “Dr. Penni” seamlessly pulled together the “Hattitude” themes of faith, hope, service, research, and healing.

Thank you St. Stephen!

Note: representing HNC at “Hattitude” were Manager of Operations Karyn Davis (whose husband and father joined her), member Linda Woodard, former president Richard Atwood, and treasurer Kathy Register.

Thank You Triangle BNI

October 15, 2018
Raleigh, NC



Golfers at the Hemophilia of North Carolina hole



Golfers support Hemophilia of North Carolina



Jack Traficanti speaks to golfers and guests about his experiences as a golfer with a bleeding disorder

The inaugural Triangle Business Networking Charity Golf Tournament, held at the Brier Creek Country Club in Raleigh was a great success. With perfect weather, the golfers set out on the course playing for prizes but also for the benefit of Hemophilia of North Carolina (HNC).

HNC was chosen as the recipient of this fundraising effort. The mission of the event is to support nonprofit charities in the Triangle area while also creating an ongoing fundraiser that will bring together individuals and business organizations to network with each other, build stronger business relationships, and to help the Triangle business area to continue to grow and thrive economically.

It was a great day of golf and also of raising awareness for people with bleeding disorders. One young HNC member, spoke to the golfers at lunch about what it's like to have a bleeding disorder and how playing golf has benefited him. Dave Ohlson also spoke to the group about what it was like to grow up with a bleeding disorder, the difficulties of trying to stay physically active, and how golf gave him that opportunity. After lunch, presentations, and announcements of winners for Closest to the Pin and Longest Drive Contests, best teams, and raffle prize winners, the event came to an end.

HNC would like to thank once again the event chair, Tom Azcona, and all the committee members, participants, sponsors, and volunteers. It was HNC's honor to be the first charity to benefit from this annual tournament.



HNC Board members enjoying the golf tournament

1st Annual Triangle Business Networking Charity Golf Tournament

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NC Triangle BNI	Brier Creek Country Club	Donate Life

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HNC Family Retreat

October 19-21, 2018
Concord, NC



The city of Concord, NC, had an influx of Hemophilia of North Carolina (HNC) members the third weekend of October. Thirty families with children 12 and under with a bleeding disorder gathered together at the Great Wolf Lodge for the annual Family Retreat.



Families started arriving before 4:00pm on Friday to enjoy some of the activities at the Great Wolf Lodge before everyone met for dinner and the Kick-Off Carnival. From the "Stack-Attack," "Cookie Face," and "Ping Pong Bounce" Minute-to-Win-It Games, to corn-hole, face painting, and the photo booth, everyone had a blast on Friday night.



On Saturday morning after breakfast, sessions officially began. Adults participated in *Bleeding Disorders Mingle* where everyone had the opportunity to meet each other and share their experiences raising a child with a bleeding disorder. Following the *Mingle*, parents broke out into two sessions. One session featured a panel of parents, including Ashley Davis, Tashara Young, and Gillian Schultz, who shared their experiences with self-infusion for their child. It was a great discussion among attendees. The other parents went to the roundtable, *What if I Don't Infuse?*, led by Charlene

Cowell, to discuss what happens when their child gets a bleed. After lunch, everyone learned about the Clotting Cascade, thanks to the presentation led by Virginia Chandler with Genentech. Whether dealing with hemophilia A or B, von Willebrand disease, or a platelet disorder, this session was very helpful in understanding how a clot is formed. Sunday's sessions for parents included *Music Therapy for Stress Management* led by Tim Ringgold. This session detailed how music is part of everyone's being and how beneficial it can be to deal with stresses of raising a child with a bleeding disorder. *Celebrating Independence*, led by Anna Bell with HFA followed. This interactive session helped parents to learn how to begin teaching their children ways of being independent and taking responsibility for their bleeding disorder.

Children participated in their own programming which including the Wolf Walk through the Great Wolf Lodge, a visit from Wiley the Wolf, sessions on bullying led by Chelsea Frimpong with NHF, learning about how their bleeding disorders are similar and different from each other, and how brothers and sisters without a bleeding disorder feel. There were also arts and crafts and games.

No visit to the Great Wolf Lodge would be complete without a visit to the water park. Families had time to visit the waterpark on Saturday afternoon and evening, as well as on Sunday after the meeting was over. All over the waterpark, it looked like the kids were having a blast (and maybe some parents too), going down the different waterslides, swimming in the wave pool, and having fun with the water features, especially the 1,000 gallon bucket that dumped water every five minutes. HNC had a pizza party in the water park on Saturday night so families could continue to enjoy their time until it closed.

HNC would like to thank the members who donated gift cards to assist in Hurricane Florence relief. Thanks to the support of our members, \$265 in gift cards was sent to the New Hanover School District. A special thanks also goes out to the Family Retreat Planning Committee who helped develop some of the activities and programs: Alisha Curtiss, Tiffany Hargett, Ashley Lorfilis, Troy Schoolcraft, and Dana Strickland.

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Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies and organizations for the 2018 HNC Family Retreat:

— Retreat Sponsors —

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— Program Grantor —

CK Colburn Keenan Foundation, Inc.

— Program Partners —

HFA
Hemophilia Federation of America

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

We Are Not Alone: 2018 Family Retreat

By: Christopher Sykes, HNC Member



“We are not alone!” What a liberating, comforting, freeing, and overall heart mending feeling. When my family arrived at the Family Retreat, 2018 at Great Wolf Lodge, we had no idea what to expect. It was the first time, outside of being at UNC Hematology Clinic that we would be around a crowd of people who are all affected, in some way, by a bleeding disorder. See, our little family has been in a whirlwind since March, 2018, when we were told that our son is no longer just “Mild Hemophilia A”, but will forever be Hemophilia with an inhibitor. Oh how the game changed, all in the blink of an eye. From birth until then, only 2 infusions were needed, no worries, no challenges. Then, BAM...let the games begin. Bleed after bleed, complication after complication, trial and error, will this one work, why doesn't that one work, all at what seemed like the speed of light. More nights spent in the hospital than at home, until hospital food became the norm, and we gained notoriety as knowing as much as every nurse and half of the doctor's treating our son. My little Rubix Cube...forever changing, always challenging, and always the strongest one in the room.

But, this isn't about the challenges we have faced, but this is about the revealing that “We are not alone”! The reception was warm and inviting, and a sense of family immediately fell over me. These were folks that understood, at least on some level, the struggles that we had faced and were still facing. Kids played, grown-ups talked and shared a meal, people laughing, smiling, and actually enjoying themselves. WOW!!! And this was just the supper and opening festival. What was going on? These were people like us...and I didn't know how it could get any better.

Day 2 brought a wonderful breakfast, meeting new families, and preparing for the day. It felt uncommonly “normal” for our kids to go to their areas by age group, almost like it was something we had done a thousand times. The ice breaker was wonderfully fun as we met other families with similar, albeit different circumstances. It's amazing how we seemed to find such comfort in organized chaos, smiles and laughs all around. Still, there was the real explosive

point for me. Hearing the testimonies of a couple families, and the challenges they had faced. I felt the pain, and the struggles, and the sense of powerlessness, and to this, I related completely. When we were asked if anyone had questions, I wanted to jump to my feet. I knew I had found something that I had needed so much for the last 6+ months, and I had no idea how to start. I remember my question. It revolved around infusing, and the struggles of having a child with “tricky, hiding” veins. All I wanted was some advice, something that I had not tried, or some tip that someone figured out. When I saw the faces looking at me, I saw recognition. Everyone knew, they had been there, they had struggled, had lost sleep and had shed many, many tears. “We are not alone!” People chimed in with their stories of infusion attempts, with their “creative ideas”, with their pointers and with their support. I know love is a strong word, but there was a common bond of love and kinship that I believe tied us all together. Afterwards, the free time to enjoy our family, in a stress-free environment, swimming, laughing, playing, eating, and relaxing...was so needed. I haven't seen my family smile like that in as long as I can remember. For the first time in a long time, nothing revolved around Hemophilia. I knew we would never be the same. The future was going to be brighter, more filled with smiles, and hope. The struggles wouldn't change, but the acceptance and knowledge that “we are not alone” would make every day happier.

Day 3 brought the music man, and how this filled my heart. I have always been a lover of music, but as anyone struggling can tell you, sometimes the music fades away. I cannot express how great it was to hear Mr. Ringgold speak and “strum” the hearts in the room. His message and lessons were priceless as my family is learning to find “Our” songs. I would listen to this message over and over and leave out knowing more, feeling more, and being “more” than when I had come in.

The music, followed by the heart filled message on handling MY stress, and how important it is...perfect combination. We all know that our demeanor affects those around us, but the way it was put that day placed it exactly where it needed to be...in front. Our hard days with infusing aren't the only day we prepare, and I learned that our stress has to be managed EVERY day, to make those days better. We are not going to be perfect at it, but at least I know it is possible to try harder, and get better.

Leaving that weekend, I was hooked on what we had found. Our son, our strong superhero, would never struggle alone, and we found the tool that would get us through; FAMILY. Not just the kind that shares blood, but this time, it's the kind that shares blood struggles, blood strengths, even blood conquering. I cannot wait until next year, and hopefully we can pass the feeling, so another family can proclaim...“WE ARE NOT ALONE”!

Be blessed, be strong, and BE!

HNC Family Festival & Walk: Thanks for Your Support!

October 27, 2018
Cary, NC

The 11th Annual Family Festival & Walk for Bleeding Disorders in the Raleigh area was truly something to remember. Originally scheduled for September 15, the event had to be rescheduled due to the impact of Hurricane Florence. While no small task, Hemophilia of North Carolina (HNC) staff was able to secure a secondary site for the event due to the unavailability of Lake Crabtree Park and were thrilled to be able to reserve a space at the USA Baseball Complex in Cary, NC. Despite a chilly, rainy morning, more than 300 community members and supporters came out to celebrate the strength of the bleeding disorders community in North Carolina.

Thank you to everyone whose commitment to the 11th Annual Family Festival & Walk for Bleeding Disorders made this all possible. The staff and Board of Directors for HNC would like to express their heartfelt appreciation to each and every member, volunteer, sponsor, donor, and contributor that gave their time and effort to making this event a success.

In addition to exceeding the fundraising goal by more than \$4,000, by raising a total of \$119,151, the community demonstrated their commitment to supporting HNC! One-hundred percent of the money raised at this event is being used to support HNC programs and services. Because of your support, HNC can continue to sustain and develop new programs and services that meet the growing and changing needs of the bleeding disorders community here in North Carolina.

Coffee was donated by Caribou which warmed up walkers and volunteers as they arrived. Fruit and other breakfast items were donated by Harris Teeter, Matrix Health, and Novo Nordisk, which helped to get folks energized to start the day. For lunch, walkers were treated to sandwiches and water donated by Sheetz in Morrisville, pizza brought by Mellow Mushroom in Cary and Realo Discount Drugs, and water donated by Pepsi. All the dogs were treated to lunch too with doggie-bags donated by PetMania.

HNC was happy to have Tara Herrschaft from Spectrum News as the event emcee. She got the festivities started by announcing that HNC's fundraising goal had not only been reached, but had been exceeded. Activities included some old favorites with some newer



things to do as well. Jecoreigraphy started off the event by getting the crowd dancing while Performance DJ kept the excitement going with great music for all to enjoy. Sponsored activities were also on the list of fun things to do with the inflatable slide from Drugco Health and a photo booth from Aptevo. Other activities included face painting, crafts, games, a visit to the Hemophilia Federation of America (HFA) History Boards, massages by Midas Massage Therapy, and the Doggy Tent by PetMania. Once everyone had a chance to enjoy the inflatable dart board or dance with Spiderman and Minion from Ricky dd's Party Entertainment, it was time to line up for the Walk.



Keeping up with tradition, HNC once again we awarded the King, Queen, and Jr. Droplet awards to people in the community who have routinely supported this event and made special contributions to the Festival this year. Congratulations to this year's Droplet winners Charles Register, Gwen Stewart, and Bryan and Grayson Schoolcraft, and thank you to Joyfully Sewn Endeavors for making the winners' sashes.

UNC's Tarhealers won the Hospital Cup once again and were in the top 10 for team fundraising with their \$999 fundraising total. Team Clot Hoppers took the Top Team award once again with the South Cows and Jaden's Jewels and Jaden's Gents following closely behind. The top three teams alone raised \$14,133 with all teams together raising more than \$32,000!

One lucky adult went home a \$150 Amazon Gift Card with other winners of adult raffle prizes taking home a \$100 Firebirds Wood

Continued page 18



Actualización del Programa Unión Latina

El programa Unión Latina de Hemofilia de Carolina del Norte (HNC) tuvo un excelente año en 2018. Nuevas familias recibieron una calurosa bienvenida a los distintos eventos realizados este año, como los cinco eventos de un día y también eventos sociales sostenidos en distintos puntos de Carolina del Norte, como Asheboro, Concord, Durham, y Winston-Salem. Adicionalmente, el primer Retiro de la Unión Latina se llevo a cabo en 2018 en Winston-Salem, en el verano. Este fue un evento realizado totalmente en Español, que duro dos días y una noche. Sesiones educacionales así como también eventos para niños fueron desarrollados en Español, de tal manera que todos y cada uno tuviesen la oportunidad de aprender acerca de los desordenes hemorrágicos que sufren sus hijos, sin necesidad de que las charlas fuesen traducidas.

HNC planea y espera que el programa de la Unión Latina siga creciendo durante el año 2019. A pesar de que el personal

de HNC no habla Español, usamos recursos disponibles en la comunidad, de tal manera que podemos ofrecer el apoyo que la comunidad de habla Hispana pueda recibir la ayuda que necesite. Si usted es un individuo bilingüe, o conoce al alguien que lo sea, y que este disponible para traducir material al Español, por favor contactar la oficina de HNC. Además, si usted tiene sugerencias para programas a realizarse en el 2019, por favor contacte HNC para poder apoyar sus ideas.

La Unión Latina es un programa desarrollado por HNC con el objetivo de apoyar y educar a individuos de habla Hispana y sus familias en Carolina del Norte, quienes son victimas de enfermedades hemorrágicas. Este programa es ofrecido en Español y es posible gracias al auspicio de Shire. Para mayor información, visite el sitio web de HNC.

Unión Latina en Speedway

1 de Diciembre del 2018
Concord, NC



El ultimo evento del 2018 de la Unión Latina fue efectuada conjuntamente con el Holiday Celebration, el 1 de Diciembre en el Speedway Club del Charlotte Motor Speedway. Los asistentes tuvieron la oportunidad de interactuar con otros miembros de la Unión Latina, así como también con otros pertenecientes al HNC mientras los pequeños participaban en actividades manuales de entretenición. Después de un agradable almuerzo, los miembros de la Unión Latina se dirigieron al Clubhouse, mirando las pistas de carrera. Yinell Núñez nos presentó Shire *Hello Talk! Self Advocacy*, que resalto como expresarse y como colaborar con su equipo de salud. Siguiendo la presentación, retornamos al Ballroom donde tuvimos

la aparición de Santa quien entregó regalos a todos los niños presentes. HNC agradece a Shire por el auspicio del Programa Unión Latina.



2019 Reunión Anual del HNC en Charlotte

2 de Marzo del 2019

Charlotte, Carolina del Norte

Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés) celebrara su Reunión Anual numero 46, el 2 de Marzo del 2019, en Charlotte. Esta reunión, de un día de duración, es la mas relevante cuyas sesiones están guiadas para todas las edades, orígenes, desordenes hemorrágicos y sus relaciones con la comunidad. Los asistentes tendrán la oportunidad de relacionarse con otros miembros de la comunidad, encontrar soporte, aprender y escuchar de expertos importante información relacionada con enfermedades hemorrágicas.

Aunque HNC esta aun afinando detalles de la agenda, estamos orgullosos de darle la bienvenida al Dr. Steven Pipe, Hematólogo Pediátrico y Director Medico del Centro para Tratamientos Hemofílicos de la Universidad de Michigan. El Dr. Pipe nos dará una charla acerca de nuevas y emergentes terapias en desordenes hemorrágicos.

Como en anos anteriores, habrá una sesión especial para aquellos que asisten por primera vez, justo antes que la reunión del HNC comience, donde les informaremos cual es la agenda

para ese día y como se ira desarrollando. También habrán otras actividades como reuniones individuales para hombres, mujeres, padres, parejas/conyugues, Unión Latina, desordenes hemorrágicos inusuales, y también la enfermedad de von Willebrand. Tendremos cuidado para niños de todas las edades, incluyendo un especialista en actividades para adolescentes.

La Reunión Anual es el momento perfecto para los miembros para plantear sus inquietudes, así como para los que asistirán a las reuniones de negocios para votar por los candidatos al Directorio del HNC.

La Reunión Anual de HNC incluyendo sus almuerzos, refrigerios y cuidado de niños, es ofrecida sin costo para sus miembros gracias a la generosidad de nuestros auspiciadores.

Mas información acerca de la agenda, así como invitaciones e inscripciones estarán disponible este invierno. Revisen sus mensajes de email en Enero, o bien contacten la oficina de HNC para mas detalles.



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SOAR Program Update

Are you a woman with a bleeding disorder? Do you have a daughter with a bleeding disorder? Then the SOAR Program is for you. SOAR provides education, resources, and support for women and girls with bleeding disorders and works to raise awareness about women and girls with bleeding disorders and advocate for better diagnosis and treatment.

You may have started to notice that HNC is posting a fact about females with bleeding disorders on its Facebook and Instagram pages every Thursday. This is part of the #DontBlush campaign developed by women in the Women’s Advocacy Coalition to further raise awareness. There has been great success with the social media campaign thus far, with more than 100 shares! Help HNC meet its goal by sharing these facts and images on your

own social media pages and ask your friends and family to do the same.

SOAR is a program of HNC for women and girls with a bleeding disorder, including those diagnosed with von Willebrand Disease, hemophilia A and B, rare factor deficiencies, platelet disorders, and carriers of any of these disorders (both symptomatic and non-symptomatic). 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.

Please contact Gillian Schultz, HNC Program Manager, for more information about the SOAR Program at soar@hemophilia-nc.org or by calling the HNC Office at (800) 990-5557.

HEAVY BLEEDING? *GET TESTED*

Women with undiagnosed bleeding disorders face serious risks after childbirth, injuries, dental procedures and surgery.



JOIN IN HNC’S NEW SOCIAL MEDIA CAMPAIGN **#DONTBLUSH**

to raise awareness about women and girls with bleeding disorders. Contact the HNC office for copies of images to post on your own social media accounts or follow HemophiliaNC on Facebook, Instagram or Twitter to share #DONTBLUSH posts.

SOAR Dinner – Hemophilia... the Female Connection

November 7, 2018

Charlotte, NC

Hemophilia of North Carolina (HNC) hosted a SOAR Dinner for women and girls with bleeding disorders on November 7 at Red Rocks Café in Charlotte. Eight women gathered for the presentation, *Hemophilia... the Female Connection*. Sue Geraghty, RN, MBA, went over the genetics of how hemophilia is inherited and how women become “carriers.” Females will be carriers of hemophilia as the daughter of a man with hemophilia, the daughter of a woman who is a carrier (she has a 50% chance of being a carrier), or through spontaneous mutation. The discussion talked about lyonization of the X-Chromosome, how in every cell, one female’s X is turned on and the other is turned off, leading to the varied factor levels among women and girls. Anyone with a factor level below 50 has hemophilia, male or female, and some women even deal with symptoms of hemophilia at higher levels. Following the presentation, Tammy Davenport spoke about her experience of being a woman with hemophilia and how it has shaped her life and her passion to educate others about bleeding disorders in women. Following Tammy’s short presentation, the women talked about their experiences, struggles with finding treatment at times, and discussion about how more hematologists are coming around to understand that women have hemophilia, and that being a carrier does not necessarily mean they are asymptomatic. Although change is beginning, it is still important that this community continues to advocate among healthcare providers that hemophilia is not just a male disorder, but women do in fact have hemophilia and other bleeding disorders as well. Following the delicious dinner, presentation, and conversation, all the women went home with a women’s care gift bag. Thank you to BioMatrix for providing the gift bags and Novo Nordisk for sponsoring the event.





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Young HNC Athletes at Junior National Championship

The 17th Annual Gettin' in the Game Junior National Championship (JNC) was hosted by CSL Behring and held in Phoenix Arizona from September 28-30, 2018. Hemophilia of North Carolina (HNC) was excited to have the opportunity to send three young members this year. Athletes had the option of participating in golf, baseball, or swimming. They learned more about the importance of physical fitness in managing their bleeding disorder and received instructions on proper stretching techniques and good athletic form while getting to know other young athletes from around the country. Read more about the event from this year's participants.

From the Otey Family and HNC Athlete, Hayden, age 9

We are very thankful for the opportunity for Hayden to participate in the 2018 Junior National Championship. It was exciting for him to share in this experience with other participants from around the United States who also have bleeding disorders. By the end of the weekend, Hayden learned new swimming skills, enjoyed friendly competition that has sparked an even greater interest in swimming, and made new friends. This event instilled in the athletes a great sense of accomplishment and encouraged them to seek safe avenues for lifelong physical activity.



Hayden with his Gettin' in the Game Medal

From the Traficanti Family and NC Athlete, Jack, age 11

The first time I attended the JNC, I was only seven years old. I only had a year of experience playing golf, and had never played outside of my home state of North Carolina. The opportunity to fly to the other side of the country to compete against kids from across the nation was both exciting and scary. I was in-experienced to say the least. But, wow, what a blast! I met other kids who had a bleeding disorder. I met Perry Parker, who made me realize that I can play golf. And I can compete and win—just as easily as anyone else!



Jack getting his 2nd place trophy at the 2018 JNC Awards Dinner

I didn't win the tournament that year, but I did receive the award for good sportsmanship. And something more important: Perry told me that he expected to see me back here one day, and he predicted I would win. That single comment has stuck with me all these years. I attended the JNC again the following year and, again, I didn't win. But like the first year, the lessons I learned and the friends I made were extremely rewarding.

I arrived in Phoenix and checked into the hotel. This time I was more excited than I was nervous. I had been here before and knew what I had to do. Instead of being the rookie: wide-eyed and awestruck, I went through the clinic with confidence. Looking around, I spotted others who were undoubtedly there for the first time, and did what I could to help them. Peyton from Alaska and Brody from Arizona and I became fast friends. We exchanged phone numbers and still chat on a regular basis.

Saturday came quickly and soon it was time to get down to business. I was determined to win. All through dinner I tried to figure out what the other players scored. It was nerve-wracking. I couldn't wait for dinner to end and the awards ceremony to start. Coach Perry started the introduction for second place saying, "I knew this young man would be back here some day...", and the rest was a blur. I scored a 48 and the winning score was a 41, shot by a 15 year-old from Pennsylvania. I am proud to be part of HNC and very thankful to the WV and NC chapters for giving me the opportunity to represent both states!

Hemophilia: The Musical

November 9-12, 2018

New York, NY

By: Jacob Hoernlein, HNC Member



Photo courtesy of BioMarin

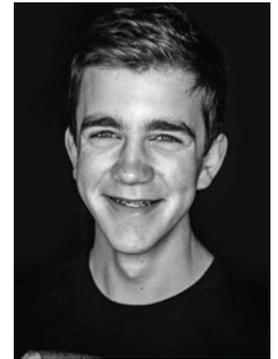
On November 9th, I flew to New York City for an experience that changed my life. The Breaking Through! Musical Theatre Intensive in New York City was a three-day musical theatre and arts workshop produced by Believe Ltd. and BioMarin. The program culminated with a performance of the original production *Hemophilia: The Musical* on Monday, November 12th. I learned many skills that will be beneficial to my life moving forward, both as a performer and as someone living with a bleeding disorder.

Twenty-five teens affected by bleeding disorders from around the United States were selected by application and audition-tape to participate. Because there is no better way to understand the lives of a teen with bleeding disorders, the content of the teens' applications was the source material for the song lyrics and script. It was really cool to see something I wrote incorporated into a story for thousands of people to hear.

The finished product was a one-act musical with 6 songs that told a variety of different stories. One character felt that she had to hide her bleeding disorder to fit in, for fear of being

told she was too fragile to do anything. Two other characters had to overcome their worries of someone finding out about their bleeding disorder to connect over their respective illnesses. Another set of characters was distressed at being told that they could not participate in sports.

The overarching story showed the daily struggles that those with Hemophilia or other bleeding disorders face and how they are able to overcome them. The program's goal was to show people who may not know a lot about bleeding disorders what they really are and to inform members of the bleeding disorders community about how the arts can improve their lives.



It was an absolutely, indescribably amazing weekend. Over the course of three days, I learned many things that I can use, not only in the theater, but also in my everyday life. A main theme of the intensive was how breathing can be therapeutic. Cast members learned different forms of breathing and their effects on the body and mind. We also learned different acting techniques, and we participated in exercises that blended the emotionality of theatre with the physicality of theatre. We were taught different skills to improve our singing voices, and we were taught about choreography and its ability to provide a visual of the content of the music to the audience. All of this was connected back to our bleeding disorders, providing takeaways of how we can apply the skills we learned to our everyday lives, living with our diseases.

On top of these workshops and rigorous rehearsals, the cast was treated to a plethora of other amazing experiences. These included touring a Broadway theater; meeting with the Producer and Manager of *Wicked*; attending a Q&A session with Broadway stars from *Anastasia*, *Be More Chill*, *Frozen*, and *Hamilton*; and, most impressively, being able to see our names in lights in Times Square.

I would like to thank everyone involved with the Breaking Through! Intensive, Believe Ltd., and BioMarin for allowing me to attend such an amazing event. And I'd like to thank Charlene Cowell and HNC for nominating me to attend.

I'd recommend this program to teens affected by bleeding disorders who have any interest in the arts. This experience was invaluable—teaching me skills that I can apply not only to the theatre, but to my everyday life. The friends I made and the things I learned will stay with me forever.

If you'd like to watch *Hemophilia: The Musical* in its entirety go to www.breakingthroughhemophilia.com for a link to the video.

HNC Family Festival & Walk: Thanks for Your Support!

continued from page 11

Fired Grill gift card, Trader Joe's gift basket, or four AMC movie passes! Kids also had a chance to win raffle prizes. One lucky winner took home a birthday party donated by White Tiger martial arts studio while six other kids won either a Dave & Busters gift basket or gift cards. Finally, the lucky winner of the Grifols trivia question drawing won a \$15 Dunkin Donuts gift card for answering the question, "In what year was HNC incorporated as a nonprofit?" It was 1977!

This event would not have been possible without the support of every member, sponsor, volunteer, donor, and contributor, so here's a big thank you to each and every one of you for a job well done!

To see pictures and video clips of the event, please visit our Facebook page www.facebook.com/HemophiliaNC. More photos and videos will be added as they continue to roll in. If you aren't already a page member, simply "like" us and continue to see HNC news, events, and pictures throughout the year.



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HNC Adult Retreat

November 17-18, 2018
Wrightsville Beach, NC

In September, as the rest of North Carolina listened to reports from the Wilmington and Wrightsville Beach areas, everyone crossed their fingers and hoped that this year's Adult Retreat would go on as planned. The Holiday Inn Resort at Wrightsville Beach was fortunate not to have sustained significant damage and was more than ready for the approximately 60 adults who gathered for the event in November.

Starting with check-in and breakfast on Saturday morning, attendees had a chance to get settled, mingle with one another, and visit the vendor booths before the morning sessions began. The first session, *Navigating Healthcare*, was presented by Jeanine Schmidt of Shire. This highly informative presentation covered the Affordable Care Act, Medicare, Medicaid, and Private Insurance and included discussions on open enrollment, co-pays, and more. Everyone learned something new that could help them as they navigate their own insurance program. After a delicious lunch, next on the agenda was *The Art of Speaking Up* presented by Javey Dallas, MSW, LCSW. Javey is a speaker with National Hemophilia Foundation (NHF) and the social worker for the HTC in Oklahoma City, OK. In this interactive presentation, attendees chose a category from a game board which would prompt a discussion on that topic. Social media, bullying (yes, adults can be bullied too!), disclosing your bleeding disorder, and other chosen topics led to some interesting and insightful discussion among the group. Before breaking for free time to check into their rooms, explore the hotel, or visit the beach, Karyn Davis, HNC Manager of Operations, led the group in a discussion about the needs of the community and how HNC can plan to meet those needs. After some free time, members met for a wonderful Italian buffet dinner, and several HNC members gathered in the hotel lounge to enjoy some live music before turning in for the night.

With the hotel being directly on the beach, some attendees started their day early and got to the beach to watch the sun rise before meeting for breakfast and the final session of the retreat. On Sunday morning, Alexis Abbate, Jackie DeConti and their colleagues from Terra Sol Sanctuary in Wilmington, NC, brought a wonderful presentation on *Everyday Mindfulness* to the group. The first part of the presentation was to explain mindfulness and why it is important to physical health, mental health, and pain management. Then, after being led through a guided meditation, everyone split up into small groups to review different techniques one could use to lead them toward being more mindful. Coloring, or focusing on a specific sound, sight, or touch even for just five minutes a day can give your mind some clarity and lead to better mindfulness overall.

Overall, the weekend was a success with only positive feedback on the venue. HNC members can look forward to something new for the 2019 Adult Retreat with a new format that will combine

the current Men's, SOAR (women and girls with bleeding disorders), and Adult Retreats. This bigger retreat will be held in Greensboro, NC, from May 31-June 2, 2019, and will include sessions for all adults as well as breakout tracks for women, men, spouses/partners, and other groups within the community.

Members also had free time to enjoy the scenery and hotel amenities



Adults of the community gathering in Wrightsville Beach enjoying some of the activities



Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies and organizations for the 2018 HNC Adult Retreat:

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 **NATIONAL HEMOPHILIA FOUNDATION**
for all bleeding disorders

2018 Holiday Celebration

December 1, 2018

Concord, NC

Lights were shining as Hemophilia of North Carolina (HNC) kicked off the 2018 Holiday Celebration at the Speedway Club at the Charlotte Motor Speedway. Over 150 members and their families attended the festive event which included lots of time for networking, a buffet lunch, crafts for the kids, and a special visit from Santa.

In the spirit of giving, over two large boxes of donations were collected for the Urban Ministry Center. The Urban Ministry Center is a nonprofit that aims to end homelessness in the Charlotte area.

The afternoon featured a presentation from Anita Smith, PNP, from the Wake Forest Baptist Health Hemophilia Treatment Center. She spoke about how treatment for bleeding disorders has changed over the years and continues to evolve. Charlene Cowell, Executive Director of HNC, then spoke on the importance of giving back to the community, both with time and donations, so that HNC can continue to sustain its ability to provide support to people with bleeding disorders across the state. The Volunteer of the Year, Phil Poovey, was announced, as well as a special thank-you to HNC's donors.

As the event wrapped up, children left with smiles after opening their gift from Santa and families left with a ticket to the Speedway Christmas lights show. It was a great event to wrap up another year with HNC.



Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2018 HNC Holiday Celebration:

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We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2018. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

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Irene Cowell
W. Allen & Sue Heafner
David Howell & Sara Miller
James Jarratt
Michael & Rebecca Manning
Andrew Matthews
Jessica Prim
Nancy Smoak

Hemophilia of North Carolina Hurricane Relief Fund

Maha Abushanab
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Charlene Cowell
Karyn Davis
James Fullam
Andrew & Bonnie Gullet
Robert McCusker
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Maria Schnaith-Ivan
Gillian Schultz
The Hemophilia Alliance Foundation
The Lone Star Chapter of The National Hemophilia Foundation

HNC Family Retreat Childcare Support

Troy Schoolcraft
Gillian Schultz

In Memory of Kasey Frye's Birthday

Kevin & Melodee Frye

In memory of Warren Jewett

The Cowell Family

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Cash and In-Kind contributions received from January 2018 - December 2018. We thank our sponsors for their continued support of the community.

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The Cary Theater • The Map Shop • Tijuana Flats • Town of Cary, The Cary Theater • Trader Joe's • Triangle Community Foundation, Inc.
Triangle Corporate Coach • Triangle Wine Co. • United Way • Veronica Samuel • WCNC • Wells Fargo Community Support Campaign
Which Wich • Will's Doggin' It Deli & Market • Woof Gang Bakery & Grooming • Wyndham International • Zaniac Parkside

Special Contributions for Scholarships (\$8,000)

Diplomat Specialty Infusion Group



HOPE Program Update

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

Hemophilia of North Carolina's (HNC) HOPE Program is for families who have a child twelve or under with a bleeding disorder. In 2018, HNC provided various opportunities for members who have children in this age range to get together, learn, and find support. From the Charlotte Checkers hockey game in March, an educational dinner in Durham in May with the focus on infusion support, educational dinners in Charlotte, Raleigh, and Greenville with a focus on preparing to go back to school, and the Family Retreat in October in Concord, HNC tried to reach across North Carolina to provide education and support for families.

The Mentoring Program has continued to be a beneficial option for parents and guardians who are looking for more. Mentors are trained to listen, coach, and be a friendly shoulder to lean on for community members who are looking for additional support. As primary care-givers of a child with a bleeding disorder, the mentors understand the challenges that parents, children, and family

members may face, and want to give back to their community so that others don't have to feel alone.

As part of the HOPE Program, HNC has created a closed Facebook Group for members looking to talk with others in North Carolina. You can access the Facebook Group through the HNC Facebook page or by searching HNC HOPE. This group is moderated by HNC Staff and you must request access to join.

Finally, HNC is planning on rolling out Regional Groups, led by Community Leaders in 2019. These will be groups of HNC members to provide support across the state in a variety of different settings. Stay tuned for dates and locations.

If you have ideas for programs and events in 2019, for more information about the HOPE Program, or if you have questions, please contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or calling her directly at (919) 272-6000 or by calling the HNC Office at (800) 990-5557. Keep your eyes on the HNC website, Facebook, Instagram, and Twitter for information about upcoming events.



Blood Brotherhood

Blood Brotherhood Program Update

After a busy 2018, the Blood Brotherhood program is gearing up for another great year in 2019.

The final event of 2018 took place on December 15 in Hickory, NC, while this newsletter was in final production; so, you can look forward to reading about it in the Spring edition of *The Concentrate* due out in April.

Already scheduled for 2019 is the Blood Brotherhood Retreat which will take place in Pine Knoll Shores, NC, from July 26-28. Mark your calendars to save the date and be on the lookout for event registration for this retreat sometime in the Spring. Plans for additional Blood Brotherhood programming throughout the

state is in the works. If there is a certain program topic or location you'd like to be placed on the schedule, please reach out to the HNC office with your ideas.

HNC's Blood Brotherhood is an extension of the Hemophilia Federation of America's (HFA) Blood Brotherhood Program. It's designed to provide opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. If you can't make an event consider connecting with adult men with bleeding disorders from the comfort of your own home with the new and improved Blood Brotherhood private online forum! Go to www.hemophiliafed.org to register.

Unión Latina Program Update

Hemophilia of North Carolina's (HNC) Unión Latina Program had a great year in 2018! New families received a warm welcome at events throughout the year with five one-day educational and social events being held across North Carolina in Asheboro, Concord, Durham, and Winston-Salem. In addition, the first ever Unión Latina Retreat was also held in 2018 in Winston-Salem during the summer. This was a two-day, one-night educational opportunity for families entirely in Spanish. Educational sessions and some of the children's sessions were in Spanish so that everyone could learn about their own or their child's bleeding disorder without needing to have the information translated for them.

HNC is looking forward to continuing the growth of the Unión Latina Program in 2019. Although none of HNC's staff speaks

Spanish, using resources around the community, HNC strives to provide the support and education that the Spanish speaking community needs. If you are bilingual, or know someone who is bilingual, and would be willing to help translate materials into Spanish, please contact the HNC office. Additionally, if you have any ideas for programs in 2019, let HNC know so that they can support you.

The Unión Latina 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.



It's not too soon to start planning for Summer Camps! Please follow instructions listed for each camp to access applications. Camps fill up quickly and campers are usually accepted on a first come, first served basis, so get your applications in as soon as possible to secure your spot.

Victory Junction Camp in Randleman, NC

For information on how to register for Summer Sessions or about Victory Junction's Family our Young Adult Weekends, go to www.victoryjunction.org or call (336)498-9055.

June 23-27, 2019 *Bleeding and Gastrointestinal Disorders (Sunday- Thursday)*

June 30-July 3, 2019 *Neurological and Genetic Disorders (Sunday- Wednesday)*

Camp Carefree in Stokesdale, NC

For information about Camp Carefree, the services they provide year-round or to find out if space is still available at the Camp Weeks listed below, go to www.campcarefree.org, email directors@campcarefree.org, or call (336)427-0966.

June 16-22, 2019 *Siblings Camp – well children with a chronically ill sibling*

July 14-20, 2019 *Kids Camp – well children with a chronically ill parent*

July 21-27, 2019 *Hemophilia, blood disorders, vWD & Turner's Camp*

Camp Rainbow at Camp Don-Lee in Arapahoe, NC

Camp Rainbow is available to patients of the East Carolina University Hemophilia Treatment Center (ECU HTC) in Greenville, NC. For information about Camp Rainbow or to find out if space is still available in the Summer Session this year, please call the ECU Hemophilia Treatment Center at (252)744-4676 or visit their website at www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm



The Royal Tree in Downtown Cary, NC



Hemophilia of North Carolina (HNC) is really excited to have a tree on display in downtown Cary, NC, for the holiday season. The Royal Tree theme came from the idea that hemophilia is sometimes referred to as “the **ROYAL** disease”, because it affected the royal families of England, Germany, Russia, and Spain in the 19th and 20th centuries. In addition, since hemophilia, with some exception, is an inherited bleeding disorder, it's tied to a person's family **TREE**.

Decorated with crowns and tiaras, the tree's decorations also include some fast facts about bleeding disorders, as well as a take-home crown for any kids that stop by to visit. This is not only raising critical awareness of bleeding disorders but also has a competition component. The tree that gets the most votes between Dec 1-15 will win \$500. If the HNC tree wins, 100% of these funds will go directly towards research! HNC will post on social media about the winner once it is announced. To see pictures of the tree and a video of “The Tree in the Making”, please visit HNC's Facebook page at www.facebook.com/hemophiliaNC (Facebook account not required).

If your town has a similar tradition and you want to participate in 2019, please contact the HNC office for more information and assistance.

2018 NHF Insurance & Reimbursement Conference

November 14-16, 2018

Baltimore, MD

By: Matthew Igelman, HNC Advocacy Chair



The "Carolina Crew" on our last day at the National Hemophilia Foundation Insurance & Reimbursement Conference. Recognize anyone?
Curtis (UNC), Sue (Hemophilia of South Carolina),
Charlene (Hemophilia of North Carolina),
Charmaine (East Carolina University),
Matt (Hemophilia of North Carolina) and Jodi (Wake Forest)

I was delighted to attend the National Hemophilia Foundation (NHF) Insurance & Reimbursement Conference on behalf of HNC and bring this valuable knowledge back to the community here. As we all know health insurance is ever-changing and increasingly confusing. The purpose of this conference was for NHF chapters and hemophilia treatment center staff to stay on top of the changes to how our bleeding disorders are covered by insurance.

The meeting was held November 14-16 in the Inner Harbor section of Baltimore and gave us the first good taste of winter as the rain from back home in NC became a crippling, unpredicted snowstorm moving up the east coast. As snow fell, the NC group learned all about emerging payor trends, drug utilization reviews and prior authorization, patient assistance programs, the 340B program, NHF's efforts across our nation, and much more. The program really covered the entire spectrum of coverage from both public and private as well as a presentation on aging out of coverage.

With insurers now passing even more costs onto consumers in the form of co-insurance, looming changes to our state's Medicaid program moving to managed care in 2019, and the still un-expanded Medicaid, there is a lot to consider regarding health coverage, and it's

more complicated than ever. We greatly appreciate the NHF's federal and state advocacy efforts and the knowledge shared at the reimbursement conference.

If you are having trouble understanding your coverage, want more information on patient assistance organizations, or are aging into new coverage, contact the HNC Office or your HTC social worker. One of them can connect you with the right resources. With open enrollment having just ended make sure you know the changes for the upcoming year by reading your new or existing policy. Consider joining North Carolina's advocacy efforts in Raleigh on February 11-12 and/or attending NHF Washington Days March 27-29, 2019, to have your voice and story heard.

HFA's 2019 Symposium: Celebrating 25 Years

April 4-7, 2019

San Diego, CA



Hemophilia Federation of America's (HFA) Symposium is an annual community-centered educational event that draws hundreds of members from the bleeding disorders community together to share information, learn new advancements, and build a network of support! Each year, HFA offers travel or hotel scholarships to first-time attendees who need financial assistance. But please note, these scholarships are on a first-come-first-serve basis and go quickly.

Registration will open at www.hemophiliafed.org in early 2019.

While it is a considerable commitment of time and money, HNC would encourage all members to make the effort to be part of this event. For more information about travel grants and registration, please contact the HNC office.

Educational Scholarships Available

Members of the bleeding disorders community are fortunate to have many scholarship opportunities available to them. Hemophilia of North Carolina (HNC) offers two scholarship programs:

The George D. McCoy Education Scholarship will award one recipient who is diagnosed with severe hemophilia A a \$1,000 scholarship. The application deadline is May 1. Contact the HNC office or visit the HNC website for an application and more information.

The Diplomat Specialty Infusion Group/Hemophilia of North Carolina Education Scholarships allow for multiple awards ranging from \$500 to \$3,000. Candidates are persons affected by a bleeding disorder including anyone who: has been diagnosed with a bleeding disorder; is a caregiver of a child or adult affected by a bleeding disorder; has a sibling or a parent in the same household affected by a bleeding disorder. At least one scholarship will be awarded to an applicant pursuing education in a health related field. The application deadline is May 1. Contact the HNC office or visit the HNC website for an application or if you need more information.

In addition to the HNC Education Scholarships (see the HNC Website for information), members can find more scholarship opportunities using the resources listed below. Additionally, students' high school guidance counselors or college financial aid officers can be excellent resources to assist members with finding monies for continuing education.

Beth Carew Memorial Scholarship from Colburn Keenan Foundation: visit www.colkeen.org/?page_id=123

Hemophilia Federation of America website Programs & Services: visit www.hemophiliafed.org/programs/educational-scholarships/

LA Kelley Communications, Inc.: visit www.kelleycom.com/scholarships/

National Hemophilia Foundation website Community Resources: visit www.hemophilia.org/Community-Resources/Scholarships



Your treatment is a must. Support should be too.

Learn about the ways the Hematology Support Center (HSC) can help. Find out if any of Shire's assistance programs are right for you.

Get the details on HSC including:



CoPay Assistance

Need help paying for your treatment? If you're commercially insured and on a Shire Hematology treatment, you may be eligible to receive 100% coverage for eligible out-of-pocket co-pay expenses up to the program maximum with Shire's CoPay Assistance Program.



Access Support

The HSC team is here to help you along your journey. They can work with you, your HCP and specialty pharmacy to explain your insurance benefits and answer your questions. They can also help you understand your options that may help cover the cost of your Shire treatment.



Insurance Education

HSC can provide you with educational information on a variety of health insurance topics, including insurance coverage, healthcare reform and guidance on insurance applications or appeals.

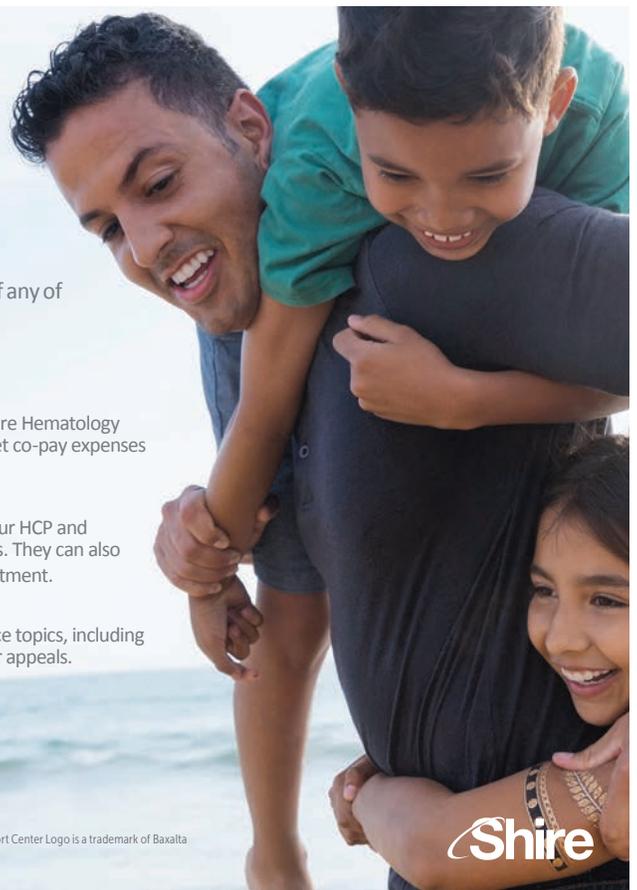
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NHF Washington Days

March 27-29, 2019

Washington, DC



The National Hemophilia Foundation (NHF) will host their annual Washington Days advocacy event March 27-29, 2019 on Capitol Hill in Washington, DC. NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Last year's Washington Days had more than 500 volunteer advocates from 47 states that met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act (ACA).

Hemophilia of North Carolina (HNC) is always in need of more advocates to attend this important event. HNC advocates group together each year, putting some seasoned advocates with those attending for the very first time, and visit more than 17 offices. It is a powerful experience for community members and their families. For more information about travel grants and registration, please contact the HNC office.

Two young HNC members at the United States Capitol

HNC Legislative Day: Join Fellow Members in Raleigh

February 12, 2019

Raleigh, NC

Save the date! It's time to advocate for the bleeding disorders community with elected officials in Raleigh.

Regardless of your age, type of bleeding disorder, role in the community, or political views, it's your time to tell your story as a representative of individuals, families, and the entire community; so people with bleeding disorders can have a voice in Raleigh.

Please join your fellow Hemophilia of North Carolina (HNC) members and represent your State Legislative District at the HNC Legislative Day on Tuesday, February 12. HNC will continue its focus on building awareness and relationships between the North Carolina State Representatives and the bleeding disorders community throughout the state. With the ever-changing landscape of the

healthcare system and other state services, it is important to have your story heard. Your story can make a difference! 2017 advocates spoke to representatives about a physical therapy issue that has since been resolved thanks to their efforts.

There will be a training session and dinner the evening of Monday, February 11. Hotel accommodations are available upon request through January 11 for attendees traveling over 30 miles who are also attending the training session on Monday, February 11.

If you cannot make it to Raleigh on February 12, contact the HNC office for information on how to reach out to your representatives at their local offices.



HNC members ready to meet with their representatives in Raleigh at the 2018 Legislative Day

Hemophilia of North Carolina 2019 Calendar of Events Highlights



January 26, 2019	"Hearts for Hemophilia" Casino Night – Durham, NC
February 2, 2019	Factor 7 Roundtable – Morrisville, NC
February 12, 2019	Legislative Day – Raleigh, NC
March 2, 2019	Annual Meeting – Charlotte, NC
April 17, 2019	World Hemophilia Day – Location TBD, NC
April 27, 2019	Charlotte Family Festival & Walk for Bleeding Disorders – Charlotte, NC
May 31-June 2, 2019	Adult Retreat – Greensboro, NC
June 29-July 2, 2019	HNC/HSC Teen Retreat – Rock Hill, SC
July 26-28, 2019	Blood Brotherhood Retreat – Pine Knoll Shores, NC
August 17, 2019	Family Day Out – Tanglewood Park, Clemmons, NC
September 7-8, 2019	Family Retreat – Concord, NC
October 12, 2019	Raleigh Family Festival & Walk for Bleeding Disorders – Morrisville, NC
December 7, 2019	Holiday Celebration – Location TBD, NC



Help HNC conserve valuable resources!

Do you enjoy receiving this newsletter delivered directly to your home, or would you prefer reading this newsletter online? Contact the HNC office to **OPT IN** to home delivery of *The Concentrate*.

If you want to continue to receive your copy of *The Concentrate* delivered by mail to your home address, please let us know! Only members who **OPT IN** to receiving this newsletter by mail before December 1, 2019, will continue to receive *The Concentrate* by mail in 2020. If you don't **OPT IN**, you will receive a link to view a downloadable version of *The Concentrate* on the HNC website. To **OPT IN**, send your first and last name, and street address by email to info@hemophilia-nc.org, calling (800) 990-5557, or text to (919) 271-4171.

If you're not receiving emails from HNC about programs and events in your area, please contact the HNC office so you don't miss out on HNC news and information.





HEMOPHILIA OF NORTH CAROLINA

260 Town Hall Dr., Suite A, Morrisville, NC 27560
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