

# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2016/17

## HNC Annual Meeting in March 2017!

HNC 44th Annual Meeting of the Membership  
March 4, 2017  
Cary, NC

Hemophilia of North Carolina (HNC) hosts educational, community and support programming across the state and throughout the year, but the most comprehensive educational and support opportunity for HNC members is at the HNC Annual Meeting. This is HNC's largest one-day event combining the entire range of individual programming that members can participate in all year long. Members of all ages, backgrounds, type of bleeding disorder and relationships within the community will have a chance to hear from expert speakers, knowledgeable medical professionals, and fellow community members to learn more about important news and information on the topic of bleeding disorders.

There is something for everyone at the HNC Annual Meeting! This year's theme will be around the importance of mental health (when dealing with a bleeding disorder). Hear from Tim Ringgold, a certified Music Therapist, as he talks about how music therapy can be an important tool in dealing with pain and stress. We are also looking forward to hearing from Dr. Alice Ma, hematologist at UNC-Chapel Hill, about emerging therapies and the future of treatment for bleeding disorders. There will be other general

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## Announcing the HNC Family Festival and 5K Walk for Bleeding Disorders!



Hemophilia of North Carolina is excited to introduce its new venture – the HNC Family Festival and 5K Walk for Bleeding Disorders. This newly named event will be taking the place of the Charlotte and Raleigh Hemophilia Walks. Just

as with the Walks in the past, the HNC Family Festival and 5K Walk will be in Charlotte in the spring and the Raleigh/Morrisville area in the fall, and will continue to be HNC's largest fundraisers.

In 2008, the National Hemophilia Foundation (NHF) Walk program began. HNC was one of the first five NHF walk sites in the country. Just ten years later, HNC has grown by leaps and bounds to be able to hold two annual, successful walks. This growth and accomplishment has had substantial results. In those 10 years, walk proceeds have grown and HNC programming has increased from 13 to more than 45 events each year. All members, supporters and sponsors should be extremely proud of the role they play in this achievement.

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### Save The Date

**Casino Night Fundraiser**  
Charlotte, NC  
January 28, 2017

**Inhibitor Camp**  
RESCHEDULED from 2016  
Victory Junction Camp  
February 17-20, 2017

**Mentoring "Lunch 'n Learn"**  
Morrisville, NC  
February 18, 2017

**Volunteer & Special Guest Dinner**  
Cary, NC  
March 3, 2017

**Annual Meeting**  
Cary, NC  
March 4, 2017

**NHF Washington Days**  
Washington, DC  
March 8-10, 2017

**Legislative Days**  
Raleigh, NC  
Date TBD

**World Hemophilia Day**  
Location TBD  
April 17, 2017

**Family Festival & 5K Walk**  
Charlotte, NC  
April 22, 2017



*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](http://www.hemophilia.org)

### Hemophilia Federation of America

(800) 230-9797  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

### Community Health Charities of NC

(919) 554-3272 (Collect)  
[www.healthcharities.org](http://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

### 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](http://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](http://htc.medicine.duke.edu)

### 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

## Resource Information

### National Hemophilia Foundation

[www.hemophilia.org](http://www.hemophilia.org)

### Hemophilia Foundation of America

[www.hemophiliafed.org](http://www.hemophiliafed.org)

### American Society of Pediatric Hematology/Oncology

847-275-4716  
[www.aspho.org](http://www.aspho.org)

### Centers for Disease Control & Prevention

1-800-311-3435  
[www.cdc.gov](http://www.cdc.gov)

### Coalition for Hemophilia B

1-212-520-8272  
[www.coalitionforhemophiliab.org](http://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](http://www.cott1.org)

### Inalex Communications

201-493-1399  
[www.inalex.com](http://www.inalex.com)

### LA Kelley Communications

1-978-352-7657  
[www.kelley.com](http://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](http://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](http://www.uneedpsi.org)

### World Federation of Hemophilia

1-800-520-6154  
[www.wfh.org](http://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.*



## HNC Annual Meeting in March 2017!

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sessions as well as breakout sessions for: families, men, women, Latino members, and spouses/partners.

The annual meeting is a chance to learn from the experts, HNC staff and fellow community members about what is going on in the world of bleeding disorders. Childcare for all ages will be available including a special teen track.

Finally, as a member of Hemophilia of North Carolina, you will have a chance to influence the future of this organization by voting for the Board of Directors nominees, which are presented to the membership annually at this meeting. Invitations and registration information for the Annual Meeting should be reaching your mailboxes soon, or call the HNC office for more information.

### *From the Office:*

## Thanks to The Hemophilia Alliance for supporting North Carolina in a time of need.

HNC Staff, along with many others across North Carolina and around the country, watched with concern as Hurricane Matthew took its toll on the eastern part of NC. We realized that many of our members from that region were cut off from their jobs and their homes or suffered property damage and extended power outages that led to loss of perishable food items or even costly medications. With that in mind, and realizing that the need would likely exceed the limits of HNC's existing Financial Assistance Program, it was an enormous relief when we got word that The Hemophilia Alliance would be able to provide grant funds to support families in our community who found themselves experiencing unforeseen financial difficulties as a result of Hurricane Matthew and the subsequent flooding.

With the assistance of the Hemophilia Treatment Centers across North Carolina, we have been able to assist 15 families thus far

with grocery cards, insurance deductibles, basic living expenses and more.

On behalf of the HNC Board of Directors and the entire membership, we would like to thank The Hemophilia Alliance for coming to the aid of people in our state who needed a hand.

Sincerely,

*Charlene, Gillian and Karyn*

NOTE: *If you are experiencing financial difficulties related to the storm, we ask that members contact the Hemophilia Treatment Centers (HTCs) and/or HNC directly, so we may assist you in finding resources for financial assistance available to you and your family.*

## Board Member Spotlight: Why I Serve

*By: Tyronna Hooker*



*Tyronna Hooker,  
HNC Board of Directors*

People have challenges and obstacles to overcome in all walks of life, including but not limited to emotional, mental, financial and health issues. The successful navigation of these issues is not done in isolation but as a community of unity. I serve as a member of the HNC Board to be a part of this community.

Hemophilia is a part of my ancestry; I am a carrier and have passed this chronic disease to my sons. Because of my family of origin, I have had the opportunity to be a part of the support system and to be a caregiver. When I was younger, the information surrounding the disease was not as prevalent as it is now; this resulted in a different experience in other family members than the experiences of my sons. It is my belief that the differences in coping mechanisms may be attributed to the level of support and the exposure and education regarding the disease. I have found that the greater the knowledge, the better the quality of life.

I serve to be a part of a Community of Unity that will educate the masses regarding this disease and to provide parents and other family members with tools to equip them in advocating for their children and loved ones.

## Volunteer of the Year: Cheri Clark



*Cheri and Crystal at the 2016 NOW Conference*

HNC's founding members recognized the vitality of this community and inspired new generations of dedicated members whose vision and tireless efforts have helped HNC thrive over the years. Each year, we honor one member as our Volunteer of the Year. It's an opportunity to acknowledge an individual who has given selflessly of his or her time and talents over the year (and usually longer) to enhance and empower HNC and the members we serve.

HNC is happy to announce that the 2016 Volunteer of the Year is Cheri Clark. Cheri has been active in the bleeding disorders community since becoming a member in 2010. She is always a friendly face and never hesitates to introduce herself to someone new. Cheri looks forward to meeting new members, making them comfortable and letting them know the importance of HNC's mission.

Cheri's passion for educating is boundless. As a nurse, she understands that bleeding disorders are not as widely understood as they should be and that nurses on the frontlines are a critical part of proper diagnosis. Each year, Cheri helps raise awareness at nursing conferences around the state on behalf of HNC.

Cheri openly shares her experiences of struggling to find answers to her symptoms well into adulthood. By attending these conferences and being willing to share her story, Cheri has made a lasting impact on each person she's met. Every time HNC exhibits at a nursing conference, at least two nurses find the booth to inform us that they have diagnosed someone with a bleeding disorder since the last conference. One nurse who had been living with symptoms for 40+ years heard Cheri's story and finally received a diagnosis of von Willebrand Disease!!

Cheri's motto is, "If I can get one person diagnosed, then it's all worth it." It's fair to say that she has far exceeded that goal. On behalf of the entire community, HNC would like to thank Cheri for all she does for the chapter, the members, and the community at large.



*Cheri attending a Nurse's Conference on behalf of HNC along with Crystal Hoernlein (HNC Member), Gina Raymond (Volunteer) and Charlene Cowell (HNC Executive Director)*

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# HNC Community Yard Sale Hits New High

October 22, 2016  
Morrisville, NC



HNC held its third annual Yard Sale fundraiser on October 22, and it was the most successful one to date! More than \$1,500 was raised to support HNC programs, but more importantly HNC was able to continue building awareness about the bleeding disorders community. Repeat customers stopped and asked questions about the cause they were supporting and offered to come back again next year, not just as shoppers but also to provide

donations for the sale! One woman was happy to find out about HNC and the programs offered for the benefit of her sister who has von Willebrand Disease, and some shoppers even signed up as HNC volunteers! This is an opportunity for members of the community to give back by donating clothing and household items they can no longer use. HNC is grateful for those who chose to support the Yard Sale by contributing items to sell. Once again, items that went unsold were donated to another charity in order to share the generosity of HNC members with others in the greater community.

We want to sincerely thank our Corporate Partners, who helped make the Yard Sale such a success: Diplomat Specialty Infusion Group and Drugco Health.



HNC is hoping to expand the Yard Sale effort around the state in 2017. If you are interested in hosting the HNC Yard Sale at a location in your region of the state, please contact HNC staff toll free at 800-990-5557. If you are wondering how you else you can participate in next year's HNC Yard Sale effort, it's very easy! Begin collecting household items and clothing that your family no longer uses and be on the lookout for announcements about how to donate items to HNC.

If you need more information about the HNC's Yard Sale or get more information about how to host one of your own on the same day, please contact HNC staff toll free at (800) 990-5557.

**Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2016 HNC Yard Sale:**

**Corporate Partners**



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# Fundraising Goal Exceeded for 9th Raleigh Walk!

October 15, 2016  
Morrisville, NC

October 15 was a beautiful day at Lake Crabtree County Park in Morrisville for the 9th Annual Raleigh Hemophilia Walk! Over 650 people and a few dozen dogs came together to show their support of Hemophilia of North Carolina (HNC) and those living with bleeding disorders throughout the state. The Walk is the largest gathering of community members each year and provides a unique opportunity to meet and connect with others in the community while also supporting HNC's largest fundraiser. With your support, HNC surpassed its



fundraising goal by raising \$110,960. The HNC staff and Board of Directors is proud to say that 100% of the money is used for the many HNC programs and services offered throughout the year!

The weather was perfect and there was plenty to do (and eat!) for all who came out to the park that morning. In-kind donors provided delicious food throughout the day. Sweet Tomatoes came out, not only with some wonderful food for breakfast and lunch, but also with their mascot, Sweetie, happily serving the walkers and supporters. Freddy's Frozen Custard & Steaks could hardly keep up with the line of walkers ready for their free sundae after their walk around the park.



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Principal Partner

Silver Regional Sponsor

**Fundraising Goal Exceeded for 9th Raleigh Walk!** *continued from previous page*



Starbucks once again donated coffee to get the event rolling and keep everybody going. The Patterson Family sponsored this year's cotton candy machine, and last but not least, PetMania donated 100 doggie bags, with plenty of treats and other goodies for the special four-legged walkers!

With everyone well-fed, walkers had plenty of energy to participate in the many activities on hand. Jecoreigraphy started things off by getting the crowd moving and then headed out to the walk route to keep walkers

motivated along the way, all while DJ Kevin McVerry kept the music going for all to enjoy. The costume contest for kids and dogs had too great a turn out to choose just one winner. Carolina Hurricanes brought out the Slap Shot Booth again along with some of their Storm Squad Cheerleaders to help start the walkers on their way. Miller Motte donated their time to come out again this year providing free massages and Juggle-Boy the stilt walker was always easy to spot in the crowd providing a fun photo opportunity. Sponsored activities completed the day's list of fun things to do with the inflatable slide from Drugco Health, caricature artist from CSL Behring, face-painter from HPC Specialty Pharmacy and photo booth from Diplomat Specialty Infusion Group. Finally, the added enthusiasm from our special guest and emcee for the day, Ken Smith from WRAL News in Raleigh, was a great way to get the crowd excited!

Keeping up with tradition, HNC once again we awarded the King, Queen, and Jr. Droplet awards to three important people in the community who continually go above and beyond with their support of the Walks. Congratulations to this year's recipients Charles Register (Clot Hoppers), Erica Cook (Jaden's Jewels and Jaden's

Gents), and Cayton Elderdice (Cayton's Clotters). Wake Forest's Wake Walkers team took home the esteemed Hospital Cup for the first time. Their extraordinary efforts were not unnoticed as they placed seventh on the Top Teams list with \$2,000 raised. Congrats to Anita Smith, the team captain of the Wake Walkers, on the win! Biogen was a repeat winner as top industry walk team with over \$6,000 in team fundraising. The South Cows surpassed the rest of the teams, both industry and non-industry, by raising an impressive \$8,633! Grifols once again brought out the greatest number of supporters with over 100 people in attendance. A lucky and very grateful member of Jecoreigraphy won the Vendor Visit Raffle grand prize, a GoPro HERO4 with an accompanying drone for extra fun donated by Cotrill's Pharmacy, Inc. with other winners of the drawings taking home game tickets donated by the Durham Bulls and Salad for a Year certificates from Panera! To finish off the prizes, a very lucky child won a Carolina Hurricanes hockey stick, signed by all the 2016/2017 team members.



This year, more than ever, members were reminded of the strength and unity of the community as walkers donated items to benefit those around the state who were impacted by Hurricane Matthew. Items collected were donated to the Food Bank and distributed to areas in need around the state. HNC continues to evaluate ways to support the community through fundraising and programming efforts. None of this would be possible without the dedicated membership, supporters and sponsors. Please plan to attend the 2017 HNC Family Festivals & 5K Walks in Charlotte (April 22) and Raleigh (October 14). Looking forward to waking together again next year!

**Latin Union in Morrisville**

September 24, 2016  
Morrisville, NC

September 24 was a perfect time to get together inside the HNC offices with members of the Latin Union Program as the heat soared into the 90's. Everyone was adjusting to the summer being over and the children were excited at what the new school year would bring! The day flew by as the conversations swirled from school to upcoming events and into the new year. One young member led a brainstorming session about what activities members might enjoy doing. The conversation brought many fun ideas to the table. HNC staff can't wait to take these ideas and make them a reality as we look to 2017!



# Family Retreat Takes to the Mountains

September 30-October 2, 2016  
Lake Junaluska, NC



*Adult sessions give parents a chance to learn from other parents*

and comfortable temperatures. Throughout the weekend, there were stories overheard of people walking around the lake and commenting about the beautiful location.

After everyone checked in on Friday afternoon, families were welcomed to the retreat with some basic information about the weekend. They had the opportunity to hear from the sponsors and learn what to expect over the next couple of days. After dinner, there was a fun Kick-Off Festival with some changes from the activities of past years. The party was complete with a campfire with s'mores, hot chocolate, and hot cider, games, crafts, a photo booth, freshly popped popcorn, and the opportunity to make a special HNC Family Tree using the fingerprints of the retreat attendees.

On Saturday there was an adult track and a separate children's track. Children were split into two groups, children under five and school-aged from five to twelve years old. The infants and toddlers were welcomed into daycare provided by the staff at Lake Junaluska and HNC volunteers. They had toys, games, crafts, and cribs and pack-n-plays for when the children needed to sleep. The school-aged children had two separate activities on Saturday. They started their day with a session presented by Carrie Koenig from the Hemophilia Federation of America (HFA) entitled *My Story of Resilience*. The interactive session taught the children about the

The 2016 Family Retreat was a hit for everyone who was able to attend. The retreat was held from Friday, September 30 – Sunday, October 2 at Lake Junaluska Conference and Retreat Center. Attendees lucked out with perfect early fall weather full of sunshine

basics of bleeding disorders, how it affects them whether personally or as a sibling, and how they are connected to the community. They made books about themselves and conversations were started between the children where they discussed their bleeding disorder, how they get their infusions or medicine, and more. Following this presentation, the children were visited by Carlton Burke from the Carolina Naturalist and had the treat of seeing a variety of different animals including corn snakes, a possum, groundhog, and an owl. This interactive presentation had the kids talking for hours.

On Saturday morning the adults had the opportunity to learn more about HNC, the HOPE Program for parents with young children with a bleeding disorder, and the new Mentoring Program. Then they went "speed-dating"! Although many of the parents haven't "dated" in a long time, it was great fun. There were different stations with questions to answer about their own experiences with a child with a bleeding disorder. The point was to meet someone new, talk for a few minutes, and then rotate and meet someone else. It was so much fun that people wanted to continue beyond the allotted time. After a short break to visit the vendors, everyone came back together to hear the presentation, *Be S.M.A.R.T, Mastering Social Media, Advocacy, Relationships, and Treatment* given by Carrie Koenig from HFA. This session provided an overview of the relationships in the bleeding disorders community and how to be an educated consumer.



*The Teddy Bear Clinic: a fun way to teach kids about bleeding disorders*

Following lunch there was free time to enjoy the area, explore, rest, or an optional off-site trip to a local corn maze. This was a fun opportunity for families to have fun finding their way around the maze and enjoy a hayride. No one was too lost and it seemed like everyone found their way out of the maze with a smile! After dinner, everyone went to Game Night with a variety of board games. There were some serious games of Uno, Jenga, and Twister along with other fun games.

Sunday continued with the adults' and children's tracks. The Teddy Bear Clinic, facilitated by Judy Igelman, returned to the Family Retreat once again this year. Children had the opportunity to make Teddy Bears including filling them with "genes" to represent the bears bleeding disorders. With the help of the chaperones in the room, all the children were able to sew a bear and examine their patient in the clinic. Some children also brought a bear that they made at a prior Teddy Bear Clinic for a check-up. Following the Teddy Bear Clinic, the children took the trolley to the miniature golf course at Lake Junaluska. They had fun trying to putt their golf balls along the course. The infants and toddlers were again cared for by the daycare staff from Lake Junaluska.

*Continued next page*

**Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2016 HNC Family Retreat:**

**Retreat Sponsors**



## Family Retreat Takes to the Mountains

*continued from previous page*



*Thanks to Hemophilia Federation of America for their continued support!*

Federation of America. HNC would also like to thank all the Board Members who attended and all of the volunteers who helped with the children's programming.

In the end, everyone said goodbye to friends, old and new, and were talking about the next event are looking forward to attend. Until next time!

The adults heard a presentation entitled *Emotional Well-Being*, led by Cristie Vidal, Pfizer Hemophilia. The session provided an opportunity to learn about how mental health is an important part of one's care, both for those affected by a bleeding disorder and for their caregivers. Following a short break, they heard a presentation from Anita Smith, PNP at Wake Forest Baptist Hemophilia Treatment Center on *Emergency Preparedness*. The morning finished up with a wrap up of the weekend and the raffle.

HNC would like to thank the sponsors as the infamous weekend would not have been possible without their support. This year's Family Retreat sponsors included Aptevo, Bayer, Biogen, CSL Behring, Pfizer Hemophilia, Novo Nordisk, and Shire as well as the support of Hemophilia

## HNC Holiday Celebration at Castle McCulloch

December 3, 2016

Jamestown, NC



*Special guest speaker, Adriana Henderson*

It was a delightful day at Castle McCulloch as the HNC community gathered on December 3 to celebrate the holiday season. It was a beautiful day and a picturesque location to get together and honor the end of a great year while enjoying some wonderful food and friends!

The special guest speaker, Adriana Henderson, delivered a touching presentation that began with her inspiration to get involved and give back and how it led her to become Founder and President of S.T.A.R. Children Relief, the foundation that runs Camp Ray of Hope in Romania for children with bleeding disorders. HNC Staff reviewed some memorable events from 2016 and let everyone know what they might look forward to in 2017. The 2016 Volunteer of the Year Award recipient, Cheri Clark, could not be at the celebration in person as she was traveling to New York on behalf of HNC to attend a conference. Cheri has been an integral part of HNC's outreach and education to the North Carolina nursing community. With her help, women, whose bleeding disorders remain significantly underdiagnosed, have had more of a voice in this important sector of medical professionals.

After a delicious meal, members in attendance had an opportunity to mingle with one another, visit our sponsor booths and participate in craft activities. Then, with much anticipation, a very special guest made his arrival from the North Pole. Santa made every child's afternoon complete with a memorable picture and a holiday gift!

HNC would like to wish all members, whether at the celebration or not, a very special holiday season and a wonderful new year. Please plan on enjoying the festivities at next year's Holiday Celebration on December 2, 2017!



**Hemophilia of North Carolina gratefully acknowledges the pledge of support from the following companies for the 2016 HNC Holiday Celebration:**

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# HNC Casino Night

January 28, 2017  
Charlotte, NC

Join in the fun as HNC kicks-off the new year with the 10th Annual “Hearts for Hemophilia” Casino Night on January 28, 2017, at Big Chill in Charlotte! This is an elegant evening out with dinner, silent and live auctions, casino games, and live music. It’s sure to be an entertaining night for all who attend. 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 continuing to broaden its outreach in the Charlotte area by looking for new partnerships interested in sponsoring the upcoming Casino Night. To purchase tickets and learn more about sponsorship opportunities at this year’s Casino Night, please visit the HNC website or call the HNC office!



*Delicious Desserts at the Annual “Hearts for Hemophilia” Casino Night*



*Photo Booth Fun at Casino Night 2016*



*Celebrating after making the winning bid at Casino Night 2016’s Live Auction*

## ***Announcing the HNC Family Festival and 5K Walk for Bleeding Disorders!***

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By taking over the reigns of the two annual Walk fundraisers, HNC will be able to customize the events specifically to its members in North Carolina. The foundation of this organization starts with each individual member, growing in strength as a community. With this in mind, HNC Board of Directors and Staff feel ready to put that strength to good use as the entire community embarks on this new effort.

The 3rd Annual Charlotte HNC Family Festival and 5K Walk for Bleeding Disorders will take place on April 22 in Uptown Charlotte, starting at the corner of 3rd Street & MLK Blvd. It will be the largest gathering of HNC members and supporters in the Charlotte area in 2017. Bring your family, friends and 4-legged companions out to support the community and build awareness of all bleeding disorders. Registration for walkers and volunteers will be open soon!

If you can’t make it to Charlotte in April, or if you would like to participate in TWO Walks this year, the 10th Annual Raleigh HNC Family Festival and 5K Walk for Bleeding Disorders will be held on October 14 at Lake Crabtree County Park in Morrisville, NC. This 5K walk and festival in the park will be just as much fun as it’s always been. Come see for yourself how great it is to be part of this supportive community!

Whether you choose to walk in Charlotte, Raleigh, or both, plan to have a great time meeting people in the community while also participating in valuable fundraising and spreading awareness. Information will be available soon at [www.hemophilia-nc.org](http://www.hemophilia-nc.org) for both events. The site will feature information for walkers, sponsors, teams and volunteers. Printed information is also available through HNC by calling (800) 990-5557 or by emailing [walk@hemophilia-nc.org](mailto:walk@hemophilia-nc.org).

# World Hemophilia Day

April 17, 2017

World Federation of Hemophilia (WFH) will be announcing plans for the 2017 World Hemophilia Day (WHD) very soon! WHD takes place each year on April 17 as a day of awareness for hemophilia and all bleeding disorders. 2017 will be the 29th annual World Hemophilia Day celebration and the WFH is pleased to be taking the opportunity to bring more attention to the women and girls in our community who live with a bleeding disorder or have someone in their lives who do.

For more information, please visit: [www.wfh.org/en/whd](http://www.wfh.org/en/whd)

Last year, Hemophilia of North Carolina (HNC) partnered with Biogen to host a very special World Hemophilia Day (WHD) event. HNC was proud to participate once again in the awareness building effort, Lighting It Up Red, as the Wells Fargo Duke Energy Building in downtown Charlotte was lit up red in honor of World Hemophilia Day! The entire event included a dinner with presentations about the spirit of the day and an interactive activity demonstrating the clotting cascade. As the group gathered on the rooftop viewing area to watch the building light up, all were reminded of the reason for the day and the enormous discrepancy that exists in the level of care available to patients with a bleeding disorder around the world.

Stay tuned to find out what HNC has in store for WHD in 2017!



*Wells Fargo Duke Energy Building Lights Up Red for WHD 2016.*






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PHONE: 864-517-0804  
EMAIL: [Richard.Datres@Octapharma.com](mailto:Richard.Datres@Octapharma.com)

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## HNC: Reunión Anual en Marzo 2017!

HNC 44ta Reunión Anual de Miembros  
4 de Marzo, 2017  
Cary, NC

Hemofilia de Carolina del Norte (HNC) es anfitrión del programa educacional y de apoyo comunitario que cubre el estado de Carolina del Norte durante todo año, sin embargo, el evento que brinda la mejor oportunidad de apoyo es la Reunión Anual de HNC. Este es el evento más importante, ya que en un solo día cubre el rango completo de programas en que los miembros pueden participar durante todo el año. Personas de distintas edades, orígenes, con distintos tipos de trastornos hemorrágicos, y relacionados con la comunidad, tendrán la oportunidad de compartir con expertos en la materia, profesionales médicos de renombre, y colegas miembros de nuestra comunidad para conocer noticias importantes e información acerca del tema de desórdenes hemorrágicos.

Habrà algo de interés para cada uno de los miembros de HNC en la Reunión Anual! El tema a desarrollar este año será la importancia de la salud mental en casos de desórdenes hemorrágicos. Tim Ringgold, Terapeuta, certificado en Música, nos explicará como esta es una herramienta muy importante cuando un paciente padece de dolores y estrés. También estamos muy expectantes

con la intervención de la Dra. Alice Ma, Hematóloga en UNC-Chapel Hill, quien expondrá acerca de terapias combinadas en el tratamiento futuro de desórdenes hemorrágicos. Habrán también sesiones plenarias y sesiones individuales para: familias, hombres, mujeres, miembros latinos, y esposos/parejas.

La Reunión Anual es una oportunidad de enterarse que es lo que expertos y empleados de HNC, así como miembros de nuestra comunidad, tienen para compartir en el mundo de enfermedades hemorrágicas. Dispondremos de cuidados de niños de todas las edades, incluyendo actividades especiales para adolescentes. Finalmente, como miembro del HNC – Hemofilia de Carolina del Norte – usted tendrá la oportunidad de hacer impacto en el futuro de esta organización, votando por los nominados al Directorio, los que son presentados en esta Reunión Anual.

Invitaciones, así como información acerca de la Reunión Anual debieran llegar a sus hogares pronto, de lo contrario comuníquese con las oficinas de HNC para más información.

## Mesa Redonda de la Unión Latina

Siguiendo la Celebración de las Fiestas del 3 de Diciembre, miembros de la Unión Latina se reunieron en Tom's Place Restaurant, en High Point, para disfrutar de una tarde de conversación acompañada



de una comida deliciosa. Con la asistencia de Patricia Espinosa-Thomson, educadora bilingüe del cuidado de salud de la empresa Shire, tuvimos una discusión tipo mesa redonda, donde se plantearon que tipo de actividades, eventos y apoyo se necesitan en la comunidad Latina. Gracias, Shire, por hacer este evento posible.



## Actualización del Programa Unión Latina

HNC se encuentra en estos momentos planificando los eventos y actividades para 2017.

Este atento a su correo electrónico, o revise la página electrónica de HNC en busca de información acerca de eventos a medida que van siendo planeados. Hay algún tema que le gustaría plantear en el Programa Unión Latina? Si es así, por favor comuníquenos vía email a la oficina de HNC para hacer saber al personal como podríamos suplir sus necesidades.

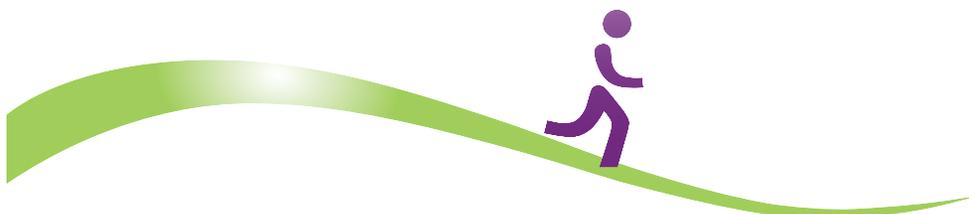
El personal de HNC se encuentra buscando voluntarios que ayuden a coordinar el Programa Unión Latina. Si usted es fluente en Español e Inglés y estaría interesado(a) en asistir en la traducción de artículos, invitaciones, emails, y hacer llamadas telefónicas, por favor póngase en contacto con Gillian Schultz, Gerente de Programa a [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org), o llame a la oficina de HNC, al número gratuito (800) 990-5557 para más información. NHC estima otro gran año de crecimiento de este programa!

## La Unión Latina en Morrisville

El 24 de Septiembre fue el momento ideal para reunirnos en las oficinas de HNC con miembros del Programa Unión Latina, mientras la temperatura alcanzaba los 90 grados. Cada uno en pensando que les traería el nuevo año escolar! Ese día se paso volando entre conversaciones acerca de los próximos eventos y el año venidero. Uno de los miembros jóvenes de la Unión dirigió una sesión donde se propusieron actividades que los miembros disfrutarían haciendo. Esto ocasionó más conversaciones en la reunión. El personal de HNC esta muy entusiasmado pensando en poder hacer realidad las ideas propuestas durante el 2017!



*La Unión Latina en Morrisville*



# Happy Birthday

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S17536 10/16

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## Educating Nurses about Bleeding Disorders

By: Cheri Clark

HNC proudly participated in the 2016 North Carolina Nurse's Association Annual Convention at the Benton Convention Center in Winston-Salem from September 28-29, 2016. SOAR members Cheri Clark and Maria Schnaith-Ivan helped to educate nurses of various disciplines on the signs and symptoms of bleeding disorders and the difficulty many women in particular have getting a diagnosis, especially when it comes to von Willebrand Disease (VWD). Many student nurses attended the conference and admitted while they learned about hemophilia in class, they could not recall much about VWD, the most common bleeding disorder, and were eager to gather more information. Despite the name, we stressed that Hemophilia of North Carolina is an organization dedicated to improving the quality of life of those affected by any bleeding disorder. The convention was attended by over 300 nurses, and some even remembered us from previous conferences. We hope that through our continued efforts, this type of outreach will make a difference in the lives of the undiagnosed.



Cheri Clark and Maria Schnaith-Ivan (left to right)  
representing HNC at the Convention

## SOAR Program Update

There has been discussion for some time about increasing the number of SOAR Program meetings, and HNC is excited to announce that there will be a variety of events scheduled throughout 2017! Be on the lookout for events across the state and near where you live. From educational sessions to social gatherings, there will surely be something that interests you. Check the HNC website, Facebook page, and email for information about events as they are scheduled. Additionally, HNC will continue to advocate at statewide nurse conferences to raise awareness among healthcare professionals and the general public.

SOAR is an HNC Program for women and girls with a bleeding disorder. 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 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](mailto:soar@hemophilia-nc.org) or call the HNC office, (800) 990-5557.

### 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](mailto:soar@hemophilia-nc.org).

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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

# Painting Afternoon Out

HNC hosted a SOAR Fundraiser on Saturday, December 10 at Wine & Design in Wake Forest. This afternoon of painting, food and drink, and fun benefitted the SOAR Program. One-third of the \$45 ticket price was donated to HNC to support the SOAR Program and its initiatives for 2017. SOAR is a program to support women and girls who have bleeding disorders. The afternoon was an opportunity for women members to gather together to meet one another and become familiar with others in the community. Thank you to our Gold Sponsors, CSL Behring and Octapharma, and Silver Sponsor, Shire, for helping to make this event possible.



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## HNC Members Representing North Carolina

The Annual Gettin' in the Game Junior National Championship (JNC), was hosted by CSL Behring and held in Phoenix, Arizona from September 30-October 2. HNC was excited to have two young members attend to represent HNC and share their experiences with you:

### **Jacob Hoernlein:**

Earlier this Fall, I had an amazing opportunity to go to CSL Behring's Junior National Championship (JNC). The JNC



*Jacob with Tim Grams, Getting in the Game Swimming Mentor*

was held from September 30 through October one in Phoenix, Arizona. This year was the fifteenth anniversary of the JNC and the first year they held my sport, swimming.

I participated in the JNC a few years back when it was in Dallas, Texas. They didn't have swimming then, so I entered

in Golf, one of the other two sports. I was very excited to hear that this year, CSL Behring decided to add swimming to the championship. I have been swimming since I was nine, in the summer going into fourth grade at my neighborhood pool. I am now thirteen and will be going into high school next year. I absolutely love swimming; it's an excellent sport for people with von Willebrand Disease and those with asthma.

Since I began swimming, my asthma has improved and my bleeds have gotten better. The JNC is a great event for kids all across the United States with bleeding disorders to meet one another and play their sports.

CSL's championship includes three sports: golf, baseball, and swimming. For each sport, a professional athlete comes to mentor the kids. The best part is, the athletes all grew up with bleeding disorders, so they know what it's like to be told they can't play a sport because it's too dangerous.

The swimming competition was very fun, even for its first year. The competition was spilt into three events: efficiency, speed, and breath control. The efficiency portion consisted of swimming with a tether holding the

swimmer back. The speed event was a simple 25-meter sprint. The breath control part required diving for rings, pennies, and bricks.

On the final night, CSL held a ceremony to award prizes to children from each event. In addition to awards for first, second, and third place in each event, there were also more unique awards, such as "Most Improved" or "Best Sportsmanship." All-in-all the JNC was a great event, and I hope to go back in the future. I recommend swimming to anyone because it can help control bleeds, like it did for me, and it is also great exercise. Most importantly, it's great fun! I would like to thank Hemophilia of North Carolina for nominating me to represent the chapter at this wonderful event.

### **Gavin Griffith:**

I really liked going to Arizona for the JNC because I got to do baseball. I made a new friend from Chicago and we got to play together. I got 2nd place for baseball and got a trophy. I liked getting to ride on the



*Gavin Representing North Carolina with his Baseball pennant*

plane also. I really liked the baseball coaches and had fun at the rap sessions with the athletes and other kids. I would really like to go back next year!

### **Russ & Tera Griffith (Parents of Gavin):**

The JNC experience was wonderful. It allowed Gavin to compete in a sport he loves with lots of kids with hemophilia just like him. He learned new skills and ways to protect and take care of his body so he can continue to play the game. He connected with lots of other boys. They provided a great experience for him and he loved representing North Carolina!

# Ryan White's Mom Speaks at Children's Museum about How to Stop Bullying

By: Megan Sanctorum

Published: October 24, 2016, WISH TV (Indianapolis, IN)

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Elementary and middle school students had a chance to learn about bullying and how to stop it on Monday.

The Children's Museum of Indianapolis is hosted a bullying prevention summit, with several special guests including Ryan White's mother and best friend. Fifth through 8th graders will have the chance learn what they can do to if they're being bullied or if they witness bullying.

Ryan White was just 13 years old in the 1980's when he was diagnosed with AIDS. White had hemophilia and contracted HIV through a tainted blood treatment. White died at just 18 years old at Riley Hospital for Children.

White's family has been very outspoken about the bullying they faced, as they dealt with his diagnosis and his battle to attend school.

He faced a lot of obstacles. He faced discrimination, he faced fear and panic and he saw what it was like when

kids were bullied and discriminated against," said Jeanne White-Ginder, White's mother.

She's hoping people can learn from her son and are inspired to do what they can to stop bullying.

"If you see somebody being made fun of, you know say something. Don't let that, don't let them.

Stop it. If everyone starts stopping it then it will stop, so I think kids need to make an effort not to be afraid and say, oh cut it out. Leave him alone," said White-Ginder.

Children also heard from a local bullying expert, Travis Brown. The speakers will offer children real solutions they can use if they're being bullied or if they witness bullying.

Monday's summit was not open to the public, but White-Ginder will give special presentations inside the Ryan White exhibit at the museum Tuesday and Wednesday at 12:30 p.m.



Jeanne White Ginder joined HNC in 2016 at the Annual Meeting in Greensboro



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If you want to read more about bullying or topics related living with a bleeding disorder please visit one of the following resources where you will find articles, downloadable resources and links to other sites on a variety of subjects:

<https://stepsforliving.hemophilia.org/>

<http://www.hemophiliafed.org/resource-library/toolkits/>



It's not too early to be making plans for summer camp in 2017! Applications are available now for the following summer camps! Please follow instructions listed for each camp to access applications.

## Victory Junction Camp in Randleman, NC Summer Application Deadline April 1

Victory Junction is a year-round camping facility that serves children, ages 6 to 16, with chronic medical conditions or serious illnesses, at no cost to their families. During the summer, Victory Junction offers disease-specific sessions for up to 128 children per session. During the fall, winter and spring, family weekends are offered to up to 32 families per weekend. For more information, go to [www.victoryjunction.org](http://www.victoryjunction.org) or call 336-498-9055.

### June 25-29, 2017 (Sunday-Thursday): Bleeding Disorders/Sickle Cell Week: Theme Heroes and Villains Week

Complete and online application using this link: <http://victoryjunction.org/application-cz/> Please remember that this is an application process and acceptance is not guaranteed due to the limited number of campers per session. Please call Victory Junction directly with questions at 336-498-9055.

## Camp Carefree in Stokesdale, NC Applications available now!

Since 1986, Camp Carefree has provided a free, one-week camping experience for kids ages 6-16 with bleeding disorders. Camp Carefree provides the needed freedom to play, learn, and have fun with others who encounter similar difficulties. The program also includes camps for well siblings who live with a chronically ill sibling (Sibling Camp) and for well children with a seriously ill or disabled parent (Kids Camp). For more information, go to [www.campcarefree.org](http://www.campcarefree.org), email [carefreedirectors@gmail.com](mailto:carefreedirectors@gmail.com) or call 336-427-0966.

June 18 – June 24, 2017: Siblings Camp

July 16 – July 22, 2017: Kids Camp

July 23 – July 29, 2017: Hemophilia, blood disorders, vWD & Turner's Camp

*All of these Summer Camps are absolutely necessary for future generations. Please consider supporting them with donations of money and/or time.*

## Camp Rainbow at Camp Don-Lee, Arapahoe, NC

Camp Rainbow is a week-long summer camping experience for children with cancer or hemophilia treated by the Brody School of Medicine at East Carolina University. Camp Rainbow is held at Camp Don-Lee, located on the Neuse River near Arapahoe, NC. Camping experience goals include: building self-confidence and independence, emotional and social development and well-being, and learning and sharing support with others who are living with a chronic blood disorder. For more information, please call the ECU Hemophilia Treatment Center at (252)744-4676 or visit their website at <http://www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm>.

Summer 2017: Camp Week TBD

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## 2016 Friends of HNC

*We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2016. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.*

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 Luke Waller    Arlette Whitaker

### Proceeds from HNC Spirit Night at Freddy's

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& Steakburgers

### Proceeds from PPD Jeans for a Cause Day

Kyle Davis for nominating HNC  
as a recipient Charity



*Thank You*



## Celebrating our 2016 Corporate Sponsors

*Cash and In-Kind contributions received from July 1, 2015 – June 30, 2016  
 We thank our sponsors for their continued support of the community.*

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- Partnership
- Empowerment

## HOPE Update

As 2016 comes to an end, HNC is reflecting on how the HOPE Program grew over the past year and looking forward to a new year. HNC was able to start a long awaited Mentoring

Program for parents who have a child with a bleeding disorder and are looking to talk with someone who's "been there, done that". The entire community is looking forward to seeing how it will grow in the future. In 2017, HNC will be hosting a variety of events around the state that are designed to meet the needs of your family, including educational dinners or luncheons, social events, activities for kids, gatherings at the Annual Meeting, Family Retreat, and more. HNC hopes that there will be something that interests you and you will be able to join us at a HOPE event in 2017.

In addition to the events that are offered through the HOPE Program, did you know that HNC can help you to get MedicAlert IDs? HNC recognizes the importance of a medical ID and believes that all individuals with bleeding disorders should have a medical ID in case of emergency, including young children. MedicAlert IDs come in many forms including necklaces, bracelets and even shoe-tags, and these items are made for all ages and sizes. If you do not have a MedicAlert ID for your child, contact the HNC office to find out more information about how you can get this service for free.

HOPE stands for Help, Opportunity, Partnership, Empowerment. The mission of HOPE is to improve the quality of life for families of the newly diagnosed through the age of twelve with bleeding disorders, so that they may HOPE to lead a fulfilling life. Together, with a

community of other parents, we can support each other. Open to any member of HNC, HOPE programs are geared specifically towards parents with young children. For more information about the HOPE Program, if you have ideas for events or are looking for an event near you, or would like more information about the Mentoring Program, please contact Gillian Schultz, HNC Program Manager at [gillian.schultz@hemophilia-nc.org](mailto: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.



HNC members who attended the Family Retreat made their mark on the HNC Family Tree

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Explore Bayer's additional leadership opportunities, Step Up Reach Out and AFFIRM, at [www.hemophialead.net](http://www.hemophialead.net).





# Blood Brotherhood Program Update

The Blood Brotherhood program here in North Carolina wrapped up 2016 and has closed out another year!

On November 19 the Blood Brotherhood Program hosted Jennifer Newman, UNC-CH Physical Therapist, for a unique opportunity to learn about the benefits of Kinesio Taping! The Winter Wrap Up took on an entire new meaning as guys got hands on training and learned proper techniques for taping of joints. Blood Brothers and their guests then enjoyed a wonderful dinner donated by Zoe's Kitchen in Morrisville. We plan to host the Kinesio Taping again into 2017 along with our other Blood Brotherhood programming. Be sure and stay tuned to the website for our announcement of 2017 Blood Brotherhood meeting dates and locations.



*Blood Brotherhood members enjoy a weekend at the beach at this year's Blood Brotherhood Retreat*



*Jennifer Newman, UNC-CH Physical Therapist, teaches members the benefits of Kinesio Tape*

On September 23-25 the Blood Brotherhood program hosted the Annual Beach Retreat. Another unique opportunity, 16 guys gathered in Kure Beach, NC and thoroughly enjoyed each others company at the beach house accommodations. Throughout the weekend several roundtable discussions led guys through private discussions on topics most important to them. The weekend truly allows guys to connect, share and create lasting friendships within the bleeding disorders community. Join the guys and enroll in the Blood Brotherhood program today!



*HNC Members practice using Kinesio Tape*

As always, thanks to Hemophilia Federation of America (HFA) for presenting this program and opportunity here in NC and many other states. In addition to local Blood Brotherhood events, HFA offers a newly revamped online forum and chat session just for Blood Brothers.

For more information on Blood Brotherhood nationally, including information on the private online forum for adult men with bleeding disorders, and the online Blood Brotherhood Chats, visit: [www.hemophiliafed.org/programs/blood-brotherhood](http://www.hemophiliafed.org/programs/blood-brotherhood)

For more information on Blood Brotherhood locally enroll through HFA online and stay tuned to [www.hemophilia-nc.org](http://www.hemophilia-nc.org) for the announcement of 2017 meetings!



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# Latin Union Program Update

HNC is currently planning the Latin Union Program events and activities for 2017. Look in your email or on the HNC webpage for information about events as they are being planned. Is there something that you would like to see from the Latin Union Program? Please email the HNC office to let the staff know how to help meet your needs.

HNC staff is currently looking for a volunteer to help coordinate the Latin Union Program. If you are fluent in both Spanish and English and would be interested in helping to translate articles, invitations, emails, and make phone calls, please contact Gillian Schultz, Program Manager at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or call the HNC office toll free at (800) 990-5557 for more information. HNC is looking forward to another great year and growing this program!

# Mentor Training Update

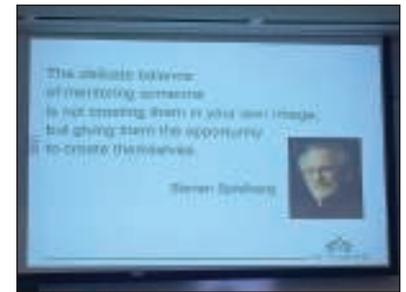
On September 17, the first group of mentors joined together in Charlotte for a Mentor Training. This training was one of many steps that our mentors have been taking in order to prepare to start the first official mentoring partnerships for the new Mentoring Program. The mentors have been selected after careful review of both the initial needs assessment that was sent out over the summer and a detailed application that they each completed. They are all parents or guardians of children with bleeding disorders and have been involved with HNC over many years.

The training course was entitled Mentoring 101 – The Fundamentals, and covered everything from defining a mentor, how to ask a question in order to fuel discussion, listening skills, understanding how body language and vocal tone affects how people interact, and the stages of the mentoring partnership. The training was led by Peter Popovich, a professor at UNC Charlotte.

Using a combination of his own materials and materials that HNC has developed to be used for the program, everyone was fully engaged in the interactive training. The attendees responded to questions, discussed their own experiences, and truly owned the learning from the course.



The Mentoring Program is a formal mentoring partnership expected to last one calendar year. The purpose of the program is to support parents of newly diagnosed and young children with a bleeding disorder so that they can feel more confident in raising their child. Monthly sessions will be held either over the phone or in person, depending on the location and availability of both the mentor and mentee. The first mentoring partnerships started this fall. If you are interested in learning more about the Mentoring Program, are looking for support and would like to learn about how to be a mentee, or are interested in becoming a mentor, please contact Gillian Schultz, HNC Program Manager at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or call the HNC office for information.



## Want to Know More

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## NCABBD: Watchdog for Issues Dear to Us All

The North Carolina Advisory Board for Bleeding Disorders (NCABBD) held its quarterly meeting on November 4, 2016, at the HNC office.

The NCABBD is an assemblage of consumers, Hemophilia Treatment Center staff and HNC staff that gathers on a quarterly basis to review matters relevant to North Carolina's bleeding disorders community. The group discusses items past, present, and future, that could affect the lives of HNC community members including politics, money, healthcare, family, lifestyles, opportunities, employment, and more.

For those who may not know, this board is an offshoot of a mandate some years ago from the Maternal and Child Health Bureau (MCHB), to keep open the lines of communication between our community and our care providers. The Advisory Board exchanges important information to help carry out the respective missions of its members.

After enjoying lunch, the group began review and discussion of various agenda items including reports from NCABBD members. These reports included topics related to:

- Advocacy, election results, possible changes to the Medicaid program and how that will impact 340B and specialty pharmacy companies, and continued support of HR3742.

- HNC programming, the HNC mentoring program, changes to the HNC Walk program, and grants from Hemophilia Alliance to provide hurricane related financial assistance the NC community.

- Information and impressions of the 2016 NHF and WFH Meetings.

- Updates from the HTC staff that were present at the meeting.

- MCHB initiatives in HTC quality improvement as well as improving access to care.

- The ATHN/CDC surveillance project update.

- 340B program updates.

The next meeting of the NCABBD will be held on February 10, 2017. The meetings are always lively, informative, and friendly.

The group is always looking for new and fresh perspectives. If you want to be part of the discussion, please consider joining this important initiative. Anyone interested in becoming a member of this advisory board, please contact the HNC Office at (800) 990-5557 or [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org).

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## Travel Scholarships for NHF Washington Days

March 8-10, 2017

Washington, DC

Advocating is one of the most important civic responsibilities we have, especially within the bleeding disorders community. We are only as strong as the people who join together to advocate for themselves and their loved ones. It's time to gather for the 2017 National Hemophilia Foundation (NHF) Washington Days event on March 8-10 in Washington, DC and we want you to join us.



**HNC has travel scholarships available to help offset the cost to members who want to make a lasting impact on the bleeding disorders community by joining us in DC!** Call the office if you have an interest in attending and we'll gladly walk you through the typical NHF Washington Days experience. Although this can seem overwhelming to some who may not have experience meeting with an elected official before, it is actually easy and you'll be paired with experienced HNC members who can help guide you! These officials are individuals who are elected in order to learn more about the issues that face the people in their area. You are the only one who can tell your story. Come share it!

*Zack Hargett, age 5, shared his Washington Days experience with more than 300 fellow advocates after last year's event. Find his story on HNC's YouTube channel:*

- Go to [www.youtube.com](http://www.youtube.com)
- Search "Hemophilia of North Carolina"
- Click on the first search result (you'll see our logo)
- Look for the video entitled "HNC's Youngest Advocate"
- Be inspired!



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A one-time, 1-month supply up to **20,000 IU** of Pfizer product delivered at no cost to your door.

### Community Resources

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**\*Terms and conditions apply; visit [PfizerFactorSavingsCard.com](http://PfizerFactorSavingsCard.com) for complete terms and conditions. For commercially insured patients only. Medicare/Medicaid beneficiaries are not eligible. The Card cannot be combined with any other rebate/coupon, free trial, or similar offer for the specified prescription. The card will be accepted only at participating pharmacies. This coupon is not health insurance.**

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

**†The Pfizer RxPathways Savings Card is not health insurance. For a complete list of participating pharmacies, visit [PfizerRxPathways.com](http://PfizerRxPathways.com) or call the toll-free number 1.877.744.5675.**

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

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



# Save One Life: 15 Years Helping Children with Hemophilia Around the World

*Reprinted with permission from Save One Life, Inc.*

Save One Life celebrated its 15th anniversary in New York City on September 29. More than 130 guests representing the US and world hemophilia community and industry gathered at the Manhattan Penthouse on Fifth Avenue for cocktails and dinner.



The guest of honor, Tony Fernández, famous Major League Baseball shortstop, was recognized for his attendance at hemophilia camp in the Dominican Republic for three years. Eric Hill, COO of Diplomat

Specialty Infusion, received the 2016 Sponsor of the Year award for co-organizing two fundraising climbs up Mt. Kilimanjaro for Save One Life, sponsoring 31 children and being the first to contribute to Save One Life's endowment fund. Barry Haarde, a cyclist with hemophilia and HIV, was recognized for completing his fifth cross-country Wheels for the World tour in September--he has now cycled over 20,000 miles and raised over \$220,000 for Save One Life. Usha Parthasarathy, mother of two children with hemophilia, received the 2016 Inspiration Award for helping to establish patient chapters for the Hemophilia Federation (India) as vice president of development, and for volunteering to help coordinate Save One Life's programs in India over the past seven years.

The highlight of the evening was a piano performance by 16-year-old Save One Life beneficiary Mihai Stefanescu of Romania, who, despite the challenge of bleeds in his fingers and wrists and limited resources to afford piano lessons, has won national and international piano competitions.

Major sponsors of the gala were FFF Enterprises/NuFactor, Octapharma and ASD Healthcare. Biogen and Novo Nordisk were gold sponsors; Alnylam, Bayer HealthCare, BioRx-a Diplomat Company and New England BioLabs were silver sponsors. CSL Behring and KYNE supported Founder's Tables.

Since 2001 Save One Life has provided direct financial assistance to some of the world's most vulnerable children: children who not only live in dire poverty, but who also face the daily challenge of a bleeding disorder—most notably, hemophilia. Hemophilia is a rare genetic disorder that prevents blood from forming an effective clot. Occurring in one out of 5,000 male births, untreated hemophilia can cause prolonged internal bleeding, painful joint deformities, crippling and even death.

Save One Life was founded by Laureen Kelley, mother of a child with hemophilia and author who wrote the world's first how-to guide on parenting children with hemophilia in the early 1990s. Her firm, LA Kelley Communications, publishes the oldest US newsletter serving the hemophilia community.

By 1996 Kelley was traveling to other countries to educate families on hemophilia—countries where many families had little knowledge of hemophilia, little access to proper medical

care or treatment, and lived in desperate conditions. These experiences prompted her to establish Save One Life to provide one-on-one, grassroots help to children and families in need.

Today Save One Life operates in 13 countries: Bangladesh, Cambodia, Dominican Republic, Ghana, Honduras, India, Kenya, Nepal, Nigeria, Pakistan, the Philippines, Romania and Uganda. It offers donors four ways to assist children: direct financial sponsorships, post-secondary scholarships, micro-enterprise grants and hemophilia camps. The transfer of funds is achieved through partnerships with over 40 patient organizations and local nonprofits that identify needy children and monitor their progress and use of funds. More than 1700 children and families have benefitted from Save One Life's activities.

One of Save One Life's scholarship recipients, Kannan K.S. of Kunnamkulam, India wrote: "I do not know how I can adequately convey my gratitude to Save One Life. You have changed my vision and my dreams. I thank you for myself and on behalf of my family for your kind and great support of my education." With Save One Life, children truly are helped...one at a time. To learn more visit: [www.SaveOneLife.net](http://www.SaveOneLife.net)



*HNC Member and Save One Life Sponsor, Reid Coleman, proudly standing with his beneficiary Mihai Stefanescu*



# Why I Advocate

By: George McCoy

According to Wikipedia, “Advocacy is a process of supporting and enabling people to:

- Express their views and concerns.
- Access information and services.
- Defend and promote their rights and responsibilities.
- Explore choices and options”

When I was born with severe hemophilia A in 1947, there was little treatment known. Doctors familiar with hemophilia were mostly in the big cities far away from my family.

I went to public school until 7th grade when the school administrators wanted me to go to a school for “crippled children.” Since there was basically no treatment available, I used crutches daily, and did miss class fairly often. My parents asked me to choose, and I wanted to stay in the mainstream (the choice was simple; I loved football, and the “crippled children” school didn’t have a team!). Fortunately, we knew the school vice principal through our church, and he reluctantly agreed to let me try one more year in the public system. All went well, and I graduated on time in 1965.

Today, federal and state laws guarantee the right of a child to a “free and appropriate public education”. Things changed over the years because someone cared enough to advocate for children like me to have equal access to public education.

After college, I tried to get a job. In those days (late 1960s, early 70s), employers could require you to tell them about any disability on the job application. I was turned away time and again. One man said, “I hired a hemophiliac once before and I’ll never make that mistake again!” Eventually, I went to work in a sheltered workshop (a special workplace only for people with severe disabilities; at that time, most employees made less than minimum wage). After several joint bleeds within a few months, I was fired for absenteeism (I faithfully called in each day to explain my absence). My boss even tried to get my job back, saying that I was highly productive when present. It was no good. I was too disabled to work even there! I started receiving a small check from Social Security Disability.

Today, federal and state laws prevent employers from asking about a disability on a job application. A person with a disability can’t be denied a chance to do the job if he or she is otherwise qualified. Things changed over the years because someone cared enough to advocate for people like me to have equal access to employment.

I moved to North Carolina in 1971 to get access to the quality medical care and research at UNC Chapel Hill, world famous for its knowledge of hemophilia. My health stabilized and I started looking for work again. Through my doctor I connected with the state vocational rehabilitation program (VR), earning a Master’s in Rehabilitation Counseling and becoming a VR counselor. That was not my first choice for a job, but I knew that to have insurance I had to work for a large employer with a group policy. Remember, at that time I could be denied health insurance due to

a pre-existing condition unless I was included in a large work place health plan. Also, my insurance could be cut off when I hit annual or lifetime caps. My vocational choices were very limited by hemophilia.

Today, federal law prevents insurance companies from denying coverage due to a pre-existing condition, or from setting annual or lifetime caps. Things changed over the years because someone cared enough to advocate for people like me to have equal access to insurance.

During the course of my life, I realized how very lucky I was to benefit from the work of others, whether in the areas of education, employment, or insurance. I began to notice how nice it was to have access to special parking, how I loved using ramps instead of stairs, having grab bars in public bathrooms, and other conveniences in moving around in our society. I realized that all of these changes - every single one - had only come about because someone cared enough to advocate.

So I advocate today because I owe it to tomorrow’s children and adults. My life is easier and more fun, even more powerful, because of the advocacy of many other people, almost all of them strangers I never knew. I feel strongly I should continue that trend, and use my skills, intelligence, and personality to make the world better. At first I was scared while advocating, especially with legislators and other government officials. But I outgrew the fear, and learned that most officials do want to make life better, and they are glad to hear what I have to say, even if they don’t always agree with my solutions.

Advocacy is a very broad activity. When you meet with your child’s teachers, you are advocating for your child’s education. You advocate when you teach about bleeding disorders to doctors, legislators, family, friends, church members, or anybody else. You may not realize it, but every day you live successfully with a bleeding disorder, you are working to make the world a better place. I encourage you to consider an even greater commitment to advocacy for people with bleeding disorders. We have come a long way since 1947, but we have farther to go, and we need to protect what we have gained from the forces that want to push us aside as not having enough value. We must never let those forces win the war for our future!

For more information on HNC and advocacy, check the HNC website to learn about our Advocacy Committee. We meet by conference call monthly. We train and support each other, set priorities, get input from experts, and create advocacy events and opportunities. We always welcome new members! If you would like to be included on the advocates email distribution list, please visit [www.hemophilia-nc.org/Advocacy/listserver/](http://www.hemophilia-nc.org/Advocacy/listserver/)



*George McCoy working with fellow HNC Members at Legislative Day in Raleigh 2015*



# Hemophilia of North Carolina 2017 Calendar of Events Highlights



<a href="#">January 28, 2017</a>	"Hearts for Hemophilia" Casino Night at Big Chill in Charlotte
<a href="#">February 17-20, 2017</a>	Victory Junction Inhibitor Family Camp
<a href="#">March 3, 2017</a>	HNC Volunteer/Special Guest Dinner – Cary, NC
<a href="#">March 4, 2017</a>	HNC Annual Meeting – Cary, NC
<a href="#">March 8-10, 2017</a>	NHF Washington Days – Washington, D.C
<a href="#">April 17, 2017</a>	World Hemophilia Day
<a href="#">April 22, 2017</a>	HNC Family Festival & 5K Walk for Bleeding Disorders – Charlotte
<a href="#">April 28-30, 2017</a>	NOW Conference – Phoenix, AZ
<a href="#">May 13, 2017</a>	HOPE & Blood Brotherhood paired event – Charlotte
<a href="#">July 1, 2017</a>	HOPE Steps for Living – HNC Office in Morrisville, NC
<a href="#">July 6-9, 2017</a>	HNC/HSC Teen Retreat – Camp Canaan in Rock Hill, SC
<a href="#">July 28-30, 2017</a>	HNC Men's Retreat – Trinity Center, Pine Knoll Shores, NC
<a href="#">July 2017</a>	HNC Adult Retreat
<a href="#">August 2017</a>	Family Fun Day – Tanglewood Park, Clemmons, NC
<a href="#">August 24-26, 2017</a>	NHF 69th Annual Meeting – Chicago, IL
<a href="#">October 14, 2017</a>	HNC Family Festival & 5K Walk for Bleeding Disorders – Morrisville
<a href="#">October 21, 2017</a>	HNC Yard Sale Fundraiser – HNC Office in Morrisville
<a href="#">December 2, 2017</a>	HNC Holiday Celebration



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## 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



