Hemophilia of North Carolina (HNC) is hosting its 45th Annual Meeting in Winston-Salem on March 10, 2018. While HNC provides a variety of educational sessions and programs across the state throughout the year, the Annual Meeting is the largest and most comprehensive one-day education event and support opportunity for HNC members. Members of all ages, backgrounds, bleeding disorders, 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 pertaining to bleeding disorders.

Past participants have benefited not only from the educational opportunities provided but also from the chance to meet and catch up with fellow members. Adults, kids, and teens will have the opportunity to expand their support system with others in the community. Childcare will be available for all ages, and there will be specialized tracks for children over 3 and for teens.

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

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Save The Date
Blood Brotherhood Winter Wrap-Up
January 13, 2018
Chapel Hill, NC

Hearts for Hemophilia Casino Night Fundraiser
January 27, 2018
Durham, NC

SOAR Fundraiser
February 2018
(Location TBD)

NHF Washington Days
March 7-9, 2018
Washington, DC

Annual Meeting
March 10, 2018
Winston-Salem, NC

HOPE Program at Charlotte Checkers
March 17, 2018
Charlotte, NC

Charlotte Family Festival & 5K Walk
April 14, 2018
Charlotte, NC

Blood Brotherhood Retreat
June 22-24, 2018
Pine Knoll Shores, NC

HNC/HSC Teen Retreat
July 5-8, 2018
Rock Hill, SC

Men's Retreat
July 20-22, 2018
Blowing Rock, 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
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

Hemophilia Treatment Centers
East Carolina University
Brody School of Medicine
600 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676
Fax: (252) 744-8199

St. Jude Affiliate Clinic at Novant Health
Emby Children's Hospital
Hematology & Oncology Clinic
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

UNC Treatment Center
UNC Hemophilia and Thrombosis Center
170 Manning Drive
3rd Floor Physicians Office Building
Campus Box 7016
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736
htcenter.med.unc.edu

Wake Forest University Baptist Medical Center
The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone: (336) 716-4324
Fax: (336) 716-3010

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.patientnotificationsystem.org

Patient Services Incorporated (PSI)
Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-800-366-7741
www.uneedpsi.org

World Federation of Hemophilia
1-800-520-6154
www.wfh.org

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

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

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

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

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.
A Year in Review and a Glimpse into 2018

Where did 2017 go?

We had an amazing year at Hemophilia of North Carolina (HNC). There were more than 40 events, ranging from educational retreats to one-day festivities like the Family Day Out. HNC staff worked hard to implement changes based on some of the feedback that we heard from the members, including spreading events across the state. We hosted events from the mountains to the ocean and many places in between. Childcare continued to be offered for all ages at major events including the Family Retreat and Annual Meeting. We heard from the membership that their email inboxes are full and many miss receiving invitations in the mail for HNC events. Because of this feedback, we are sending invitations in the mail for upcoming events, unless you choose to receive only email communications.

HNC had two very successful Family Festival & 5K Walk fundraisers, in Charlotte and Raleigh, together raising over $181,000. These funds are put directly back into the robust programming and services that HNC offers to the bleeding disorders community of NC, including: many events you’ve seen highlighted throughout the year; emergency financial assistance for community members; MedicAlert IDs offered free to anyone in NC with a bleeding disorder; gas cards provided to the Hemophilia Treatment Centers to help patients get to the clinic; grants to attend the national conferences; critical year-round advocacy efforts; donations to each of the three summer camps in NC that host special camp weeks for the bleeding disorders community; awareness-raising opportunities such as nursing conferences; and so much more.

We have also launched a Mentoring Program for families with children that have bleeding disorders. This unique program allows young families to connect with another family that has “been there, done that” and are trained as mentors. In addition, the program allows opportunity for all mentors and mentees to connect online and in-person. Mentoring events have ranged from informal meet-and-greets to educational sessions led by Hemophilia Treatment Center staff. We’re really proud to have developed this novel program to help empower families in our community so they can be knowledgeable advocates for themselves and their children.

Although we already do a lot, we always want to do more. We rely on the support of our members, volunteers, individual donors, corporate supporters, and the general public to continue HNC’s growth. Our biggest goal for 2018 is to implement more of what members have been asking for. One of the highlights you’ll hear more about this year is an overnight educational retreat for our Unión Latina Program, which will be presented completely in Spanish. This has been one of many goals that HNC staff has had for the past few years and we are so excited to be able to offer it in 2018. We’re also looking to increase our awareness and advocacy surrounding women and girls with bleeding disorders so look out for more information on this as we move into a new year.

Thanks to a very generous donor, HNC has been able to continue to build an endowment for future generations. We’re very proud of the support that HNC provides to the bleeding disorders community and this gift allows us to keep HNC a sustainable organization that can continue in its mission. Per our annual audit of our 2016-2017 fiscal year, we are happy to say that out of every dollar spent, 87 cents of that went directly back into programs and services.

There is a lot to be excited about in 2018. We look forward to continuing the programs and services we offer while seeing what other unmet or underserved needs we can fulfill. Thanks to everyone who helps us make this possible!

Sincerely,

Charlene, Gillian and Karyn

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Maha AbuShanab: HNC 2017 Volunteer of the Year

HNC is pleased to announce the 2017 Volunteer of the Year, Maha AbuShanab. She is originally from Qatar and came to the United States with her family almost 6 years ago. Living in the Morrisville area, one day she happened to come into the building where the HNC office is located looking for volunteer work, and we are so glad she did! Since that time she has been coming to the office regularly with a big smile, a hug, and usually something home-baked. Maha mostly helps prepare the mailings members receive from HNC throughout the year including the newsletter and event invitations. Nobody in her family is affected by bleeding disorders, so Maha is always asking questions trying to learn more about the community she is supporting. In fact, you may have met her at the 2017 Volunteer Appreciation Dinner and Annual Meeting last March in Cary, NC. She’s even recruited her daughter to start volunteering with HNC as well. HNC and its members are lucky to have Maha’s help and hope she will continue to support HNC and all the members in the years to come.

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Maha AbuShanab: HNC 2017 Volunteer of the Year
The 2017 Family Retreat was an informative weekend for all those in attendance. The Family Retreat is a three-day, two-night event with a focus on families who have children 12 and under with a bleeding disorder. Sessions and programs are geared towards parents and children in this age range. This year’s retreat was Friday, September 15 – Sunday, September 17 at the Sea Trail Resort and Conference Center in Sunset Beach, NC. Luckily, Hurricane Irma had already passed the area, and the weather for the weekend was beautiful.

After check-in in on Friday afternoon, families were welcomed to the retreat with some basic information about the weekend, sponsors introduced themselves, and everyone participated in a fun icebreaker to get to know one-another. Following the welcome session and dinner, the Kick-Off Festival was a blast. Activities included karaoke, face painting, some photo booth fun, sand art, and other carnival games.

On both Saturday and Sunday, children and adults participated in educational tracks with a variety of sessions. Children were broken into 3 groups; children under three were welcomed into a daycare room full of toys, books, mats, pack-n-plays, and more. The other children were broken into two groups, sometimes based on their ages and sometimes based on whether they have a bleeding disorder. Sessions for the kids included: Sibling Talk Show presented by the National Hemophilia Foundation (NHF) for unaffected siblings to discuss their brother’s or sister’s bleeding disorder in a safe environment and discover what makes them special; Smart Games to teach younger kids in a fun way about bleeding disorders; Advo, Advo, Advocacy: Let’s Help Others, You & Me presented by the Hemophilia Federation of America (HFA) where using the book The Lorax, children were able to identify what an advocate is and how they can be advocates in the community; and sessions about Sea Turtles, Marine Life, and Robotics.

Adults had a variety of sessions to address different opportunities and situations in the bleeding disorders community. They learned about Victory Junction, a camp in Randleman, NC for children with serious diseases and disabilities including bleeding disorders. The adults also learned about advocacy on the local and legislative levels through a presentation from HFA. The culminating activity of this program included sharing one’s “Elevator Speech” with one in particular that was funny and got to the point quickly about the situation being advocated for. Parents learned about how to be prepared for an emergency and what to do when visiting the emergency room. Breakout sessions included a session about von Willebrand Disease, the evolving landscape of hemophilia treatment, parenting, and a session in Spanish about overcoming challenges.

After the sessions on Saturday, members had free time to enjoy the pool, the beach, or just relax. For those who went to the beach, though the surf was a little choppy, kids and adults looked like they were having a great time in the water or searching the shore for seashells. On Saturday night after dinner, families attended Family Game Night. There was an interactive game of “Factor Feud” along with a variety of board games set up around the room for people to enjoy.

To finish off the Retreat on Sunday, HNC staff led a wrap-up session where attendees expressed their thoughts about the weekend and shared their ideas for the future,
followed by evaluations, the vendor visit raffle, and boxed lunches. At the end, everyone said their farewells to friends, old and new, until next time.

HNC would like to thank the sponsors and Program Partners who helped make the weekend possible. A big thank-you also goes out to the Board Members and volunteers who helped throughout the weekend.

HNC is currently working on the details for the 2018 Family Retreat, expected to be in October 2018. Stay tuned to the HNC website and Facebook page for details to come.

HNC Latin Union & Event: You Have the Right
September 24, 2017
Concord, NC

On Sunday, September 24, members of the Latin Union gathered at Dave & Buster’s in Concord, NC. In honor of Hispanic Heritage month, Yinell Nunez from Shire shared a slideshow presentation that had everyone guessing about different Latin America locations. Following the slideshow, Martha Boría from the Hemophilia Federation of America (HFA), presented You Have the Right, which explored patients’ rights when visiting medical professionals. Following the presentation and lunch, guests visited the arcade in Dave & Buster’s. Thank you to Shire for sponsoring HNC's Latin Union Program.

Mentoring Lunch ‘n Learn
October 7, 2017
Huntersville, NC

Participants of the Mentoring Program gathered on October 7 at the Carolina Raptor Center in Huntersville, NC for the final Mentoring Lunch ‘n Learn of 2017. With cloudy skies and the threat of rain, mentors, mentees, and their families met for a picnic lunch in the Festival Area. Dr. Paulette Bryant from the St. Jude Affiliate Clinic at Novant Health Hemby Children’s Hospital Hemophilia Treatment Center, presented information about the role of the Hemophilia Treatment Center (HTC). Gillian Schultz, HNC Program Manager, described the role of Hemophilia of North Carolina (HNC) and the different services and programs that HNC provides to the bleeding disorders community. Following the lunch, families walked across the path to the stage to learn about the different kind of raptors that live at the Carolina Raptor Center. The staff from the Carolina Raptor Center brought three raptors as part of the show, including a hawk, vulture, and owl. Needing to end just a few minutes early as the rain started to fall, families left to go home and dry out with a little more information about HNC, the HTC, and raptors.

The Mentoring Program is a newer initiative that pairs newly diagnosed families or those looking for additional peer and emotional support with a more experienced parent of a child with a bleeding disorder. For more information about the Mentoring Program, contact Gillian Schultz, Program Manager at gillian.scultz@hemophilia-nc.org or call her directly at 919-272-6000.
HNC Family Festival & Walk: A Huge Success!

October 14, 2017
Morrisville, NC

The 10th Annual Family Festival & 5K Walk for Bleeding Disorders in Morrisville was a huge success thanks to the dedicated members, volunteers, sponsors, donors, and contributors that gave their time and effort to this event. More than 650 people and a few dozen dogs came out to Lake Crabtree Park to attend HNC’s 10th annual event and show their support of this community. This is the largest gathering of the community each year, providing members an opportunity to meet and connect with fellow community members while supporting this important fundraiser. This year’s fundraising goal was exceeded by more than $15,000 with a total raised of $125,002! 100% of the money raised at this event is used to support HNC programs and services, and with successful fundraisers like this, HNC can continue to develop new programs and services that meet the growing and changing needs of the bleeding disorders community here in North Carolina.

It was a perfect autumn day with plenty of things to do and lots of great food to eat. In-kind donors generously provided food for members to enjoy throughout the day. With coffee donated by Starbucks, pastries from Peppers Market in Morrisville, and juice and granola bars from local Harris Teeter stores, walkers started the day well with a great breakfast. Freddy’s Frozen Custard & Steakburgers came out again this year to provide free sundaes. There was cotton candy sponsored by Accredo. Sheetz Morrisville donated sandwiches and Johnny’s Pizza in Cary provided some delicious pizza at-cost to finish the event with a wonderful lunch. Last but not least, the dogs were treated to doggie-bags donated by PetMania.

The Festival activities included some old favorites with some newer things to do as well. Jecoreiography started off the event by getting the crowd dancing while Performance DJ kept the excitement going with great music for all to enjoy. Some members of the community shared milestones and facts about bleeding disorders reminding the crowd of the importance of coming together in support of HNC. Sponsored activities were also on the list of fun things to do with the inflatable slide from Drugco Health, a caricature artist from Aptevo Therapeutics, and the photo booth from HPC. Once everyone had a chance to enjoy the Carolina Hurricanes Slap Shot Booth, get a photo with Juggle-Boy the stilt walker, or dance with Spiderman or Minion from Ricky

Continued next page
dd’s Party Entertainment, it was time to line up for the Walk.

As a special tribute to the 10th annual event in the Raleigh area, each participant was given a colored bracelet according to how many years they’ve attended. Walkers were called to the starting line with those who had participated in all 10 events lining up first with their purple bracelets down to the first year walkers finishing up the line-up with their red bracelets with several colors in between. Once the rainbow of bracelets was in place, the walk began.

Keeping up with tradition, HNC awarded the King, Queen, and Jr. Droplet awards to three important 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 Cowell, Ashley Lorfilo, and Hayden & Declan Otey, and thank you to Joyfully Sewn Endeavors for making the winners’ sashes.

UNC’s Tarhealers took back the coveted Hospital Cup. Their extraordinary efforts were not unnoticed as they placed sixth on the Top Teams list with $1,780 raised, but it was the Clot Hoppers who topped the team fundraising list of both industry and non-industry teams with an impressive fundraising total of $6,218. Grifols once again brought out the greatest number of supporters with 235 people in attendance. One lucky adult went home a 32 GB iPad donated by Cottrill’s Pharmacy, Inc. with other winners of adult raffle prizes taking home a coloring set, a BP gift card, and a Firebirds Wood Fired Grill gift card! Kids also had a chance to win raffle prizes. Three lucky winners took home an autographed photo of Jeff Skinner of the Carolina Hurricanes, a $20 Dave & Busters gift card, and a virtual reality 3D Headset.

It can’t be stated enough that this event couldn’t be possible without the support of every member, sponsor, volunteer, donor, and contributor. Each and every person who participated deserves a big thank you for a job well done!

HNC would like YOUR input. Please complete a short survey that won’t take more than 3 minutes. Your responses will help guide HNC as plans begin for the 2018 Festivals in Raleigh and Charlotte. To access the survey, type this link into your browser: www.surveymonkey.com/r/SCDBHBQ

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.

Save The Date
Join us for the 11th Annual HNC Family Festival & 5K Walk for Bleeding Disorders at Lake Crabtree Park in Morrisville on September 15, 2018!
SOAR Dinner
October 17, 2017
Charlotte, NC

SOAR members gather to learn about the effects of Hemophilia on women and girls

It was a packed house for the final SOAR Dinner of 2017! Women and teen girls from North & South Carolina attended the dinner, *Women with Hemophilia*, at Firebirds Wood Fired Grill in Charlotte. Sue Geraghty, RN, provided information about the genetics of hemophilia, what it means to be a carrier, and the effects of hemophilia on women and girls. The topic of carriers was a lively one, with many women learning the importance of finding out their factor level. It is now known that women are not always just carriers as was thought in the past, but many are now known to have mild hemophilia. Just like men with hemophilia, they learned that they should see their doctor about a treatment plan. Following an engaging presentation, delicious dinner and dessert, the women parted ways. Thank you to Novo Nordisk for sponsoring this educational dinner.

Blood Brotherhood Retreat
October 20-22, 2017
Blowing Rock, NC

Blood Brothers gather in Blowing Rock, NC, for the Annual Blood Brotherhood Retreat

The Blood Brotherhood group here in NC gathered in the mountains of North Carolina for the Annual Blood Brotherhood Retreat on October 20-22. The Blood Brotherhood program is for adult men living with a bleeding disorder and the retreat each year provides a unique opportunity to share, connect and create lasting friendships among this rare community. The Blowing Rock Conference Center was a perfect location providing picturesque mountain views, campfires, and great accommodations. Fifteen guys participated in roundtable discussions and got the chance to share their experiences, challenges, and successes.

Retreat participants had some time out and about on Saturday night to enjoy a trip on the Tweetsie Railroad for their annual Ghost Train and some scenic views of the Blue Ridge Parkway around sunset. The retreat is a great opportunity to learn from the experts: the men actually living everyday life with their rare bleeding disorder. From coping strategies, unbelievable E.R. trips, and new products coming out, the combined experience in the room stretches decades.

Hemophilia of North Carolina (HNC) is grateful to Hemophilia Federation of America for the continued support of the Blood Brotherhood Program and the program sponsors. Stay tuned to the HNC website for 2018 Blood Brotherhood educational meetings and consider joining the Blood Brotherhood program here in NC in the coming year. We kick off the year with our Winter Warm-up event on January 13 in Chapel Hill, NC. This event will feature Jennifer Newman, UNC-CH Physical Therapist, who will provide a presentation and some time in the arthritis pool for a water workout. Looking to beat the cold of winter? Hope to see you there!
HNC held its fourth annual Yard Sale fundraiser on October 21, and continued to spread awareness about the bleeding disorders community. Some regular customers stopped in as well as some new ones. As always, when HNC staff or members participate in community activities such as this, people who have a family member with a bleeding disorder or who have one themselves find out about HNC and discover a resource they hadn’t known existed before. In addition to providing outreach in the community, this is also an opportunity for members of the community to give back to HNC 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.
Hattitude for Hemophilia Fundraiser
November 4, 2017
Winston-Salem, NC

The 4th Annual Hattitude for Hemophilia Luncheon and Fashion Show took place on Saturday, November 4, in Winston-Salem. This fun and festive event is hosted by the Jaden’s Jewels and Jaden’s Gents team to support their HNC Family Festival team. Jaden’s Jewels and Jaden’s Gents is part of the outreach ministry of St. Stephens Missionary Baptist Church.

Church members transformed the hall for a beautiful banquet venue with each table host providing a unique décor for their table. The centerpiece for each table was a pound cake with each cake looking more delicious than the last, and of course all the men and women who attended wore a hat.

The program for the afternoon included a dance performance, skits, poetry, inspirational readings, and heartfelt speeches, but the emcee stole the show keeping the crowd of more than 150 engaged with her humor and spirit. During the event, Erica Cook, captain of the Jaden’s Jewels and Jaden’s Gents, and Pastor James Cook each took a turn at the podium to talk about the importance of giving back. In addition, Karyn Davis, HNC Manager of Operations, had an opportunity to address the attendees and personally thank the members of St. Stephens for naming Hemophilia of North Carolina as a recipient of their church’s outreach ministry. Since first participating in fundraising for HNC in 2012, Jaden’s Jewels and Jaden’s Gents has raised more than $28,000!

HNC sincerely thanks everyone who is involved in the success of Jaden’s Jewels and Jaden’s Gents team. Their dedication to giving can be summed up in a quote read by Gwen Stewart, team captain, where Martin Luther King Jr. used a parable to describe why it is important to help our neighbors. The powerful message she told to someone who is questioning, “How can I pay money I don’t really have to give. What will happen to my day? How will I pay my bills? The question is not what will happen to me, the question today is what will happen to people with bleeding disorders if I do not come out to support this event?”

The name and theme of the event, Hattitude for Hemophilia, has a significant meaning. Women, not limited to those impacted by a bleeding disorder, too often hang their head rather than holding it high. By wearing a hat, it helps to lift their head so that they remember to walk with confidence, as they should.
Educational Dinner: Protecting Yourself and Overcoming Obstacles
November 17, 2017
Cary, NC

HNC partnered with Bio-Matrix and CSL Behring for an educational event at Dave & Buster’s in Cary. The program was called Protecting Yourself and Overcoming Obstacles, presented by Officer John Vieke. John’s presentation was inspiring and filled with humor as he told his story about growing up with severe hemophilia while fulfilling his dream to become a law enforcement officer. Through dedication, hard work, and perseverance, Officer Vieke was able to make that dream a reality. What did it take? He worked hard to get his degree in Criminal Justice and graduate from the police academy with honors while also being committed to physical fitness, working with his hematologist, and adhering to his prescribed treatments. After the dinner and presentations, Dave & Busters game-cards were provided, so attendees could enjoy some of the fun and games available.

HNC encourages members to attend educational dinners in their area as a way to learn more about living with and navigating through life with a bleeding disorder and to meet others in the community. If there is a topic of interest you wish to be brought to your area of the state, please contact the HNC office.

On left, members enjoyed trying on the Officer Vieke’s SWAT gear

2017 Holiday Celebration
December 2, 2017
Greenville, NC

HNC held its annual Holiday Celebration in Greenville this year with more than 30 families from around the state. Taking place at the Hilton Greenville in Greenville, NC, families were greeted with a festive atmosphere, crafts for kids, a buffet lunch, balloon art by Laura Bower, raffle prizes and a very special visit from Santa.

A highlight of the afternoon was guest speaker, Lora Joyner, PT, physical therapist at the East Carolina University (ECU) Hemophilia Treatment Center, who shared her message about resilience with attendees. In addition, everyone had a chance to give back as the event included a collection of small items for Save One Life, and international non-profit that helps people in developing countries living with bleeding disorders.

Everyone left that day with a little something extra. Whether it was a child’s gift from Santa, a raffle prize, some inspiration from Lora Joyner, or a new acquaintance from the HNC community, this was an excellent opportunity to come together as a community to celebrate the end of a great year.

On left, members enjoyed trying on the Officer Vieke’s SWAT gear

Members young and old were excited to see Santa

Kids of all ages created fun holiday themed crafts

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

Gold Sponsors
- CVS specialty
- Diplomat

Silver Sponsors
- Cottrell’s
- Drugco Health
- Genentech
- Matrix Health Group
- Novo Nordisk
- Octapharma
- Shire

Supporting Sponsors
- Accredo Specialty Pharmacy
- CSL Behring
Actualización de Unión Latina

El programa Unión Latina de Hemofilia de Carolina del Norte sigue creciendo. El 2017 fue un gran año para el programa de Unión Latina. Con un total de seis eventos, los miembros tuvieron la oportunidad de aprender sobre trastornos de sangre y mantenerse saludable, con todas las presentaciones hechas en español.

Marzo trajo la primera sesión del año: una sesión durante la reunión anual. En esta sesión los asistentes tuvieron la oportunidad de aprender estrategias y también compartir su historia acerca de tener un trastorno de sangre. En mayo, los miembros aprendieron a mantenerse activos y saludables en el zoológico de Carolina del Norte. En junio, la Unión Latina aprendió sobre alimentación saludable y cómo cocinar comidas saludables y divertidas a la vez. El mes de septiembre trajo dos eventos, uno en Dave & Buster donde los miembros aprendieron sobre sus derechos cuando se trata de tener un traductor en citas médicas y la segunda en el Retiro Familiar donde se dieron clínicas de cómo lidiar con situaciones difíciles que pueden o ya han encontrado al padecer un trastorno de sangre. El evento final de la Unión Latina está programado para el 2 de diciembre, después de la Celebración Navideña.

La Unión Latina es un programa HNC para apoyar y educar a las personas latinas y a sus familias en Carolina del norte que se ven afectadas por trastornos de sangre. Los programas se proveen en español y es posible gracias a una beca de Shire. Para obtener más información, visite nuestra página de web: www.hemophilia-nc.org/latin-union

La Unión Latina en Dave & Buster’s

24 de septiembre 24, 2017
Concord, NC

El domingo 24 de septiembre, la Unión Latina se reunió en Dave & Buster’s en Concord, NC para aprender sobre los derechos cuando visitan el doctor. La presentación, Tú Tienes el Derecho, fue presentado por Martha Boria de la Hemophilia Federation of America (HFA). Después de la presentación, las personas pudieron disfrutar de las máquinas dea Dave & Buster’s. Lee la experiencia de una familia que atendió al evento.

por Lizbeth Munoz

Es un placer haber atendido a una reunión más de la unión latina con hemofilia, convivir y disfrutar del momento con gente maravillosa y que mi familia y yo aprendamos nuevas cosas, en esta reunión no solo conocimos nuevos lugares hermosos que hay en diferentes países latinoamériCos también algo muy importante que es el derecho que tenemos como pacientes de hospitales en pedir asistencia, los que no tenemos dominio del idioma inglés, que es un derecho tener a alguien que pueda interpretarnos para así saber con certeza lo que nos están diciendo y no solo en hospitales si no en toda institución federal donde necesitemos apoyo. De verdad un gran placer haber estado ahí y un agradecimiento para quien hacen posible cada reunión y que mejor cuando es en nuestro Idioma. Gracias Gillian
Stay empowered by the possibilities.

For people with hemophilia, Factor treatment temporarily replaces what’s missing.\textsuperscript{1} With a long track record of proven results, Factor treatment works with your body’s natural blood clotting process to form a proper clot.\textsuperscript{2,3}

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.

SOAR Program Update

We are excited about the growth of the SOAR Program in 2017. There were dinners focused on advocacy for women with bleeding disorders. HNC held a SOAR Educational Day event. We continue to exhibit at nurses’ conferences across NC to help healthcare providers learn about bleeding disorders in women so that they can more accurately diagnose a woman with a bleeding disorder. 2017 had something to offer many women across North Carolina. In 2018, we plan to grow what the SOAR Program offers to women and girls across the state. We will continue to educate and advocate for women to be properly diagnosed and treated. The first SOAR Dinner of 2018 is going to be in January, so keep your eyes on the HNC webpage, Facebook page, and your email about the next educational opportunity.

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

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

NOW: National Outreach von Willebrand

November 17-19, 2017
Phoenix, AZ

NOW is a national educational conference for individuals and families who are living with von Willebrand Disease (VWD). It is a forum to learn about new medical advances, to gain tools that can help you better manage VWD, and to share with others facing the same or similar challenges. Expert healthcare professionals are brought to the conference to address issues unique to VWD. With funding by a grant from CSL Behring, the Arizona Hemophilia Association is excited to organize this national conference focused specifically on von Willebrand Disease. Two HNC members were able to attend the conference this year. Following is some information about their experience in their own words. If you are interested in attending this event in the future be on the lookout for announcements from HNC. While HNC promotes this important event, all registrations for attendance and applications for travel assistance are handled directly by Arizona Hemophilia Association.

If you would like to be placed on the mailing list for updates on future conferences, email Arizona Hemophilia Association at NOW@arizonahemophilia.org or follow their NOW Facebook Page for updates.

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.
A whirlwind - that’s one way to describe what happens in less than 48 hours with a full schedule centered around learning about, and living with, von Willebrand Disease. The bulk of the informational & educational sessions occurred Saturday. Dr. Montgomery’s address on VWD was definitely full of information, some of which I knew, and some of which was new to me. All was useful. I was thoroughly mesmerized by Dr. Sinha’s discussion of the Science of Stress (and how to manage it) - detailed studies of how stress affects our bodies & especially our brains, sleep, digestion, nutrition, etc. Much of what I personally have experienced with several chronic illnesses was clarified. I found challenging methods for dealing with these stressors, and hope to make use of them in the future. A second session from him dealt with learning how to sleep better; here again, this is a subject I need to learn for myself. On Sunday, Jerry Erwin, a certified trainer & leadership coach, a dynamic speaker, challenged us to discover WHO we are, and what charges our batteries - also learning what drains them, so as to avoid those drains.

One of the other significant benefits from attending this meeting was the opportunity to network with other people with VWD. While I’m still in the “senior” category, I wasn’t the absolute oldest person in the room with the disorder! Oh, yes, one of the interesting facts gleaned from the medical experts is the discovery that VWD levels tend to increase as patients age. They don’t yet know what that means, perhaps that we need more, though that wouldn’t explain how or why our bodies learn to make more with age. It’s just one more piece of the puzzle.

The final bonus for me personally was my ability to take advantage of the trip, and add a couple of days up front for personal time (paid for by me, of course), and the opportunity to spend the better part of one day on the south rim of the Grand Canyon.

By: Cheri Clark

Once again, I had the pleasure of attending the NOW Conference in lovely Phoenix, Arizona in November. This is a very beneficial conference for anybody with VWD, as the opportunities for education and networking are immense. It is designed for those of us in the bleeding disorders community with von Willebrand Disease to come together, connect, learn, collaborate and share information. Numerous breakout sessions include topics related to VWD and also others such as stress, nutrition, exercise, and advocacy. Several experts in the field, including Dr. Robert Montgomery, were available to answer questions throughout the weekend.

My personal favorite speaker was Dr. Ronesh Sinha. He is very passionate about his work, and I learn something new each time I hear him talk. He did a session called Sleep Better Workshop this year and spoke about how insomnia is linked to so many diseases including diabetes, depression, and Alzheimer’s Disease. We were also taught key ways to increase our sleep quality and duration.

I am always ready and willing to share my personal journey with VWD with others and listen as they share their stories with me. We spent time over the weekend doing just that. My hope is that through these connections we learn from each other and share information to help ensure that women are being diagnosed more easily and at a younger age than I was. The NOW conference offers something for every man, woman, and child in attendance, and I would highly suggest attending if you have von Willebrand Disease and have never been.
The Annual Gettin’ in the Game (GIG) Junior National Championship (JNC), hosted by CSL Behring was held in Phoenix, Arizona from November 3-5. HNC was excited to have three young members attend to represent North Carolina and share their experiences with you:

On left, athletes from around the country gather for the final banquet

By: Addison Dowdy
Hello, my name is Addison Dowdy and this past November I was invited to attend the CSL Behring Junior National Championship in Phoenix, Arizona. I participated in the swim portion of the championship. The weekend was full of wonderful activities including a welcome reception, swim clinics, a swim meet and a grand finale banquet. The GIG athletes helped me improve my swimming skills and were great to talk to about my bleeding disorder and how they, themselves overcame the obstacles due to bleeding disorders to become better athletes. I am so thankful for this opportunity. I made lots of friends from all over the country. Thank you CSL Behring and the GIG Athletes!

Addison Dowdy, Age 10, is a North Carolina Athlete who participated in swimming.

By: Riley Blair
This past November I went to the Getting in the Game Junior National Championships. It was a great the competition that was very fun and the other kids made it a blast. I especially enjoyed the trainers who helped us improve our skills. Overall it was a great time!

Riley Blair, Age 15, is a North Carolina Athlete who participated in swimming.

By: Donna Blair-Painter
We are excited to tell you what a wonderful time we had last month at the CSL Behring “Getting’ in the Game” Junior National Championships. It was amazing to meet so many families from the bleeding disorders community. We were inspired by the “Getting’ in the Game” athletes and their stories. As a parent, it was great to be able to share backgrounds, experiences, and advice with other parents. It was priceless to see my son, Riley, and all the kids making new friends and supporting one another during practice and competition. The event culminated at the Saturday night awards dinner. The sheer positive spirit and unbridled excitement these kids displayed that night as well as all weekend long was phenomenal! We were truly privileged to be able to attend this remarkable event and have taken home many lasting friendships and memories.

Donna is a parent of North Carolina JNC Athlete, Riley, who participated in swimming.

By: Zackary Hargett
I played baseball and I met a boy named Aaron in Arizona for kids with bleeding disorders. I got to go to the San Francisco Giants spring training baseball stadium. The Mets pitcher got to pitch me 10 baseballs. We got to eat the amazing food served to me. I had a really good time with my friends that have hemophilia.

Zackary Hargett, Age 9, is a North Carolina Athlete who participated in baseball.
HNC Casino Night Heads Back to the Triangle
January 27, 2018
Durham, NC

Join in the fun at HNC’s 11th Annual “Hearts for Hemophilia” Casino Night Fundraiser to be held on January 27, 2018, in the Grand Ballroom at the Durham Convention Center. This is an elegant evening out with dinner, silent and live auctions, casino games, raffle prizes, and live music. Whether you try your luck at blackjack, roulette, craps, and Texas hold ‘em poker, or just enjoy the music and the atmosphere in the heart of Downtown Durham’s City Center District, HNC’s Casino Night is 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 continually looking for new opportunities to broaden its outreach by looking for new partnerships with businesses 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 give us a call!

Leadership Begins With U

Introducing Leadership U, a paid summer internship* for full-time college students whose lives have been touched by hemophilia. Work alongside leaders at Bayer, meet with advocacy groups in New York City and Washington, DC, and start shaping the future of the hemophilia community.

*Includes lodging and transportation costs

Now Accepting 2018 Summer Internship Applications at
LivingWithHemophilia.com/Lead2018

Explore Bayer’s additional leadership opportunities, Step Up Reach Out and AFFIRM, at www.LivingWithHemophilia.com/Lead
Save the Date: 2018 Charlotte Family Festival & 5K Walk

April 14, 2018
Charlotte, NC

Save the Date for the 4th Annual HNC Family Festival & 5K Walk for Bleeding Disorders on April 14, 2018, in Charlotte! The fundraising goal has increased to $55,000 and we need your help to reach it! Being held in uptown Charlotte in front of BB&T Ballpark and Romare Bearden Park, prepare for a morning of fun, entertainment, and of course a 5K Walk around Bank of America Stadium and BB&T Ballpark. Bring your family, friends, coworkers, and 4-legged friends as you raise money and awareness in support of HNC.

As a part of our largest fundraiser, the Family Festival & 5K Walk benefits the bleeding disorders community here in North Carolina to provide critical programs and services. You can help us to reach the goal by registering for the event when the website goes live, promoting your walk team with your friends, family, church, coworkers, and neighbors. Other ways to help reach the goal include holding your own fundraising event at home or work or set up a walk team with your coworkers. Have your children set up a lemonade stand and have them donate some of the proceeds to your walk team, ask your boss about having a jeans day at work, or contact local restaurants about holding a fundraising night. Of course, the more people who participate, the more money that is raised. So, invite everyone that you know to join you. Keep your eyes on the HNC website and Facebook page to find out when you can begin to register for the 2018 Family Festival & 5K Walk in Charlotte.
World Hemophilia Day: Sharing Knowledge Makes Us Stronger
April 17, 2018

April 17, 2018, will mark the 28th World Hemophilia Day! The World Federation of Hemophilia will focus on the importance of sharing knowledge. The bleeding disorders community is filled with the first-hand knowledge and experience needed to help increase awareness, as well as to improve access to care and treatment. Find important educational resources and hear from top experts at elearning.wfh.org.

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 2018!

HOPE Program Update

As HNC is wrapping up 2017, the HOPE Program for families has had another great year. With educational dinners across the state on topics from unaffected siblings, physical therapy, back to school, and maintaining healthy joints, there have been a variety of topics discussed. For the first time, the HOPE Program partnered with HNC’s Blood Brotherhood Program which provided parents, children, and affected men with bleeding disorders time to learn from each other. HOPE members had the opportunity to visit the NASCAR Hall of Fame in Charlotte and go bowling at Buffaloe Lanes in Cary. Another successful Family Retreat was held in September in Sunset Beach. The HNC Mentoring Program is continuing to grow as the first round of mentees have finished their partnerships and new partnerships are forming.

HNC is looking forward to 2018. We realize that we may not have held an event in a location where you were able to attend. With a large state to cover, limited resources, and a small staff, our ability to hold events is limited. We are exploring different ways that we can reach YOU in 2018. If you have ideas on locations or topics that you would be interested in, please let us know.

For more information about the HOPE Program or if you would like to learn more about the Mentoring Program, please contact Gillian Schultz, HNC Program Manager, at gillian.schultz@hemophilia-nc.org, by calling Gillian directly at 919-272-6000, or by calling the HNC office at 800-990-5557. You may also check the HNC webpage, Facebook page, and your email for updates on upcoming programs and events.

Latin Union Program Update

Hemophilia of North Carolina’s Latin Union Program continues to thrive. 2017 was a great year for the Latin Union Program. With a total of six events, all of which were provided in Spanish, members had the opportunity to learn about bleeding disorders and staying healthy. March brought the first session of the year; a breakout session at the Annual Meeting where attendees had the opportunity to learn strategies to share their story about having a bleeding disorder and staying healthy. In May, members learned how to stay active and healthy at the NC Zoo. In June, the Latin Union learned about healthy eating while participating in a hands-on activity as they cooked some fun and healthy meals. September brought two events, one at Dave & Buster’s where members learned about their rights when it comes to having a translator at medical appointments, and the second at the Family Retreat where guests learned about dealing with challenging situations that they may or already have encountered with a bleeding disorder. The final Latin Union event was on December 2, following the Holiday Celebration.

The Latin Union is an HNC Program designed to support and educate Latino individuals and families in North Carolina who are affected by bleeding disorders. Programming is provided in Spanish and is possible thanks to a grant from Shire. For more information, visit the HNC website.
NCABBD: Your Voice Matters, Members Needed

We need your voice! The North Carolina Advisory Board for Bleeding Disorders (NCABBD) gathers a panel of consumers, Hemophilia Treatment Center staff, and HNC staff on a quarterly basis to review matters relevant to North Carolina’s bleeding disorders community. The group discusses topics impacting the lives of HNC community members including politics, money, healthcare, family, lifestyles, opportunities, employment, and more. Participation on this advisory board is not only a great way to stay up to date on topics related to bleeding disorders but also an opportunity to lend your voice on important matters that impact the entire community.

NCABBD held its quarterly meeting on October 6, 2017, at the HNC office. After enjoying lunch, the group began review and discussion of various agenda items including reports from NCABBD members. These reports included topics related to:

- Need to bring more consumers from various subsets of the community to the NCABBD meetings
- Advocacy committee’s monitoring of issues at the state and national level
- The Carolinas HealthCare/UNC Health Care systems partnership

- HNC upcoming events and programming, HNC Board and Committee development, HNC/HTC Collaboration, HNC’s Family Festivals, and more
- Updates from the HTC and 340B program representatives that were present at the meeting
- The ATHN/CDC surveillance project and Maternal and Child Health Bureau updates

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.

The next meeting of the NCABBD will be held on January 5, 2018, at the HNC office in Morrisville. The meetings are always lively, informative, and friendly.

Anyone interested in becoming a member of this advisory board, please contact the HNC Office at 800-990-5557 or info@hemophilia-nc.org.
Peyton’s Make-A-Wish Came True
October 31, 2017
Charlotte, NC

Peyton Holland, one of HNC’s members, has been through a lot over the past few years. In addition to severe hemophilia and VWD, Peyton also has a clotting disorder, making treatment especially difficult. He was granted a wish from the Make-A-Wish Foundation. Put yourself in a 9-year-old’s shoes – what would you ask for?

Peyton’s wish was to throw a Halloween party at Levine Children’s Hospital in Charlotte, where he spent a lot of his time this past year. He said that just because they are stuck in the hospital doesn’t mean they shouldn’t get to have a party and enjoy some fun. Make-A-Wish Foundation, in partnership with other businesses like FedEx and St. Paul’s Lutheran Church, made it happen.

The afternoon was filled with costumes, candy, toys, and laughter. Peyton was the star of the show as he danced alongside his idols, Jecoreiography (who some may remember from the HNC Walks). There was a room filled with games and snacks. Costumes were donated to anyone who needed one. Even the service dogs were dressed up!

At the end of the day, Peyton got his wish. “All the kids are super sad right now in the hospital but now it’s changed from a sad day to a happy day,” Peyton said. HNC is truly lucky to have such a compassionate young person as one of the future leaders for the bleeding disorders community.

Victory Junction Camp in Randleman, NC
Application Deadline for Summer Sessions - MARCH 1st.
For additional information about 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 24-28, 2018  Bleeding and Gastrointestinal Disorders
(Sunday- Thursday)

July 1-4, 2018  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 17-23, 2018  Siblings Camp – well children with a chronically ill sibling

July 15-21, 2018  Kids Camp – well children with a chronically ill parent

July 22-28, 2018  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

It’s not too soon to start planning for Summer Camps! Please follow instructions listed for each camp to access applications.
A very special gathering of family, friends, colleagues, blood brothers and fellow HNC members took place to celebrate the life of George McCoy who passed away in August after fighting pancreatic cancer. Through laughter, and even a few tears, the stories of George’s life were shared with over 100 guests who came out to commemorate a life well lived.

There were stories of George’s childhood family, his move to North Carolina to be nearer to cutting-edge research for people with hemophilia, his work with the NC Department of Health and Human Services (DHHS), being a founding member of HNC and his dedication to the organization the past 40 years, and his love of music, art, & travel. Speakers were George’s husband, Phil Poovey, and friends from throughout George’s life. HNC Executive Director, Charlene Cowell, former HNC Executive Director, Susan Cowell, former DHHS co-worker, Lenore Guidoni, UNC physician and researcher, Dr. Alice Ma, HNC co-founder, Kathy Register, and HNC board member & blood brother, Matt Igelman, all shared stories about George that were both touching and inspirational.

Whether you called him a husband, brother, mentor, blood brother, colleague, or friend, you probably learned a little more about the man who dedicated his life to making this world a better place.

HNC is proud to announce that George requested donations be made in his name to Hemophilia of NC that will become a scholarship as a memorial to his commitment to education and advocacy.

Contributors to the George D. McCoy Scholarship Fund

William & Jane Brown  
Charles & Carol Bryan  
Violet & Ronald Burt  
Thomas & Stephanie Campbell  
Maryneil & James Catlin  
Charles & Susan Cowell  
Charlene Cowell  
Kenneth Culbreth  
Sandra Daughtry  
Karyn & Kyle Davis  
Judith Harrell  
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Larry Holland  
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Sam Hull  
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Leah C. Lockett  
Frances McMillan  
Stephen & Leigh Noblitt  
Barbara Parramore  
Marvin Pipkin & Mike Dunn  
Phil Poovey  
Charles & Katherine Register  
Theresa Rosenberg  
Kathleen Schari  
Harvey E. Wahls
2017 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2017. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

General Donations
Mark & Jo Anne Buckley
Irene Cowell
Mr. & Mrs. W. Allen Heafner
Mr. James Jarratt
Carrie Regler
Curtis Sellers

In Honor of Charles Register
Jean & Barrie Hurwitz

In Honor of Donald Barnes
Janet H. Blue

Special Endowment Gift
Jack & Margaret Prim

HNC Holiday Celebration
Tyronna Hooker
Mike Hoernlein
Steve Humes
Matt Igelman
Amy Shair-Miller
Luke Waller

Celebrating our 2017 Corporate Sponsors
Cash and In-Kind contributions received from January 2017 - December 2017
We thank our sponsors for their continued support of the community.

Diamond ($15,000 or More)
- Bayer HealthCare
- Bioverativ
- CSL Behring
- CVS Specialty
- Drugco Health
- Grifols
- Hemophilia Federation of America, Inc.
- Novo Nordisk
- Pfizer Hemophilia
- Shire

Platinum ($10,000 - $14,999)
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- Diplomat Specialty Infusion Group
- Genentech
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- Community Health Charities
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- Hemophilia Alliance Foundation
- Johnny’s Pizza
- National Hemophilia Foundation
- Novant Health
- Option Care
- Sheetz
- Specialty Therapeutic Care
- The Alliance Pharmacy

Bronze ($500 - $999)
- United Way
- Goodyear Tire & Rubber Co.
- St. Stephen Missionary Baptist Church

Friends of the Community (Up to $499)
- AmazonSmile Foundation
- Appalachian State Athletics
- Autobell
- Battleship North Carolina
- Blockade Runner Beach Resort
- BlueGreen Vacations
- Dan Campbell, Artist
- Carolina Panthers
- Charlotte Ballet
- Charlotte Checkers
- Chuy’s Tex Mex
- Dental Oasis
- Discovery Place
- Embassy Suites
- Freddy’s Frozen Custard & Steakburgers
- Grace Park Animal Hospital
- Grand Rentals
- Greensboro Children’s Museum
- Guitar Center
- Harris Teeter
- Hemostasis & Thrombosis Research Society Inc.
- Inland Point Plantation Stables
- Inner Peaks Climbing Center
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- Joyfully Sewn Endeavors
- Lenovo Employees Care
- Little Gems by Kari
- Manco & Manco Pizza
- Marbles Kids Museum
- Modern Salon & Spa
- Moore Printing
- NC State Athletics
- NC Zoo
- Network for Good
- North Carolina Symphony
- OHSOPriddly
- Otterbox
- Pampered Chef
- Paraclete XP
- Peppers Market
- Pepsi
- PetMania
- Performance DJ, Kevin McVerry
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- Red Hat
- Richard Petty Driving Experience
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- Salem Electric Co.
- Sam’s Club
- SciWorks
- Sea Trail Resort
- Something Different Restaurant
- Starbucks
- Total Wine & More
- Triangle Community Foundation, Inc.
- Tribeca Tavern
- UNC Tarheels Athletics
- Uncle Bill’s Pancake House
- US National Whitewater Center
- Walt Disney World
- WCNC
- Will’s Dogg n It Deli
- Wells Fargo
- Yadkin Bank

Special Contributions for Scholarships ($8,000)
- Diplomat Specialty Infusion Group

Thank You
Pfizer Sanford Celebrates National Manufacturing Day
October 4, 2017
Sanford, NC

Pfizer unveiled expansion plans for its Sanford manufacturing site to include a new Gene Therapy facility with a celebration called “View into the Future” in observance of National Manufacturing Day on October 4, 2017. Pfizer plans to invest $100 million dollars in its expansion of the Sanford manufacturing facility, as part of its commitment to deliver potentially transformative gene therapies to people suffering from genetic diseases, including hemophilia. Invited guests included North Carolina Governor Roy Cooper, educational and industry partners, Pfizer leaders, and patient advocacy groups including Hemophilia of North Carolina (HNC).

Charlene Cowell, HNC Executive Director, gave a moving presentation at the event about how meaningful it is to have innovative gene therapy being developed right here in North Carolina where so many groundbreaking achievements in hemophilia research have already taken place. Through research at UNC Chapel Hill alone, North Carolina can boast about housing the first colony of hemophilia dogs in the 1940s, development of the PTT test in the 1950s, and being chosen as the first site for the clinical trial of a recombinant factor in the 1990s where HNC’s founding member, George McCoy, received the first dose.

HNC was honored to participate in this celebration of North Carolina’s impact on innovation and research.

DEDICATION AND PERSONAL SUPPORT

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

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

Working for you in the Mid Atlantic—From the Virginia shoreline to the Delaware River

Name: Linda Pollhammer
Home state: Maryland
Fun fact: Funny, feel-good movies are my favorite. Nothing sad—I love to laugh!
Family traditions: Music is a HUGE part of my family’s life. There’s always music playing in the house.

What motivates you as a liaison? As a nurse educator, I’ve had experience with hemophilia since 2010. Working with the community and helping them with their challenges is where I’m in my element.

“GETTING INVOLVED IN THIS COMMUNITY IS REWARDING BECAUSE OUR COMMUNITY IS OUTSTANDING.”
—Linda Pollhammer

To get in touch with Linda, call Pfizer Hemophilia Connect 1.844.989.HEMO(4366)
ON THE NATIONAL & LEGISLATIVE FRONT

HFA Symposium 2018
April 26-29, 2018
Cleveland, OH

The Hemophilia Federation of America (HFA) will hold its Annual Symposium in Cleveland, OH, from April 26-29, 2018. 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 scholarships to first time attendees who need financial assistance. Registration is now open at www.hemophiliafed.org.

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.

The Hemophilia Memorial
By: Charlene Cowell

It was an indescribable feeling when I walked up to the newly constructed Hemophilia Memorial, tucked away within the AIDS Grove in San Francisco, CA. Years in the making, there is now a special memorial to honor those in this community who lived through the AIDS crisis and the lives lost too soon. That was a dark time, a time of confusion and sadness. The AIDS Grove, and now the Hemophilia Memorial, reminds people of the tragedy and the impact it had. But more than anything, I think it reminds us of the brave, strong individuals and families who fought to correct the problem so that future generations do not have to endure the same pain. It is inspiring in that sense.

They’ve started to engrave the names of those who have been submitted for the Hemophilia Memorial’s circle. As I moved my fingers from the inner circle out, I passed many familiar names. People who I knew and people who I had never had the opportunity to meet. I reflected on the good times I had with some of the people listed here and on the what they’ve taught me including my mentor, George McCoy.

I sat there for a long time, admiring the beauty of the memorial and the solace that it brought to my heart, knowing that there is a physical place we can now go in order to honor our community. It’s a place for the general public to educate themselves on the role the hemophilia community had in the AIDS crisis and a place for our community to bring future generations to learn about their history. I hope that you all will have an opportunity to visit one day and pay respect to those who lived through this time. You can find more pictures from my trip on the HNC Facebook page (www.facebook.com/hemophiliaNC).

Inscribed at the Hemophilia Memorial: “Our hearts bled from love, pain, and suffering. From fear and isolation. We battled on the fringe. Warriors fighting stigma, ignorance, and inaction. We came together as families, communities, and fierce friends to build community and protect one another. We felt betrayal. We learned resilience. We promise this will never happen again.”
ON THE NATIONAL & LEGISLATIVE FRONT

The Next Influential Advocate for Bleeding Disorders is You. Yes, You!

By: Crystal Hoernlein

On October, 24 men and women from the bleeding disorders community converged on Washington, DC, to join forces and participate in Hemophilia Federation of America’s (HFA) first “TEACH” Immersion (Together we Empower, Advocate, and Collaborate for Hemophilia and other Bleeding Disorders).

HFA’s TEACH Immersion ran like a well-oiled machine producing better advocates through training on effective advocacy techniques, legislative processes, and current policies affecting the community.

The participants immersed in the program went to Capitol Hill to meet with Senator Schumer’s staff and learn about effective methods for influencing our legislators. In a nutshell, data drives the policy agenda. Our personal stories are compelling. But when they are backed by data, they can nudge policy makers to act.

HFA’s Project CALLS program helps the bleeding disorders community by collecting the data and identifying trends that can provide the case for change. The information collected through CALLS is used on the national, state, and local levels with legislators, regulators, and private payers.

Get to know your representatives and senators! Regardless of party affiliation, they are in office to serve you. Invite them to HNC events, visit with them during legislative days, and build those relationships.

Social media is a quick and direct way to connect patients with policy makers, but many congressional staffers say that few social media posts grab their Member’s attention. So how do you make an impact?

Tips for getting social:

1. Comment on a legislator’s original post (this attracts more attention than comments and posts left on their social media pages).

2. Individuals carry more weight than organizations, so share your input. Ten to thirty similar comments are more likely to catch a legislator’s attention. Your voice can make an impact!

3. Using media in your comments and posts is great! Take pictures with staffers to post after meetings. Everyone in a group should create their own individual post.

4. Keep your hashtags simple. Avoid using bleeding disorders lingo like “factor,” “HTCs,” etc., and be sure to tag your representative or senator!

Advocacy isn’t just about policy. It begins in your home, with your family. It can start at your daycare or elementary school. There are so many ways to become involved with improving the quality of life of those with bleeding disorders. Just jump in! Immerse yourself!

HFA’s TEACH Immersion was a huge success. If you’re interested in learning more, check out HFA’s advocacy page. It’s a great resource.

www.hemophiliafed.org/advocacy/

Scholarships Available

Members of the bleeding disorders community are fortunate to have many scholarship opportunities available to them. In addition to the Hemophilia of North Carolina 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.kelley.com/scholarships.html

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

Crystal Hoernlein, HNC member, at TEACH

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Hemophilia of North Carolina 2018 Calendar of Events Highlights

January 13, 2018  Blood Brotherhood Winter Wrap-Up – Chapel Hill, NC
January 27, 2018  Casino Night – Durham, NC
February 2018  SOAR Fundraiser – TBD
March 10, 2018  HNC Annual Meeting – Winston-Salem, NC
March 17, 2018  HOPE Program at Charlotte Checkers – Charlotte, NC
April 14, 2018  Charlotte Family Festival & 5K Walk – Charlotte, NC
June 22-24, 2018  Blood Brotherhood Retreat – Pine Knoll Shores, NC
July 5-8, 2018  HNC/HSC Teen Retreat – Rock Hill, SC
July 20-22, 2018  Men’s Retreat
August 19, 2018  Family Day Out – Clemmons, NC
September 15, 2018  Raleigh Family Festival & 5K Walk – Morrisville, NC
December 1, 2018  Holiday Celebration – Concord, NC

Talk to your doctor to see if ADYNOVATE may be right for you.

For more information, please visit www.ADYNOVATE.com
Thank you to our special friends and generous sponsors for making 2017 a wonderful year for HNC!