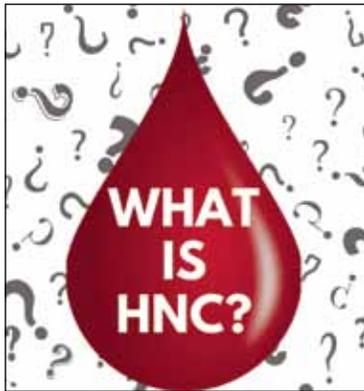


# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2019

## What is HNC?



Whether you've been a long-time member of Hemophilia of North Carolina (HNC) or just recently became one, there may be things you don't know about the programs and services HNC provides to people around the state who are affected by bleeding disorders.

### Educational and Social Events Throughout the State

Every year, HNC holds more than 50 events around the state. These events include educational dinners on a variety of topics scheduled throughout the year, one-day events and overnight retreats that incorporate both educational and social support that benefits members, and two Family Festival & Walk

fundraisers. These events are designed to bring the bleeding disorders community from around North Carolina together to learn from the experts and from one another, while also giving HNC members the opportunity to develop their own network of resources to support themselves and the treatment of their bleeding disorder.

*Continued page 7*

## We Want to Hear from YOU! HNC Needs Assessment

You can help frame the future of Hemophilia of North Carolina!

As a community organization, Hemophilia of North Carolina (HNC) makes every effort to offer the bleeding disorders community meaningful programs and services. Over the past several years, there have been many swift and impactful changes to this community, including novel therapies that have changed the lives of some people with hemophilia, as well as changes to the kinds of programs and services that HNC is able to bring to you. This everchanging landscape is only expected to continue in the future. For many people with bleeding disorders, the life that they can expect to lead has dramatically improved from even a decade ago! However, the need for support has not changed. Even as the demographics of the community evolves, to include women with bleeding disorders, rarer bleeding disorders, and an aging population, HNC is here for all of you – to advocate, educate, and deliver supportive programs and services.

In the coming weeks, you will be receiving an email about a Needs Assessment. The input that you provide in this survey

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## Save The Date

**Travel Raffle Drawing**  
January 9, 2020  
Morrisville, NC

**Charlotte Festival Information & Team Captain Meeting**  
January 11, 2020  
Matthews, NC

**HNC Event with Levine & St. Jude HTCs**  
February 1, 2020  
Charlotte, NC

**HNC Event with Wake Forest Univ. HTC**  
February 22, 2020  
Winston-Salem, NC

**NHF Washington Days**  
February 26-28, 2020  
Washington, DC

**Annual Meeting**  
March 7-8, 2020  
Raleigh, NC

**HNC Event with UNC Chapel Hill HTC**  
March 21, 2020  
Chapel Hill, NC

**HNC Event with East Carolina Univ. HTC**  
March 28, 2020  
Greenville, NC

**World Hemophilia Day**  
April 17, 2020

**HNC Family Festival & Walk**  
April 18, 2020  
Charlotte, NC

**HFA Symposium**  
April 23-26, 2020  
Baltimore, MD



*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

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

## About This Publication

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

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

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

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

## Hemophilia Treatment Centers

### East Carolina University Brody School of Medicine

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

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

1021 Morehead Medical Drive, Suite 50100  
Charlotte, NC 28204  
Phone: (980) 442-4363

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

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

### UNC Hemophilia and Thrombosis Center

170 Manning Drive  
3rd Floor Physicians Office Building  
Campus Box 7016  
Chapel Hill, NC 27599-7016  
Phone: (919) 966-4736

### Wake Forest University School of Medicine

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

## Additional Medical Resources

### Duke University Medical Center Hemostasis and Thrombosis Center

DUMC Box 3422  
Durham, NC 27710  
Phone: (919) 684-5350

### Mission Hospital Pediatric Hematology/ Oncology Program

21 Hospital Drive  
Asheville, NC 28801  
Phone: (828) 213-9770

## 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

**LA Kelley Communications**  
1-978-352-7657  
www.kelleycom.com

### PAN Foundation

Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.  
1-866-316-7263  
panfoundation.org

### Patient Notification System

The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.  
1-888-UPDATE-U  
www.patientnotificationsystem.org

### Patient Services Incorporated (PSI)

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

### World Federation of Hemophilia

1-800-520-6154  
www.wfh.org

## VISION STATEMENT

Hemophilia of North Carolina's vision is for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations.

*Hemophilia of North Carolina is a chapter of the National Hemophilia Foundation, a member organization of the Hemophilia Federation of America, a member agency of Community Health Charities, a member of the NC Center for Nonprofits.*



## FROM HNC'S BOARD OF DIRECTORS

# Calling for Nominations to the 2019-2020 Board of Directors

By: Amy Shair Miller, Governance Committee

Hemophilia of North Carolina (HNC) is looking forward to welcoming new board members in 2020. The Board of Directors has been working hard for all of our members and we want your help to find new people to be elected to the Board of Directors. Board positions will be elected by the membership at the Annual Meeting. Names of candidates for nomination are requested to be submitted no later than **January 7, 2020**.

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

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

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

**CALL TO ACTION:** If you know of anyone that might be a good candidate for nomination to our board of directors, please email [nominations@hemophilia-nc.org](mailto:nominations@hemophilia-nc.org) or contact Charlene Cowell, HNC Executive Director, by phone at (800) 990-5557 or email at [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org).

## FROM HNC'S BOARD OF DIRECTORS

# Key HNC Personnel Participate in Board Leadership Training Program



*Charlene and Steve at the ESC Board Bootcamp*

In the summer of 2019, Hemophilia of North Carolina (HNC) was offered the opportunity to apply to attend the Board Leadership Boot Camp program sponsored by the Executive Service Corps of the Triangle (ESC). ESC provides affordable consulting and capacity building services to Triangle

nonprofits to help them achieve their missions.

The Board Leadership Boot Camp program is a series of sessions designed to inform nonprofit board leadership about best practices in critical areas that will impact board effectiveness. The program has a value of \$3,000, but is made possible by Executive Service Corps of the Triangle and Triangle Community Foundation for only \$50 per nonprofit.

The series is aimed at board chairs, board members, and senior staff who are key to board leadership, and the goals are to:

- Strengthen the performance of nonprofit boards of directors,
- Increase understanding of roles, and
- Promote better board leadership through increased knowledge.

HNC's application to participate was successful, and the organization committed to sending three people to six two-hour sessions held from September 10 through December 10 at The Frontier building in Research Triangle Park. Representing HNC were Charlene Cowell, Executive Director; Steven Humes, Board President; and Phil Poovey, Board Vice President.

The sessions addressed these six different topics: the dimensions of nonprofit leadership; characteristics of an effective board; how to run better board meetings; nonprofit fundraising; nonprofit financial leadership; and nonprofit sustainability. Excellent printed educational materials were provided to buttress the learning experience. Leading the sessions were ESC consultants, who are typically retired or semi-retired executives who volunteer their time as a way to give back to the community. All have a lifetime of valuable experience and are trained to understand the unique requirements of the nonprofit sector.

Charlene, Steven, and Phil were unanimous in their praise of the program's value, and all felt that what they learned will help improve the effectiveness of HNC's board and staff performance over time. HNC is grateful that such a high-caliber program is available here in the Triangle at a remarkably low cost.

# Joseppe Vilches: HNC 2019 Volunteer of the Year



*Joseppe and his family at NHF Washington Days*

Hemophilia of North Carolina (HNC) is pleased to share the news of this year's Volunteer of the Year, Joseppe Vilchis. Since becoming an active member of HNC, Joseppe has made a significant, positive impact on several of HNC's programs. From the first time Joseppe and his brother, Jean, attended one of the HNC Legislative Days, it was clear that they would be dedicated advocates for people with bleeding disorders in both Raleigh and Washington, DC. Additionally, as a bilingual community member, Joseppe has taken the time to assist HNC staff with important initiatives within the Unión Latina Program. By providing translations, interpreting when necessary, making phone calls to Spanish speaking members, and even leading a session at the 2019 Unión Latina Retreat, Joseppe has taken the steps to use his time and talents to benefit other HNC members and become a leader in the community.

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



*Joseppe and his brother, Jean, meet with Representative Price at NHFWashington Days*

**New**  
**HEAD-TO-HEAD**  
Pharmacokinetic (PK) Study Data

See half-life, clearance and other PK data from the crossover study comparing **Jivi**<sup>®</sup> and **Eloctate**<sup>®</sup>

Visit **PKStudies.com** to find out more.

► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

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LET'S GO

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# Register for the 2020 Charlotte Family Festival & Walk on January 1st!

April 18, 2020  
Charlotte, NC

January 1 is not only a day to celebrate the new year. It's also the opening day of registration for the 6th Annual HNC Family Festival & Walk for Bleeding Disorders scheduled to take place on April 18, 2020, in Uptown Charlotte!

The Charlotte Family Festival is returning to the same location in 2020, on Mint Street between BB&T Ballpark and Romare Bearden Park. The atmosphere of Uptown Charlotte will be buzzing with excitement as members and supporters of HNC gather for a morning of fun, entertainment, and of course a walk around Bank of America Stadium and BB&T Ballpark.

Start your team or register as an individual. Bring your family, friends, coworkers, and 4-legged friends out to Charlotte the morning of April 18 to support HNC's programs and services. The bigger the crowd, the more funds can be raised to support HNC's programs and services, so help get the word out in your local communities.

**Attention Team Captains:** Register your team early so HNC can send you information about the Information & Team Captain Meeting on January 11 in Matthews.

HNC will be using a new fundraising management platform, Qgiv, for the 2020 Family Festivals' registration and fundraising. Be on the lookout for emails and updates to the Festival webpage of the HNC website for instructions about registration, creating a team, and more!



## HNC Collaboration With Your HTC

Hemophilia Treatment Centers (HTCs) provide comprehensive care for people with bleeding disorders. In North Carolina, patients are lucky enough to have five HTCs around the state to choose from. In 2019, Hemophilia of North Carolina (HNC) staff met with all of the HTCs to review HNC's programs and services. HNC and the HTCs have always had a collaborative relationship, but were looking for ways to enhance these partnerships in the future. At the meetings, everyone agreed that it would be a great idea to have a collaborative program for members with just HNC and the HTC.

In 2019, HNC applied for a grant through the Hemophilia Alliance that would allow them to partner with the HTCs in North Carolina to provide programs that will feature speakers from the respective treatment centers. Save the date for the following events.

**February 1** – Charlotte, with both the HTC of Levine Cancer Institute & Levine Children's Hospital and St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital

**February 22** – Winston-Salem, with Wake Forest University School of Medicine

**March 21** – Chapel-Hill, with the Harold R. Roberts Hemophilia Diagnostic Treatment Center at UNC Chapel-Hill

**March 28** – Greenville, with East Carolina University Brody School of Medicine

Please mark your calendars. More details about the events will be available on the HNC website in the coming weeks.

# HNC Annual Meeting – Now a Two-Day Event!

March 7-8, 2020

Raleigh, NC

Hemophilia of North Carolina (HNC) is excited for some big changes to the 2020 Annual Meeting. HNC will host its 47th Annual Meeting March 7-8, 2020, at the Hilton Raleigh North Hills. For the first time ever, the Annual Meeting will be a two-day event, with hotel accommodations being provided on Saturday night for HNC members and their immediate households. This year’s theme is *Advocacy: How it Can Help YOU!* There will be sessions for everyone in the bleeding disorders community. Attendees will have time to network, learn, find support, and hear from expert speakers about topics significant to living with a bleeding disorder.

As in past years, there will be a First-Time Attendees Session where HNC members who have never been to an Annual Meeting can learn about what to expect throughout the weekend. Other sessions will include breakouts for men, women, parents, partners/spouses, Unión Latina, rare bleeding disorders, and von Willebrand disease. There will be childcare for all ages, including a specialized teen track. The HNC Annual Meeting is also the time for members to let their voice be heard and work together to drive the future of HNC. The annual Business Meeting includes an overview of HNC’s financial status, programming and services, and importantly, this is when YOU vote for HNC’s Board of Director nominees.

The HNC Annual Meeting, including hotel accommodations on Saturday night, lunch on Saturday and Sunday, dinner on Saturday, breakfast on Sunday, snack breaks, and childcare, is provided free to HNC members thanks to the generous support of event sponsors and donors.

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

## March is Bleeding Disorders Awareness Month



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

Get a proclamation from your city or town and help Hemophilia of North Carolina (HNC) declare March as Bleeding Disorders Awareness Month in as many towns across North Carolina as possible! Call your local mayor’s office to determine how proclamations are issued in your city. Contact information can usually be found on your town’s website. Issuing a proclamation may take a few months, so in order to have the proclamation completed by March, members should begin the process as soon as possible. If you’re unsure how to complete the proclamation forms, members can reach out to the HNC office for assistance. If your proclamation application is accepted, be sure to express your thanks to the city representative who issued it to you.

Hemophilia Federation of America (HFA) will begin a fact-a-day social media campaign on Facebook and Twitter which members can share on their own profiles. Members can also update profile images with HFA’s support ribbon or use downloadable images for their cover photos or profile pictures. These and other ideas for spreading awareness throughout

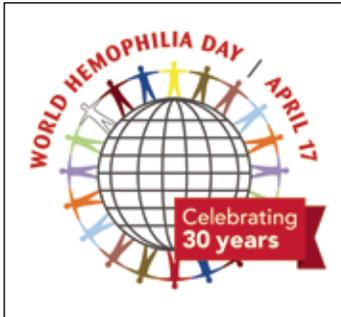
the month of March can be found on the HFA website in the Bleeding Disorders Awareness Month section.

National Hemophilia Foundation (NHF) will once again be spearheading the Red Tie Campaign raising funds and awareness to find better treatments and cures for bleeding disorders. Visit [redticampaign.org](http://redticampaign.org) more information on how to participate in the 2020 campaign.

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

# World Hemophilia Day

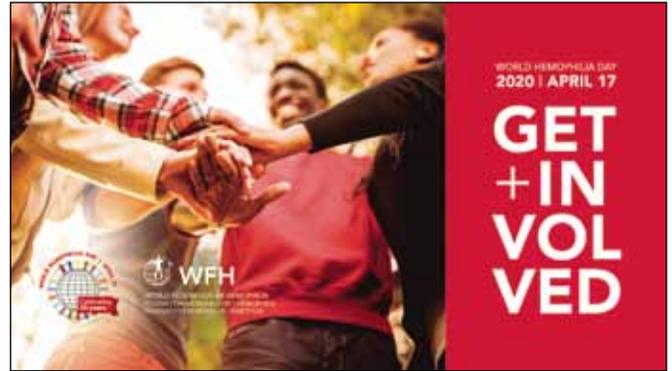
April 17, 2020



April 17 will mark the 30th World Hemophilia Day! The theme of the 30th anniversary is “Get+involved” as a call to action for everyone and to drive forward the World Federation of Hemophilia’s mission of “treatment for all”. Help to raise awareness of inherited bleeding disorders and make access to adequate care possible everywhere around the world.

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

Hemophilia of North Carolina (HNC) will recognize World Hemophilia Day on April 17 with buildings lit red in North Carolina and on April 18 at the Charlotte Family Festival & Walk.



## What is HNC?

*continued from page 1*



### Gas Cards for HTC Appointments

HNC provides gas cards to all NC Hemophilia Treatment Centers (HTC) to help patients with travel to and from their appointments. HNC members who need this kind of assistance can speak to their HTC directly to learn more about how this benefit is administered at their center.

### MedicAlert IDs

HNC provides a MedicAlert ID and first year MedicAlert Membership to any individual who is diagnosed with a bleeding disorder and is also a resident of NC or a patient at a NC HTC. If you do not have a MedicAlert ID, please contact the HNC office to request one.



### Emergency Financial Assistance

This Program provides funds to eligible individuals and families who need assistance with expenses incurred in the care, treatment, or prevention of a bleeding disorder, and/or basic living expense emergencies. If you need financial support and a member of your household is diagnosed with a bleeding disorder, are a resident of NC or a patient at a NC HTC, please contact the HNC office to complete an application for financial assistance.

### Programs for Different Groups in the Community

HNC maintains programs to support the diverse demographic needs of the community. Read more about HNC’s Blood Brotherhood, HOPE, SOAR, and Unión Latina programs on pages 11 and 20 of this newsletter.

### More

In addition, HNC has two scholarship programs for students seeking higher education, provides grants for NC families affected by a bleeding disorder who wish to travel to national conferences, and has an active Advocacy Committee. If you want to learn more about any of the programs or services mentioned in this article, either visit HNC’s website [hemophilia-nc.org](http://hemophilia-nc.org) or call the HNC office.

# Hattitude: A Community Attitude of Giving

September 21, 2019

Winston-Salem, NC

By: Karyn Davis, HNC Manager of Operations



The Cook Family, Gwen Stewart, and Karyn Davis enjoying the Hattitude Event

I was once again honored to attend and participate in the St. Stephen Missionary Baptist Church Hattitude event, a day to support and raise funds for the Family Festival and Walk team *Jaden's Jewels and Jaden's Gents* and for Hemophilia of North Carolina (HNC).

This year's celebration was a tribute to African heritage. With the cuisine and attire of the day focused on African culture, looking across the room was a spectrum of colors and patterns that delighted the eyes, while the abundance of food on hand dazzled the taste buds. As a fundraiser, members and friends of the St. Stephen's family can sponsor a table or purchase individual tickets. Then, each table-host organizes food items for those at their table to enjoy and table decorations to create a room filled with spectacular African artistry. The celebration itself was a mixture of prayer, poetry, dance, and singing that honored the African heritage.



Finally, and an important part of the day, there were plenty of hats and headwraps in keeping with the spirit and history of the Hattitude event. Hats represent strength when facing a challenging situation because when a person wears a hat, they keep their head held high no matter what obstacle is in front of them.

"Team Jaden" was inspired by one young member of the church, Jaden, who as a baby was diagnosed with von Willebrand disease. Since that time, other church members have been diagnosed with bleeding disorders. The team continues in support of those church members and all people who are affected by bleeding disorders. Since beginning their walk team several years ago, "Team Jaden" continues to be the largest non-industry team at our Family Festival and Walk in Raleigh, making their statement each year with dozens of candy pink shirts scattered through the crowd and raising almost \$40,000 over the past several years to support HNC Programs and Services.

Thank you to the Cook family, Gwen Stewart, and the entire St. Stephen family for continuing to make HNC and people with bleeding disorders a focus of your mission to give and serve in the community!

## 71st NHF Bleeding Disorders Conference and Tribute to CEO

October 3-5, 2019

Anaheim, CA

It was another successful National Hemophilia Foundation (NHF) Bleeding Disorders Conference (BDC), as over 2,500 people traveled to California for three days of education and connectivity. These conferences allow community members from across the US, and some from around the world, to get together and learn from one another and experts in the field. This year was also about paying tribute to Val Bias, CEO of NHF since 2008, as he retires at the end of 2019. Val, who lives with hemophilia, has a long history as an advocate and leader in the bleeding disorders community. It was an emotional conference for many as they expressed their gratitude and well-wishes for Val. Additionally, it was a reminder of the amazing community here in North Carolina where several members were highlighted for their contributions with Adyn and Jacob taking home Teen Impact Awards., Kristy Lee being named Genetic Counselor of the Year, and Austin Caldwell speaking at two sessions about his experiences with bleeding disorders.

*Continued next page*



# 71st NHF Bleeding Disorders Conference and Tribute to CEO

*continued from previous page*

Hear from one of the families that Hemophilia of North Carolina (HNC) was lucky to send:

*By: Erin Otey, HNC Member*

*In October we were able to attend our first NHF Bleeding Disorders Conference. This was largely made possible through a travel grant we received from HNC. Although we have been in the bleeding disorders community for several years, we continue to value learning opportunities. We feel this conference was very educational as the sessions provided information on current treatment approaches, the future of treatment, and offered practical help for those affected and caring for those affected with bleeding disorders.*

*It also gave us new perspective on a national level. We were able to meet people from all over the country with different life experiences to share. Despite the differences, there was a common thread of unity and concern for those in the community. Everyone was working together to provide support, information, advocacy, and awareness. We are thankful that these national resources are available. We are also very grateful to have a strong state chapter with great staff who care deeply about the members of HNC.*

We're excited that the NHF BDC will be on the east coast in 2020! Save the date for August 6-8 in Atlanta, GA. If interested in attending, please reach out to the HNC office to learn more about HNC's Conference Travel Grants.



*HNC staff with the Otey family at the NHF Bleeding Disorders Conference*



**Kristy Lee, MS, CGC, is the Genetic Counselor at UNC's Hemophilia Treatment Center, and the well-deserved winner of the National Hemophilia Foundation 2019 Genetic Counselor of the Year award. Congrats, Kristy, and thanks for all you do!**



*The hemophilia treatments of today were once the dreams of yesterday. Proof that when*

## SCIENCE AND THE COMMUNITY

*come together, great things happen.*

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# *We Want to Hear from YOU!*

## *HNC Needs Assessment* continued from page 1

will help to drive the direction of HNC for years to come, so no matter what your relationship is with HNC, your opinions matter! Whether you are an active member who attends events regularly, volunteers, and/or supports the organization through fundraising or donations; or you receive HNC information in your mail or email, but don't regularly come out and participate in person, please take the time to complete this important survey. All adults in your household are encouraged to take the Needs Assessment. If you have children who are away at college or other adult family members who are not receiving our communications, HNC would like to hear from them as well. Please note that it is expected to take about 20 minutes to complete, but your feedback is essential in determining the future of HNC. As an appreciation for your time, anyone who completes the Needs Assessment will be entered into a prize drawings which will be held throughout the year. If you have questions, or would like the Needs Assessment sent to you in the mail, please contact the HNC office at (800) 990-5557.

## A Beautiful Day at Lake Crabtree for the 12th Annual Family Festival & Walk

October 12, 2019  
Morrisville, NC



Members and supporters who came out to Lake Crabtree Park on October 12 had a picture-perfect day to celebrate Hemophilia of North Carolina (HNC) and the amazing community it supports at the 12th Annual Raleigh Family Festival & Walk for Bleeding Disorders. The staff and Board of Directors of HNC would like to express their heartfelt appreciation to each and every member, volunteer, sponsor, donor, and contributor that gave their time and effort to making this event a success.



The final fundraising total for this event was a staggering \$117,886 with one-hundred percent of the proceeds going toward supporting HNC programs and services right here in North Carolina! Because of the support of so many, HNC has the ability to sustain current programs and services while also continuing to work toward enhancing programs to meet the ever-changing needs of the community.



With the early morning call for volunteers to set up and get ready for the day ahead, coffee donated by Caribou was a welcome treat. That, along with fruit, cereal bars, and other items donated by Harris Teeter helped

get everyone ready for the day ahead. For lunch, walkers were treated to sandwiches and water donated by Sheetz, pizza discounted by Dominos, both located in Morrisville, and chips donated by Costco. Water donated by Pepsi was on hand so participants could stay cool and hydrated for all of the amazing activities of the day. All the dogs were treated to lunch and treats too with doggie-bags donated by PetMania.

Jeff Hogan, Morning News Anchor from WRAL, was the emcee for the morning. He got the festivities started with the help of Performance DJ as the crowd got warmed up with some familiar dance steps, a costume contest for kids and dogs, and the announcement of the day's big award winners:

- Top Team: Clot Hoppers
- Top Individual Fundraiser: Charlene Cowell\*
- King Droplet: Rohan Shirumalla
- Queen Droplet: Lorin Fentress
- Junior Droplet: Jaden Cook
- Hospital Cup: Wake Walkers

*\*At the event, in recognition of his extraordinary efforts as a first time team captain and fundraiser, Charlene Cowell declined to accept this award and asked that it be awarded instead to Rohan Shirumalla.*

Activities were available for people of all ages. Drugco sponsored the basketball activity and photo booth. Other activities included: an inflatable slide, face painting, crafts, games, and free massages by Midas Massage Therapy. Special guests included Troll and Sponge Bob characters from Lee's Professional Mascot Service, Juggle-Boy the stilt-walking juggler, as well as Tinkerbell, Periwinkle, and Joy from UNC's Moment of Magic who helped with kids crafts!

*Continued page 14*

## Actualización del Programa Unión Latina



El evento final de la Unión Latina para este año 2019 fue realizado en conjunto con Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés), el 7 de Diciembre, en Durham. En el evento se presentó Curtis Gray, LCSW, UNC del Centro de Tratamiento en Chapel Hill, acerca de la importancia de saber manejar el estrés. La presentación fue traducida simultáneamente por Full Circle Interpreting, de tal manera que los asistentes pudieran comprender y participar en la celebración. La tarde también incluyó una visita muy especial del Santa Claus.

Este año 2019 les brindó diversas oportunidades a los miembros de la comunidad Hispana con situaciones de enfermedades hemorrágicas, de reunirse, socializar, y aprender como vivir con desordenes hemorrágicos.

Los programas fueron presentados durante la Reunión Anual en Charlotte, eventos de 1 día en Raleigh, Ashville, y Huntersville, las Fiestas de Celebración en Durham, y en el Retiro de la Unión Latina en Winston-Salem.

El año 2020 tendrá múltiples eventos incluyendo la reunión anual de HNC el 7 y 8 de Marzo en Raleigh.

Manténgase informado al respecto visitando la página web y también el sitio de Facebook, donde se publicarán los anuncios de eventos, sus fechas y localidades.

Si usted estuviese interesado en un tópico en particular, o localidad donde le gustaría que HNC les hiciera una presentación, por favor escriba un email a Gillian Schultz, Gerente de Programas de HNC: [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) o envíe un texto al (919) 272-6000.



El Programa de la Unión Latina provee apoyo y educación a individuales de origen latino y sus familias en Carolina del Norte afectadas por desordenes hemorrágicos. La programación es ofrecida en Español y es posible gracias a un aporte de Takeda. Para más información por favor ingrese a la página web de HNC.

## Reunión de Miembros de la Unión Latina en Frankie's

20 de Octubre, 2019

Concord, Carolina del Norte

El 20 de Octubre, Hemofilia de Carolina del Norte (HNC por su sigla en Inglés), la Unión Latina sostuvo un evento en Frankie's Fun Park, en Charlotte. Patricia Espinosa-Thomson representante de Takeda desarrolló una mesa redonda acerca de cómo estar preparado para casos de emergencia. Las razones para recurrir a una sala de emergencia; la importancia de aplicar una infusión antes de someterse a exámenes en la sala de emergencia; que preguntas hacer mientras esta en la sala de emergencia; información que debiera de tener antes de salir de vacaciones; que cosas debieran de estar incluidas en el plan de emergencia familiar; y la importancia de usar joyas/accesorios médicos fueron algunos de los temas tratados.

Después del almuerzo y de una conversación informativa, los invitados recorrieron y se divirtieron con las actividades de Frankie's, incluyendo la sala de juegos, mini golf, bowling, y mucho más!

Gracias Takeda por auspiciar el Programa de la Unión Latina.

## SOAR Program Update

Are you a woman with a bleeding disorder, mom of a girl with a bleeding disorder, or girl with a bleeding disorder? Did you know that Hemophilia of North Carolina (HNC) has a support program for you? The SOAR (support, outreach, advocacy, resources) Program is here to help you!

On December 5-6, HNC exhibited at the North Carolina School Nurse's Conference in Greensboro to raise awareness about girls with bleeding disorders in school. As school nurses are often the ones who see girls coming in for feminine hygiene products and deal with bloody noses, it's important that they are aware of what to look for and where to direct people if they notice students exhibiting signs of a bleeding disorder.

In 2020, HNC will continue to advocate for and raise awareness about women and girls with bleeding disorders. There will be SOAR breakout sessions at the Annual Meeting on March 7-8 and at the Adult Retreat from June 5-7. In addition, because

of feedback received from community members, HNC is planning a SOAR Day featuring a full day of networking, education, and support on June 27. Stay tuned to the HNC website and your email for formal announcements about these events.

SOAR is a program of HNC for women and girls with a bleeding disorder, including those diagnosed with von Willebrand Disease, hemophilia A and B, rare factor deficiencies, platelet disorders, and carriers of any of these disorders (both symptomatic and non-symptomatic). The mission is to improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential.

Please contact Gillian Schultz, HNC Program Manager, for more information about the SOAR Program at [soar@hemophilia-nc.org](mailto:soar@hemophilia-nc.org) or by calling the Gillian at (919) 272-6000.

## HNC Raising Awareness with NC Nurses

September 19-20, 2019  
 Winston-Salem, NC

Hemophilia of North Carolina (HNC) was once again able to exhibit at the North Carolina Nurse's Association (NCNA) Annual Convention at the Benton Convention Center in Winston-Salem to educate nurses about the signs and symptoms of a bleeding disorder and how women in particular have difficulty getting a timely and accurate diagnosis.

There were nurses of many different disciplines and backgrounds present at the convention, and nurses from various types of clinical and educational settings who were interested in finding out more about bleeding disorders and how they could help to narrow the timeline for diagnosis, especially in women. Many nurse educators were interested in HNC's resources as they looked ahead to design lessons for future nurses that would emphasize some of what they learned at the HNC booth that day.

As is typically the case at the NCNA convention, nurses who had attended in the past came by because they remembered HNC from past conventions. Some wanted to check back in for updated information while others just stopped by to say hello. HNC is encouraged that this kind of outreach is making a difference in the lives of the undiagnosed and hopes to be able to continue this effort into the future. A special thanks goes out to HNC members Cheri Clark and Jama Fleming for taking the time to attend the NCNA Convention and for their dedication to outreach on behalf of HNC.



## Young HNC Athletes at Junior National Championship

The 18th Annual Gettin' in the Game Junior National Championship (JNC) was hosted by CSL Behring and held in Phoenix, Arizona from November 8-10, 2019. HNC was excited to have the opportunity for three young members to attend this year. Athletes had the option of participating in golf, baseball, or swimming. They learned more about the importance of physical fitness in managing their bleeding disorder and received instructions on proper stretching techniques and good athletic form while getting to know other young athletes from around the country. Read more about the event from this year's participants.



### *From Mara L., parent of Harley, JNC swimming athlete - age 7*

I was impressed with all the swimming knowledge given to each of the students, especially from the coaches. Watching my daughter interact with other children with bleeding disorders truly warmed my heart. I grew up knowing no one else with VWD, until college. It was scary and I felt alone. Watching her feel part of a team and not be afraid of her disease, was priceless.

Once home, she asked me if she can continue swimming on a team, since she had such a blast!

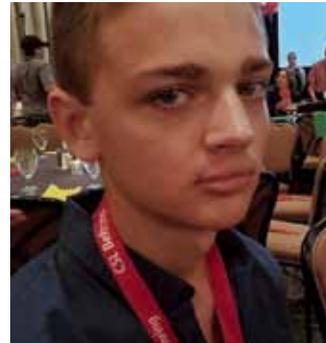
### *From Wesley D., HNC golf athlete - age 8*

I had the opportunity to play golf in the JNC in Scottsdale, Arizona! When I arrived I met many new friends. We had a golf practice with Perry Parker, a Golf Pro who also has hemophilia. He was so nice, funny, and good at golf. The next day, I competed in a golf tournament. And I had my own Pro Caddy, Stan. I played really well and learned some new golf tips. That night I won a gold medal! I had a lot of fun. Thank You HNC!



### *From Riley B., HNC swimming athlete, age 17*

My recent trip to CSL Behring's Junior National Championships was an amazing experience. I competed in swimming and loved that we got a chance to improve our skills with world class coaches. It was also great meeting other kids in the bleeding disorders community as well as seeing old friends. The best part was how encouraging everyone was of each other throughout the competition and how excited we all were to be there. It was a phenomenal experience and one I would recommend to everyone!



## *A Beautiful Day at Lake Crabtree for the 12th Annual Family Festival & Walk* continued from page 10



One lucky adult went home with a \$100 Amazon Gift Card and other winners of adult raffle prizes took home a Trader Joe's gift basket, AMC movie passes, tasting event certificates from Triangle Wine in Morrisville, and other gift cards! Kids also had a chance to win raffle prizes that included Fun Money Gift Cards from Frankie's Fun Park, AMC movie passes, Dave & Buster's gift cards, and a Barnes & Noble gift card.



Finally, the lucky winner of the Grifols trivia question drawing had to correctly answer the question, "How many MedicAlert IDs did HNC provide to patients in the last year?" The answer, HNC provided 207 MedicAlert IDs in one year.

The success of the Family Festival & Walk would not have been possible without the dedication of every member, sponsor, volunteer, donor, and contributor who committed themselves to the Family Festival & Walk Fundraiser. HNC would like to thank everyone for a job well done!

To see pictures and video clips of the event, please visit our Facebook page [www.facebook.com/HemophiliaNC](http://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.



## *Bombardier Blood, A Special Screening for HNC*

November 2, 2019  
Morrisville, NC



*HNC Staff with Laurie Kelley of Save One Life getting ready to watch the film*

Hemophilia of North Carolina (HNC) was honored to have the opportunity to provide a special screening of the documentary *Bombardier Blood* on November 2 at the Park West Stone Theatre in Morrisville.

Everyone in attendance was awed and inspired to be able to join Chris Bombardier's journey to the top of the earth's seven summits, specifically his journey to the top of Mount Everest. There were many personal, physical, and emotional obstacles that Chris, who is diagnosed with severe hemophilia B, had to overcome before he could reach the highest

heights as the first climber with a bleeding disorder to successfully climb the highest summits on each of the earth's continents. The documentary took viewers through Chris' preparation for these climbs and brought to light the many differences in access to treatment for people with bleeding disorders in different parts of the world.

By partnering with filmmaker Patrick Lynch and Believe Limited, Chris used this opportunity as a way to raise funds for Save One Life, an international nonprofit organization that is dedicated to improving the life of those living with bleeding disorders in developing countries. Members who attended HNC's special screening were able to participate in a question and answer session with Save One Life President and Founder, Laurie Kelley. This gave everyone a chance to hear first-hand accounts of some of what took place in the film, what it's like to visit

*Continued next page*

## Bombardier Blood, A Special Screening for HNC

*continued from previous page*

patients and treatment centers in developing countries, and what people with bleeding disorders in these remote locations must overcome just to receive basic medical resources.

Because of the generous donations of HNC members who participated in a collection for Save One Life at this event, HNC was able to donate \$565 to a special fund to cover beneficiaries who have lost their sponsor. This will enable Save One Life to cover sponsorship costs and provide stability for vulnerable beneficiaries and their families until a new sponsor can be found.

Finally, here's some good news if you could not attend this special screening but want to see the movie in the future. When *Bombardier Blood* is finished with its scheduled private screenings and film festivals, it will be made available for viewing through video streaming services nationwide. HNC will make an announcement letting members know how they can see the movie once those details are made available.



*Laurie Kelley of Save One Life answers questions about the making of the documentary*

## Factor 7/Rarer Bleeding Disorders Roundtable

November 2, 2019

Morrisville, NC

Hemophilia of North Carolina (HNC) strives to support people with all bleeding disorders. With the majority of people affected by bleeding disorders having either von Willebrand disease (VWD) or hemophilia, those who have rarer bleeding disorders including rare factor deficiencies or platelet disorders may sometimes not know where they belong. HNC wants you to know that you have an important place in the bleeding disorders community in North Carolina and that HNC believes support and education for *all* bleeding disorders is essential for an inclusive community.

While first being promoted as an event for factor 7 deficiency, HNC opened the door to the Factor 7 Roundtable Meeting for people with any rare bleeding disorder, though the focus of this particular meeting was more directed to individuals with factor 7 deficiency. HNC heard the need for education specific to the diagnosed bleeding disorder, as well as psycho-social aspects of living with a bleeding

disorder. One idea that was discussed is for HNC to bring topics to members *anywhere* in North Carolina by having webinars about rare bleeding disorders made available for people who are unable to attend in-person events.

HNC hopes to continue the conversation in 2020 about the needs of those living with rare bleeding disorders, and you can help guide that discussion by completing the HNC Needs Assessment (see Page 1 of this newsletter). There will be a session at the HNC Annual Meeting on March 7-8 for rare bleeding disorders. HNC also encourages you to attend other events throughout the year that provide community for all bleeding disorders.

If you have a rare bleeding disorder, HNC would like to hear from you about your specific needs. Please contact Gillian Schultz, HNC Program Manager at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or call or text her directly at (919) 272-6000.

## Women's Night Out

November 9, 2019

Charlotte, NC

*By: Tiffany Hargett, Secretary, HNC Board of Directors*

Many of our community members know it's hard to make it to too many events because we live so far away. I was lucky enough to make it to the painting night in Charlotte a few weeks ago. I was met by two wonderful reps: Kathy Robinette and Keanu Garland of InfuCareRX at Dish It Out. We had great food and even better conversations. It was a great night to relax and talk to other women about everyday life and what we love (dogs). If you ever get the chance to make it to one of the women's nights I highly recommend you make the drive. I promise it will be a great time and a chance to get some girl time in.



# ECU Bleeding BBQ Bash

November 9, 2019  
Greenville, NC

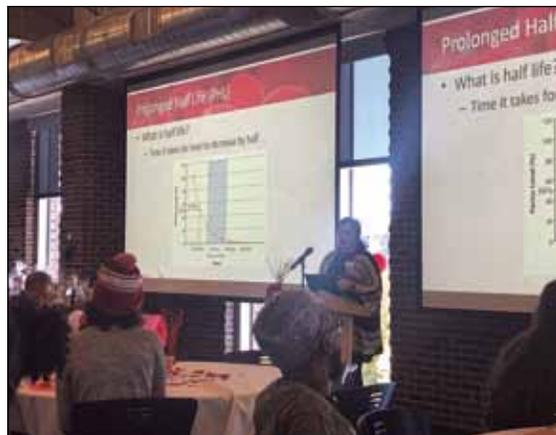


What a fun way to start winding down the year! The East Carolina University (ECU) Hemophilia Treatment Center (HTC) hosted a Bleeding BBQ Bash for patients at their HTC. Hemophilia of North Carolina (HNC) was excited to be a part of this big day! Charlene, HNC Executive Director, was able to meet over 100 individuals and families from around the eastern part of the state. Many were already HNC members but a few weren't, so Charlene was able to

get them connected. Charlene was also blown away when seeing ECU patients that used to hang out with her at HNC Teen Retreats who are now married and graduated college. How quickly time flies!

If you're interested in participating in one of HNC's collaborative events with your local HTC, please read more about your chance to do that in the article *HNC Collaboration With Your HTC* on page 5 of this newsletter.

*East Carolina University HTC speaker*



**IN THIS TOGETHER**  
**Saturday, 7:18 pm**  
Checking out a music festival with his girlfriend  
Marc, hemophilia A

Not an actual patient

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

**Let's make today brilliant.**

[bleedingdisorders.com](http://bleedingdisorders.com)



**BAXALTA AND SHIRE ARE NOW PART OF TAKEDA**

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# Fayetteville Paint Night

December 2, 2019  
Fayetteville, NC



It was a great way to kick off the busy holiday season for some women in the community who came out to the painting night event at the Wine & Design Fayetteville location. With wine, hors d'oeuvres, and a room full of women with something in common, it's no wonder that the painting part of the evening was a little delayed as everyone enjoyed getting to know one another better. It was a welcome way for everyone to be able to wind down and focus on something other than the to do list waiting for them at home. As the painting progressed, the conversation continued, and everyone left with a beautiful work of art and a closer connection to other members of the community. Thank you to DrugCo Health for making this event possible.

# A Great Way to Catch Your Breath During the Busy Holiday Season: 2019 HNC Holiday Celebration

December 7, 2019  
Durham, NC



Members of all ages came together for a festive day at the Hilton Durham near Duke University as Hemophilia of North Carolina (HNC) celebrated the end of another successful year!

There was plenty of food, time to mingle with other HNC families, seasonal crafts for kids to enjoy, and a lot of laughter at this year's celebration. As everyone settled in with their lunch, it was time for the featured presentation from Curtis Gray, Licensed Clinical Social Worker for the Hemophilia Treatment Center at UNC Chapel Hill. Curtis discussed how to manage stress during the holidays. In a funny yet sincere way, the presentation led attendees through the traps of holiday stress and approaches to deal with it through mindfulness, breathing, and more. Following the presentation, HNC announced the 2019 Volunteer of the Year (see article on page 4 of this newsletter).



Finally, it was the moment everyone was waiting for – the arrival of Santa and Mrs. Claus direct from the North Pole! With jingle bells, singing, and a lot of excitement, Santa and Mrs. Claus had a chance to visit with any children who wanted to meet them and then read a story. Each child and teen received a holiday gift, and adults had a chance to win one of several exciting door prizes. In addition, HNC offered tickets to the Durham Museum of Life & Science to anyone interested in a fun after-event activity.



In the spirit of giving back, the collection of donations to benefit Ronald McDonald House of Durham & Wake brought too many items to count. HNC members coming together in support of another deserving charity is a great way to end a great year!



# Educational Dinners Across the State

September 17, 2019   September 28, 2019   October 17, 2019   November 3, 2019   November 14, 2019   November 16, 2019  
 Concord, NC   Durham, NC   Charlotte, NC   Charlotte, NC   Durham, NC   Raleigh, NC

*Hemophilia of North Carolina (HNC) traveled across the state this fall to provide a variety of educational opportunities in several North Carolina cities. HNC would like to thank its industry partners for making all of these educational opportunities possible.*

## **Concord, NC: Understanding VWD**

It was an informative evening on September 17 when HNC members gathered to learn more about von Willebrand disease (VWD). Betsy Koval, Takeda Clinical Educator was prepared with props and visuals to help everyone better understand von Willebrand factor's role in the formation of a clot, and the different types of VWD. VWD has several types, include Type 1, Type 2 (and its four subtypes), and Type 3. The different types are classified based upon whether the von Willebrand factor is impaired or whether a person is deficient in von Willebrand factor. Everyone left the event with a better understanding of VWD. Thank you to Takeda for sponsoring this event.

## **Durham, NC: The Science of Connection**

HNC members gathered Maggiano's on September 28 in Durham for the Educational Lunch, *The Science of Connection: Strengthening Relationships in Times of Change*, where guest speaker, Bob Szybist, MAPP, from the University of Pennsylvania Positive Psychology Center led an informative presentation. Attendees learned how to have an IDEAL conversation with others in order to help facilitate best outcomes when facing challenging conversations. Through listening and role-playing, attendees helped one another prepare for a real-life conversation. HNC would like to thank Genentech for making this event possible.

## **Charlotte, NC: Dental Health in Bleeding Disorders**

On October 17, the room was packed with HNC members from across the Charlotte region, to learn more about the importance of dental health and its effect on bleeding disorders. From the basics of establishing a regular routine of brushing at least twice a day with young children and regular check-ups with your dentist, as well as having a dentist who is familiar with bleeding disorders; to what to do if you need more invasive dental work done including root canals or getting teeth pulled, it was eye opening to hear about how dental health is so important. Thank you to Octapharma for sponsoring this educational dinner.

## **Charlotte, NC: Top Golf**

The Top Golf facility in Charlotte was buzzing on November 3 as HNC members from around the Charlotte area teed up. Once everyone got their buffet lunch, David Ohlson shared his story of growing up with hemophilia and his drive to stay positive and be as active as possible. Following his presentation, some of the

children in the room shared how they stay active, including one young boy who plays flag football and another young man who has been playing golf for several years. Finally, the moment everyone was waiting for, an opportunity to practice their golf swings. A golf pro was on-hand to assist anyone looking to improve their golf swing. It was a fun opportunity for the community to get together! Thank you to CSL Behring and Diplomat Specialty Infusion Group for making this event possible.

## **Durham, NC: The Health Insurance Roadmap**

It was a timely educational dinner on November 14 as HNC partnered with Takeda to host a session called *The Health Insurance Roadmap*. With open enrollment for health insurance, everyone could use an opportunity to learn more about how to navigate the often-overwhelming task of choosing the right insurance. Joe Gniadek, Associate Director of Rare Disease Reimbursement and Access Manager for Takeda, made sure that everyone left with new information. The program included an overview of insurance options, information to help navigate transitions that will impact coverage, and the information needed to respond to insurance denials of coverage. This knowledge is extremely helpful when making informed decisions about healthcare insurance. Thank you to Takeda for making this event possible.

## **Raleigh, NC: Drive Shack**

Several HNC families enjoyed lunch, golf, and the inspirational presentation *Believing in Yourself: Getting in the Game of Life* from CSL Behring Common Factors Advocate, Perry Parker. Taking place at Drive Shack, Perry shared the story of some of his successes and set-backs as he worked to become a professional golfer while living with hemophilia. As part of the presentation, Perry discussed the importance of physical fitness and stretching and demonstrated some techniques to the group. Then, it was time for everyone to try out their golfing skills on the driving range. Whether a beginner or an avid golfer, everyone learned more about golf, dedication, and resiliency from Perry that day. Thank you to CSL Behring and Diplomat Specialty Infusion Group for making this event possible.

*If there is a topic that you would like to hear about in your area, please contact the HNC office at (800) 990-5557 or [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org).*

## 2019 Friends of HNC

*We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2019. 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  
Sue and W. Allen Heafner  
Mr. James Jarratt  
Allen & Linda Kurtz  
Jessica Prim  
Daryl Steinbraker

*Save One Life*  
Donna Blair-Paynter  
Charlene Cowell  
Karyn & Kyle Davis  
Allen & Linda Kurtz  
Heather Nassaur  
Brenda Plassman  
Phil Poovey  
Charles & Kathy Register  
John Sakakeeny

*For the George D. McCoy Scholarship*  
Charles & Sue Cowell  
Charlene Cowell  
Phillip Poovey

*In Memory of Kyle Brinkhaus, son of Diane & Willian Brinkhaus*  
Richard Gaiennie, Gaiennie Lumber Co.

*In Memory of Vincent Jim Paquin*  
Sandra Paquin

*Toward HNC Family Retreat Childcare*

Troy & Shannon Schoolcraft  
Bob & Heidi Traficanti

*Toward HNC Holiday Celebration Museum Activity*  
Allen & Linda Kurtz  
The Turner Family



## Celebrating our 2019 Corporate Sponsors

*Cash and In-Kind contributions received from January 2019 – December 2019. We thank our sponsors for their continued support of the community.*

### Sponsor of Excellence (\$50,000 or More)

Takeda

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Accredo • Aptevo Therapeutics • CVS Specialty Pharmacy • Hemophilia Federation of America, Inc. • HPC Specialty Pharmacy  
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### Silver (\$1,000 - \$4,999)

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### Friends of the Community (Up to \$499)

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Humble Pie Raleigh • Instant Imprints Raleigh • Levine Cancer Center HTC • Lewis Wilson Art • Lynn's & Daphne's Hallmark Shops  
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NC Arboretum • NC State University Athletics • NC Symphony • NC Zoo • Oriental Trading • Pepsi • PetMania  
Pacos Tacos and Tequila • Port O Call • Pro's Epicurean • Raleigh Improv • Social Pet Hotel & Daycare • SpiceCubed Caterina  
Starbucks Coffee • The Cary Theater • The Great Raleigh Trolley • The Great Wolf Lodge • The Map Shop • The Pharmacy  
Total Wine & More • Trader Joe's Cary • Triangle Corporate Coach • UNC Chapel Hill Athletics • UNC Finley Golf  
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### Special Contributions for Scholarships (\$8,000)

Diplomat Specialty Infusion Group



- Help
- Opportunity
- Partnership
- Empowerment

## HOPE Program Update

Did you know that Hemophilia of North Carolina (HNC) provides support specific to families who have children diagnosed with a bleeding disorder? The HOPE (help, opportunity, partnership, empowerment)

Program is designed to help parents navigate challenges that exist while raising a child with a bleeding disorder, while simultaneously providing a community of support for entire family, so that no one has to feel alone.

In 2019, HNC hosted several educational dinners across the state with topics including infusion support and preparing to go back to school. The Family Retreat in September at the Great Wolf Lodge was once again one of the most popular HNC events of the year, with families connecting for a weekend of networking, education, and importantly – fun! Additionally, HNC kicked off the Community Connections Program across North Carolina with groups being formed in Asheville, Wilmington, Lexington (Winston-Salem), Jordan Lake, and Mocksville. For parents looking for a little more, HNC offers a Mentoring Program to support them.

2020 is going to be another great year for the HOPE Program! The Family Retreat (now called the HOPE Family Retreat) will be returning to the Great Wolf Lodge from September 11-13. Other educational dinners

are being planned. The Community Connections Program is growing, with more events being added in 2020. In addition, expect more traffic on the HNC HOPE Facebook group in 2020. You can request access to the HOPE Facebook group through the HNC Facebook page.



Community Connections gathering in Asheville

HNC's HOPE Program provides support to families who have children twelve and under diagnosed with a bleeding disorder. If you have ideas for events in your area, are looking for information about a particular topic, want to know more about the Mentoring Program, or for any other information about the HOPE Program, please contact Gillian Schultz, HNC Program Manager, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org), by calling or texting Gillian directly at (919) 272-6000, or by calling the HNC office at (800) 990-5557. You may also check the HNC webpage, your email, Facebook, Twitter, and Instagram pages for updates about upcoming programs and events.



## Blood Brotherhood Program Update

Men with bleeding disorders need their own space to connect with one another. That's where Hemophilia of North Carolina's (HNC) Blood

Brotherhood comes in. The Blood Brotherhood Program provides a community for guys who are connected by similar circumstances. At events held throughout the year, men can get together, share experiences, learn from each other, and have fun together.

Events for 2020 are being planned now, including time to get together at the Annual Meeting on March 7-8 and at the Adult Retreat from June 5-7. If you are a man with a bleeding disorder, age 18 or older, please let us know what kinds of events you are looking for next year. As the community continues to age, and younger

guys are experiencing greater outcomes than in past generations, HNC wants to know what kinds of programs you would like to see. Please contact Gillian Schultz, HNC Program Manager at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or call (919) 272-6000 to speak with her directly about your ideas or if you have questions.

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



## Unión Latina Program Update

The final Unión Latina event for 2019 was held in conjunction with the Hemophilia of North Carolina (HNC) Holiday Celebration on December 7 in Durham. The day featured a presentation from Curtis Gray, LCSW, UNC Chapel Hill Hemophilia Treatment Center, about the importance of managing stress. It was simultaneously interpreted by Full Circle Interpreting so that attendees could fully understand and participate in the Holiday Celebration. The afternoon also included a special visit from Santa Claus.

2019 provided multiple opportunities for Spanish speaking members in the bleeding disorders community to get together, socialize, and learn about living with a bleeding disorder. Programs were presented at the Annual Meeting in Charlotte, one-day events in Raleigh, Asheville, and

Huntersville, the Holiday Celebration in Durham, and at the Unión Latina Retreat in Winston-Salem. There will be multiple events in 2020 including at the HNC Annual Meeting on March 7-8 in Raleigh. Stay tuned to the HNC website and Facebook page for an announcement of all 2020 Unión Latina dates and locations. If there is an educational topic or location you would like us to go to, please contact Gillian Schultz, HNC Program Manager at [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) or by text at (919) 272-6000.

The Unión Latina Program provides support and education to 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 Takeda. For more information, visit the HNC website.





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

### **Victory Junction Camp in Randleman, NC**

Applications for 2020 camps are now open! For information on how to register for Summer Sessions (below) or about Victory Junction's Family our Young Adult Weekends, go to [www.victoryjunction.org](http://www.victoryjunction.org) or call (336) 498-9055.

**June 21-25, 2020** *Bleeding and Gastrointestinal Disorders*

**June 28-July 1, 2020** *Neurological and Genetic Disorders*

### **Camp Carefree in Stokesdale, NC**

Applications for 2020 camps will open in February. You can follow Camp Carefree on Facebook for announcements. For additional information about Camp Carefree, the services they provide year-round, or to find out more about the Camp Weeks listed below, go to [www.campcarefree.org](http://www.campcarefree.org), email [directors@campcarefree.org](mailto:directors@campcarefree.org), or call (336) 427-0966.

**June 21-27, 2020** *Siblings Camp – well children with a chronically ill sibling*

**July 19-25, 2020** *Kids Camp – well children with a chronically ill parent*

**July 26-August 1, 2020** *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, email Jacquelyn Sauls at [saulsj@ecu.edu](mailto:saulsj@ecu.edu), or visit their website at [www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm](http://www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm)



## ON THE NATIONAL & LEGISLATIVE FRONT

# HFA's 2020 Symposium: Charting Our Future

April 23-26, 2020  
Baltimore, MD



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

## Educational Scholarships Available

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

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

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

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

**Beth Carew Memorial Scholarship from Colburn Keenan Foundation:** [www.colkeen.org/?page\\_id=123](http://www.colkeen.org/?page_id=123)

**Hemophilia Federation of America:** <https://www.hemophiliafed.org/for-patient-families/resources/educational-scholarships-internships/>

**Hemophilia of North Carolina:** [hemophilia-nc.org/scholarships](http://hemophilia-nc.org/scholarships)

**LA Kelley Communications, Inc.:** [www.kelleycom.com/scholarships/](http://www.kelleycom.com/scholarships/)

**National Hemophilia Foundation:** [www.hemophilia.org/Community-Resources/Scholarships](http://www.hemophilia.org/Community-Resources/Scholarships)

## HNC Grants to Attend National Events

Hemophilia of North Carolina (HNC) will once again be awarding travel grants to qualified families to attend several national meetings in 2020. The National Hemophilia Foundation (NHF) Washington Days advocacy event in Washington DC in February, the Hemophilia Federation of America (HFA) Symposium in Baltimore, MD in April, and the NHF Bleeding Disorders Conference in Atlanta, GA in August, and other national events are wonderful opportunities for HNC members to meet other families and learn from the experts around the country.

HNC's grants may be used for event registration fees, transportation, lodging, and/or incidental expenses. Additional details and a grant application form can be found on the HNC website or requested by calling the HNC office at (800) 990-5557.

## HNC Advocacy Committee Updates

### MEDICAID MANAGED CARE DELAYED

Hemophilia of North Carolina (HNC) has been alerting members of major changes that were scheduled for NC's Medicaid Program in 2020. However, due to the NC budget not being passed, these changes have been delayed. This means that anyone currently on NC Medicaid should not expect any changes related to this transition in 2020. Anyone with questions can call the Medicaid Contact Center at (888) 245-0179.

### BE AN ADVOCATE!

Please consider making one of your New Year's resolutions to get more involved in advocacy. Whether advocating for the bleeding disorders community or another cause that you're passionate about, the world needs more advocates! To learn more about how to be an advocate for the bleeding disorders community, contact Hemophilia of North Carolina (HNC) at (800) 990-5557 or [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org).

The National Hemophilia Foundation (NHF) will host its annual Washington Days advocacy event February 26-28, 2020 on Capitol Hill in Washington, DC. NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Last year's Washington Days had more than 450 volunteer advocates from 47 states that met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act (ACA).



# Hemophilia of North Carolina 2020 Calendar of Events Highlights



<a href="#">January 9, 2020</a>	Raffle Drawing – Morrisville, NC
<a href="#">January 11, 2020</a>	Charlotte Family Festival Information Meeting – Matthews, NC
<a href="#">February 1, 2020</a>	HNC Event with Levine HTC & St. Jude HTC – Charlotte, NC
<a href="#">February 22, 2020</a>	HNC Event with Wake Forest HTC – Winston-Salem, NC
<a href="#">February 26-28, 2020</a>	NHF Washington Days – Washington, DC
<a href="#">March 7-8, 2020</a>	Annual Meeting – Raleigh, NC
<a href="#">March 21, 2020</a>	HNC Event with UNC Chapel Hill HTC – Chapel Hill, NC
<a href="#">March 28, 2020</a>	HNC event with East Carolina Univ. HTC – Greenville, NC
<a href="#">April 18, 2020</a>	Family Festival & Walk for Bleeding Disorders – Charlotte, NC
<a href="#">April 23-26, 2020</a>	HFA Symposium – Baltimore, MD
<a href="#">May 2, 2020</a>	Fishing Event – Location TBA
<a href="#">June 5-7, 2020</a>	Adult Retreat – Lake Junaluska, NC
<a href="#">August 6-8, 2020</a>	NHF Bleeding Disorders Conference – Atlanta, GA
<a href="#">August 13-16, 2020</a>	HNC/HSC Teen Retreat – Rock Hill, SC
<a href="#">September 11-13, 2020</a>	HOPE Family Retreat – Concord, NC
<a href="#">October 17, 2020</a>	Family Festival & Walk for Bleeding Disorders – Morrisville, NC
<a href="#">December 5, 2020</a>	Holiday Celebration – Location TBA



## FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



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**Stay empowered  
by the possibilities.**

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