

# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

WINTER 2020

## Updates to our Membership Database – Help Us to Reach You



Hemophilia of North Carolina (HNC) is in the process of upgrading its membership database. As part of the upgrade, HNC staff has realized many of the current entries are out of date. This database is used to send you information about upcoming events, resources that may help you to manage your bleeding disorder, advocacy alerts, and other pertinent information for the bleeding disorders community. Sometimes, HNC may use your contact information to target a specific bleeding disorder or certain age range. Many times, though, HNC does not have the information that it needs to best meet YOUR needs.

HNC is asking that you take 5-10 minutes to update your membership information. Your email address, address, and phone number are especially important. In addition, if you are comfortable providing more information, please let us know your (or your family member's) bleeding disorder diagnosis and that of other people who live in your household. You can add as many details as necessary in the comment section of the online membership form. *Continued page 5*

## Getting to Know the HNC Board

By: Phil Poovey, Vice President

I am Phillip R. Poovey and I became a Hemophilia of North Carolina (HNC) Board Member on July 1, 2019 for a two-year term. I had previously been an active volunteer, assisting in the HNC office in Morrisville with whatever projects needed doing and working closely with Karyn Davis and Charlene Cowell. I became involved with HNC many years ago through the work of my late husband, George D. McCoy. George had severe hemophilia A and had helped to found the organization that grew into Hemophilia of NC with Charles and Kathy Register and a few others in the late 1970s. George had served on the board many years ago and maintained his support for the organization throughout his life with financial support and helping to develop a training program

*Continued page 7*



*Phil (right) with his late husband George (left)*

### In this Edition:

UPCOMING EVENTS	Page 6
RECENT EVENTS	Page 8
SUPLEMENTO DE LA UNIÓN LATINA	Page 11
SOAR SUPPLEMENT	Page 13

### Save The Date

**HNC Annual Meeting**  
March 2021  
Virtual

**World Hemophilia Day**  
April 17, 2021

**HNC Festival & Walk**  
April 17, 2021  
Charlotte, NC

**HNC Medical Symposium**  
May 1, 2021  
Virtual

**HNC Summer Conference**  
July 9-11, 2021  
Lake Junaluska, NC

**HNC/HSC Teen Retreat**  
August 7-10, 2021  
Rock Hill, SC

**HNC Festival & Walk**  
October 2, 2021  
Morrisville, NC

**HNC Holiday Celebration**  
December 4, 2021  
Greenville, 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](http://www.hemophilia.org)

#### Hemophilia Federation of America

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

#### Community Health Charities

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

### About This Publication

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

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

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

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

### Hemophilia Treatment Centers

#### East Carolina University Brody School of Medicine

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

#### Hemophilia Treatment Center of Levine Cancer Institute and Levine Children's ADULT:

1021 Morehead Medical Drive, Suite 50100  
Charlotte, NC 28204  
Phone: (980) 442-4363  
**PEDIATRIC:**  
1001 Blythe Blvd., Suite 601  
Charlotte, NC 28203  
Phone: (704) 381-9900

#### St. Jude Affiliate Clinic at Novant Health

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

#### Hemophilia Foundation of America

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

#### American Society of Pediatric Hematology/Oncology

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

#### Centers for Disease Control & Prevention

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

#### Coalition for Hemophilia B

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

#### ClinicalTrials.gov

A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

#### Committee of Ten Thousand (COTT)

1-800-488-2688  
[www.cott1.org](http://www.cott1.org)

#### LA Kelley Communications

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

#### Patient Services Incorporated (PSI)

Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.  
1-800-366-7741  
[www.unneedpsi.org](http://www.unneedpsi.org)

#### World Federation of Hemophilia

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

### VISION STATEMENT

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

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

## MESSAGE FROM THE EXECUTIVE DIRECTOR

What a year... isn't that quite the understatement? When we started moving to virtual events in March, we definitely never thought we'd still be doing them as we enter a new year. But here we are. Even though there is nothing like being surrounded by fellow community members in person and sharing hugs, we're proud to have been able to make this switch to virtual so that we can all remain connected, even if it is from a computer screen. We're also glad that this has given us the opportunity to meet community members who have never been able to attend in-person events, whether because of travel or schedule restrictions. Most importantly, it has reinforced the concept of resiliency for which our community is known.

COVID aside, Hemophilia of North Carolina (HNC) has been doing much more than the virtual events that you see us promoting regularly. We are currently in the final stages of developing a three-year strategic plan for the organization. We're starting to analyze the results from the community needs assessment, which will drive the final strategic plan priorities. HNC is also growing in size! After years of recognizing the need for a staff person dedicated to fundraising and development in order to sustain and expand the organization's programs and services, HNC is finally

in a position to hire someone. We look forward to introducing this person, hopefully in the next edition of this newsletter!

I want to end my message with an unrelated but important note. If you know me, you are probably aware of my openness in speaking about mental health. It's something I'm very passionate about because of my personal struggles with depression and anxiety. Even the strongest of people can struggle. Sadly, so many suffer in silence for fear of the negative stigma that surrounds mental health. For everyone reading this, I ask you to help me break this stigma. If you are someone who has or is currently dealing with mental health challenges, please share with others because you never know who else might be going through something and needs to talk. If you are on the receiving end, please be kind. I'll end my message with one of my favorite quotes and a reminder that we, HNC's staff and board, are here for you.

*"Try to be a rainbow in someone's cloud." ~ Maya Angelou*

Warmest wishes,  
*Charlene*

## Our Request to You

This has been a year when so many are having to pull back. In spite of the challenges before us, Hemophilia of North Carolina (HNC) has committed to pushing forward and doing more for people affected by bleeding disorders. As we come to the close of 2020, we would like to share how this year's contributions have been used and are asking those who can provide a donation of any size to please consider doing it now.

Since the beginning of the year, HNC has:

- provided over \$36,000 in financial assistance to families in need – a 77% increase over the previous year;
- connected with 112 new member families;
- quickly pivoted to a virtual platform so we can continue to provide critical support and education to the bleeding disorders community;
- participated in virtual health symposiums and conferences to continue raising awareness of bleeding disorders;
- advocated – now virtually – on local, state, and national levels to ensure that people with bleeding disorders can get the medical care they need; and
- avoided any layoffs or staff reduction due to the pandemic.

Here is why we need your help, now more than ever: Our largest fundraising effort of the year – October's Family Festival & Walk in Raleigh – fell \$20,000 short of its goal, largely due to the pandemic. We depend on these proceeds to provide emergency assistance, lifesaving Medical IDs, and transportation assistance to people with bleeding disorders across the state so they can get to their Hemophilia Treatment Centers for vital medical care.

Please help us continue doing what we do well: meeting the needs of our community. Make a donation in any amount to help us reach our goal for the year. You may make a secure credit card donation online at [www.hemophilia-nc.org/donate](http://www.hemophilia-nc.org/donate) or by sending a check using the envelope that should be enclosed in this edition of the newsletter. Every penny makes a difference!



# Your Voice Makes a Difference: HNC Needs Assessment

Thank you to everyone who spent the time to complete the Hemophilia of North Carolina (HNC) Needs Assessment. The window for completing the Needs Assessment has now closed, and 118 people lent their voice to this important survey. The results are currently being analyzed. Once the analysis is complete, HNC staff will review the findings to see what is being done well and what is not. Based upon the results, HNC staff will evaluate its current programs and services to make sure that YOUR needs can be met in the future.

## Volunteer of the Year: Carol Hill

Hemophilia of North Carolina's (HNC's) founding members recognized the vitality of this community and inspired new generations of dedicated members whose vision and tireless efforts have helped HNC thrive over the years. Every year, one member is honored as HNC's Volunteer of the Year. It is an opportunity to acknowledge an individual who has given selflessly of their time and talents during the year (and usually longer) to enhance and empower HNC and the members we serve.

HNC is happy to announce that the 2020 Volunteer of the Year is Carol Hill. Carol has been extremely active since joining over a year ago. She is always a friendly face, whether at an in-person or virtual event. After joining HNC, Carol began immersing herself in every possible activity, from events to committees. She is always the first to volunteer for a task and gives back whenever she can. On behalf of HNC's board and staff, thank you to our 2020 Volunteer of the Year, Carol Hill!



## HNC Bylaws Amended in First Major Overhaul Since 1997

*By: Kathy Register, Board Treasurer*

In late 2019, Board members Steve Humes (president) and Phil Poovey (vice president) were advised at a workshop sponsored by the NC Center for Nonprofits that a periodic review of nonprofit bylaws is essential to ensure the document is current. Bylaws in North Carolina must:

- Comply with NC general statutes;
- Be consistent with the nonprofit's Articles of Incorporation;
- Realistically reflect the actual operations of the nonprofit;
- Allow for the use of modern technology including electronic communication; and
- Meet standards by which modern non-profits most efficiently operate for the benefit of its membership and community.

An ad hoc Hemophilia of North Carolina (HNC) Bylaws Committee, chaired by Vice President Phil Poovey, worked from January through June of 2020 to review HNC's current bylaws (finalized in 1997) and propose recommendations for updating them. Alisa Huffman, an attorney with expertise in the field of non-profit governance, was a consultant to the committee, and donated her time and guidance. The committee members were Amy Shair, immediate past HNC president; Kathy Register, HNC board member, treasurer, past president, and co-author of the 1997 bylaws; Charles Register, HNC webmaster and past president; and Charlene Cowell (*ex officio*), Executive Director.

The group's goal was to create a document that meets the standards outlined above, and provide solid guidance for HNC to serve all stakeholders in the bleeding disorders community, while preserving those elements of earlier bylaws that have served HNC well over time.

With the help of Huffman's expertise, the committee studied, researched bylaws of other organizations, and ultimately overhauled a good portion of the 1997 bylaws to reflect the necessities of changing times and the realities of HNC's expansive growth since 2000. Major changes included defining different membership classifications, removing the annual contribution requirement, establishing the

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## HNC Bylaws Amended in First Major Overhaul Since 1997

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board of directors as a self-sustaining board, and expanding the use of electronic media for official business. Minor changes included altering syntax and reformatting for clarity. The document was then reviewed by the full Board of Directors, who in turn recommended them to the full membership for adoption. They were adopted by acclamation at a specially called membership meeting on October 8, 2020. The work continues: the HNC Board is working to tweak some of HNC's official policy language to complement the new bylaws, as is standard practice.

It is interesting to note that the 1997 bylaws require membership action to be carried out at in-person meetings. But due to the COVID-19 pandemic restrictions prohibiting large gatherings, NC Governor Cooper issued a temporary Executive Order allowing nonprofit organizations to meet and vote electronically. HNC staff worked their usual miracles by informing membership of this meeting with the requisite notice, and curated the well-attended Zoom meeting in which the vote was taken.

The new bylaws and minutes to the October 8 meeting can be found at [hemophilia-nc.org](http://hemophilia-nc.org).

## Updates to our Membership Database – Help Us to Reach You *continued from page 1*

Please know that HNC truly values your privacy and confidentiality. Your contact information is not shared with anyone or any other organization, and it is kept secure.

An online membership form is available on the HNC website: [www.hemophilia-nc.org/membership](http://www.hemophilia-nc.org/membership), or by scanning the QR code.



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Not an actual patient.



# HNC Annual Meeting – Throughout the Month of March

Virtual

Many things are looking different due to the COVID-19 pandemic. The same holds true for the Annual Meeting. The Annual Meeting in 2020 was the last time that Hemophilia of North Carolina (HNC) was able to get together in person. Although HNC staff was hoping that the community could get together again for the 2021 Annual Meeting, it is still not safe for so many in the community to gather together. But do not fear! Like other events, the Annual Meeting will be transitioning to a virtual event, to take place throughout the month of March!

The theme of the 2021 Annual Meeting will be *A Time of Change*. The agenda and details are still being put together. Some topics will include von Willebrand disease, rarer bleeding disorders, advocacy, aging with a bleeding disorder, and so much more. There will be sessions for men and women with a bleeding disorder, parents of children with a bleeding disorder, children, and teens. Although the sessions will be online, there will still be time to network, learn more about the pharmaceutical companies and specialty pharmacy services that are available to the bleeding disorders community, as well as have the opportunity to hear from expert speakers.

More information about the agenda, as well as invitations and registration forms, 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) have March declared 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 are not sure 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.
- Join Hemophilia of North Carolina (HNC) during the Annual Meeting. Sessions will be held throughout the month of March about various topics of interest in the bleeding disorders community.
- Hemophilia Federation of America (HFA) spearheads 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) for more information on how to participate in the 2021 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.

## Medical Symposium

May 1, 2021

Save the date for the first Hemophilia of North Carolina (HNC) Consumer Medical Symposium. This event was originally scheduled to take place in spring 2020 but was postponed and ultimately canceled due to the COVID-19 pandemic. HNC is looking forward to holding its first Consumer Medical Symposium on May 1, 2021. This will be a virtual event, taking place on HNC's Zoom platform, for the entire bleeding disorder community.

There is so much information available about living with a bleeding disorder as well as new medical advances over the past few years. But how much do you understand? And how much of the information that you have seen is accurate? Hear from the experts in the field of hematology -- your medical providers -- about the more scientific side of bleeding disorders. Possible sessions will include genetics, novel therapies, understanding rare bleeding disorders, hemophilia, VWD, and more. Additional information will be available soon on the HNC website.



# Save the Date for the Charlotte Family Festival & Walk for Bleeding Disorders

April 17, 2021

Charlotte, NC

Hemophilia of North Carolina (HNC) cannot predict the future. However, HNC can say for sure that the date for the Charlotte Family Festival & Walk for Bleeding Disorders will be on Saturday, April 17, 2021 – on World Hemophilia Day!

At this time, HNC staff and the board of directors are evaluating whether or not there will be an in-person event, virtual event, or some combination of both. An announcement with more details will be made in mid-January to let you know the format of the 2021 Charlotte Walk. But no matter how the event is held, your help and support are needed. So start thinking now about your team and encouraging your family, friends, and coworkers to join you, all in support of HNC's programs and services. The more people who get involved, the more funds that can be raised.

**Attention Team Captains:** A Team Captain meeting will take place in early 2021 to help get you ready for the Charlotte Family Festival & Walk for Bleeding Disorders.



## HNC Programs and Events – All for YOU

Do you have ideas about programs that you would like Hemophilia of North Carolina (HNC) to provide? Is there a topic that you want to learn more about? Let HNC know! Send your suggestions for topics (whether virtual or in-person), locations for when the community can get together again, or other ideas to Gillian Schultz, HNC Program Manager, at [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) or by calling (919) 272-6000.

## Getting to Know the HNC Board *continued from page 1*



*George talking to families of bleeding disorders at the NC General Assembly prior to their meeting with their local state legislators and discussing issues important to their community.*



*George on Capitol Hill in Washington DC on the way to meet with NC's senators.*

of advocacy for persons with bleeding disorders at the local, state, and federal levels of government.

After George passed away in 2017, I was able to start a scholarship in his memory. Starting in 2019, we awarded the first \$1,000 George D. McCoy scholarship to a person with severe hemophilia A for post secondary training. A second \$1,000 award was made in 2020. I am very proud of the scholarship program and was honored to be elected to the HNC board in 2019. I have recently participated with a committee to rewrite the HNC Bylaws, and these were approved this fall by a statewide online membership discussion and vote. 2020 has been an exceedingly challenging year for us all but especially so for our members with bleeding disorders. We are happy that we have been

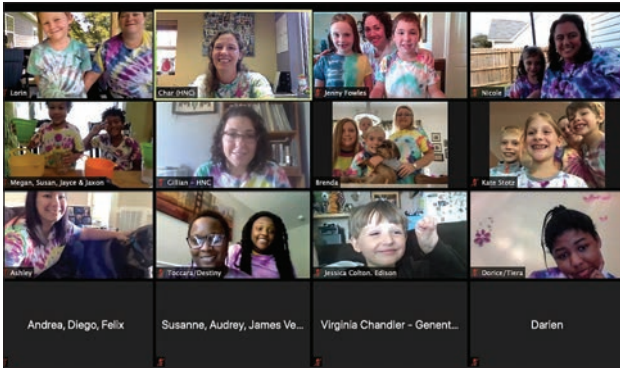
able to provide education, information, and financial assistance to our members' families that have been affected by the Covid-19 pandemic. The board is developing a strategic plan to guide HNC in the future, looking ahead to new challenges and opportunities in serving persons with bleeding disorders in NC.



*George at the 2016 HNC Fall Festival in Morrisville.*

# HNC Family Retreat – Together While Apart

September 11-20, 2020



The COVID-19 pandemic could not stop families from connecting for the annual Hemophilia of North Carolina (HNC) Family Retreat. Though different than in past years, this year's virtual event was still a hit! Over two weekends, and with a few presentations throughout the week, adults had the opportunity to gain valuable education and information about raising a child with a bleeding disorder, while children had the opportunity to have fun and learn more about bleeding disorders! Families who attended received a box of goodies, including shirts and tie-dye, and materials needed for a science experiment about blood clotting.

On Friday, September 11, families gathered on Zoom for a fun Kahoot! trivia game. Everyone had a great time guessing the answers to questions

that ranged from sports, to pop culture, to bleeding disorders, and so much more. On Saturday, September 12, there were programs

for both parents and children. The highlights of the day included a session about *Braving Change*, led by Tanya Stephenson, CORE Manager for Sanofi Genzyme, and an interactive Scavenger Hunt that had kids and adults racing around their houses to find different things. On Sunday, September 13, parents learned about *Maintaining Connections in a Time of Social Distancing*, presented by Betsy Koval from Takeda, and then everybody tie-dyed shirts. On Thursday, September 17, parents learned about what children with a bleeding disorder need when going to school in the session, *Back to School: How to Advocate for Your Child with a Bleeding Disorder*, presented by Juliana Bloom. They then learned all about the science of gene therapy in the session *Gene Therapy Research: Understanding the Science*, presented by Tracy Gaslin from BioMarin.

Finally, on Sunday, September 20, the day started with a session about how a clot is formed, in the *Clotting Cascade*, presented by Virginia Chandler from Genentech. This presentation was followed by a science experiment led by Gillian Schultz, Program Manager, that had children (and parents) learning about different steps necessary to form a clot, including the role of factors



VIII and IX, von Willebrand factor, and platelets. It was a fun and messy experiment that everyone truly enjoyed! The event concluded with a Read Along from Joy and Rosetta from the movie *Inside Out*.

Both weekends provided parents the opportunity to learn more about the companies that sponsored the event during the Industry Open House. HNC would like to thank the sponsors, Moment of Magic, and the Hemophilia Federation of America (HFA), for their support of this event.

Although the event was not what anyone had anticipated at the beginning of the year, it was a hit! HNC is looking forward to being able to get together for these kinds of events again when the COVID-19 pandemic is over.



# Special Documentary Screening – Let's Talk: Mental Health

October 3, 2020

Members of Hemophilia of North Carolina (HNC) joined Hemophilia of South Carolina (HSC) for a screening of the documentary film, *Let's Talk: Mental Health* produced by Believe Limited and Mental Health Matters Too. The film followed five bleeding disorders community

members dealing with their struggles with mental health. Following the film, attendees participated in a panel discussion with director Patrick James Lynch of Believe Limited, Debbie de la Riva, mental health expert, and Bobby Wiseman, who was featured in the film.



# Celebrating Hispanic Heritage Month

October 10, 2020

Hemophilia of North Carolina (HNC) community members celebrated Hispanic Heritage month, which was observed from September 15 to October 15. Hispanic Heritage month celebrates and recognizes the contributions of the Latino community. HNC partnered with Takeda to host an event that featured activities, including a fun game that tested everyone's knowledge of Latin American culture. From pictures of famous places to multiple choice quizzes about actors, it was definitely a learning experience while also providing much-needed laughter and time together! Thank you to Takeda and to all of the families that joined HNC to honor Hispanic Heritage month.



# Fun for All at Games and Grifols Event

October 13, 2020

Everyone can benefit from laughter and fun these days! On October 13, several members of the community got together on Zoom for a lively night of games. First up was a game of virtual BINGO, where not only was there a winner, but everyone had the

opportunity to learn more about Hemophilia of North Carolina. Following BINGO was a scavenger hunt that had everyone running around their homes looking for different items. Thank you to Grifols for partnering on this uplifting event!

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## Dan Bull

Empowerment advocate

### About Dan

Dan is a Hemophilia Community Liaison who is passionate about helping people take control of their lives. He understands that empowering those with bleeding disorders to take an active role in their treatment makes all the difference in the Mid-Atlantic community.

### Connect with Dan

[DLBU@novonordisk.com](mailto:DLBU@novonordisk.com)  
(240) 285-3948

## Hemophilia Community Liaison



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## Raleigh Family Festival & Walk – A Virtual Success

October 17, 2020



On October 17, Hemophilia of North Carolina (HNC) held its largest fundraiser, the Raleigh Family Festival & Walk for Bleeding Disorders, virtually! More than \$96,000 was raised to support HNC's mission of improving the quality of life of persons affected by bleeding disorders.

HNC staff learned a lot after flipping the Charlotte Festival & Walk to a virtual event this past spring. Through weekly activity and fundraising challenges on social media, the community became engaged and excited for the virtual event. On October 17, HNC staff, along with emcee Richard Dideriksen, hosted the event on Facebook Live and Zoom. There were announcements, Zumba, trivia, and more during the live streaming activities. Many teams walked 5K in the week leading up to October 17 or after the streaming activities on October 17. Even though the community could not be

together in person, everyone joined together in spirit and had a great time!

Congratulations to the award winners:

- Top Team: Clot Hoppers
- Top Individual Fundraiser: Charlene Cowell/Chris Rain
- King Droplets: Chris Rain & Phil Poovey
- Queen Droplet: Anita Smith
- Junior Droplet: Penelope Sirianna
- Hospital Cup: UNC Tarhealers

Of course, this event would nothave been possible without the support of the fundraisers, donors, volunteers, and sponsors who made it such a success!

**Save the date for the 2021 Raleigh Family Festival & Walk for Bleeding Disorders:  
October 2, 2021, at Lake Crabtree County Park in Morrisville.**



**Hemophilia of North Carolina (HNC) would like to once again thank our kind and generous fundraisers for their commitment to the recent virtual Raleigh Family Festival & Walk. Below includes messages from some of these individuals.**

*This year's walk was like no other we have experienced in the past – but the need is the same. Thanks HNC for all you do!!*

~ Jeff Spears

*Thank you and virtual hugs to our friends and family, and to our fellow Clot Hoppers!*

~ Kathy and Charles Register

*In memory of George D. McCoy*

~ Phil R. Poovey

*We are truly thankful for the incredible support of our family, friends, and HNC.*

~ Team Wonderfully Made

*We are so proud to be able to raise funds and awareness for an important cause and an amazing community!*

~ The Cowell & Conger family

*Our donation was given with lots of love and support of our little buddy, Liam Fentress, of Team Liam.*

~ The Augsburg Family

*You all do a wonderful job and the community and I are so grateful for all that you do.*

~ Yasmina Abajas, MD

Amy Shair Miller

Team Liam

Teme Levbarg & Richard Dideriksen

Ty Hooker (Team Hooker)

## Actualización del Programa Unión Latina

El objetivo del Programa Unión Latina es proveer apoyo a los miembros de habla hispana de la comunidad con desordenes hemorrágicos. Por medio de presentaciones educacionales y el retiro anual, este soporte es entregado a las personas de habla Española y sus familias completamente en Español.

En la recién pasada temporada de otoño, Hemofilia de Carolina del Norte (HNC por sus siglas en ingles) desarrollo varios eventos para la Unión Latina, incluyendo el Mes de la Herencia Hispana y el Retiro de la Unión Latina, al mismo tiempo que otorgaron una interpretación en Español del Evento de Transformación de Medicaid y la celebración de Las Fiestas. HNC mira con entusiasmo poder proporcionar más de estas oportunidades en el año 2021.

El Programa Unión Latina da soporte y proporciona educación a individuos de origen Latino y sus familias en Carolina del Norte, que sufren de enfermedades hemorrágicas. El Programa es ofrecido en Español y es posible gracias al subsidio de Takeda. Para más información, visite el sitio de internet de HNC.

## Celebrando el Mes de la Herencia Hispana

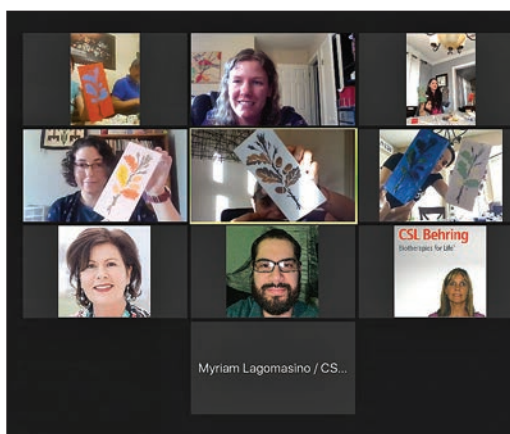
10 de Octubre del 2020

Miembros de la comunidad de Hemofilia de Carolina del Norte (HNC por sus siglas en ingles), celebraron el Mes de la Herencia Hispana, que se recuerda entre el 15 de Septiembre y el 15 de Octubre. El Mes de la Herencia Hispana celebra y reconoce las contribuciones de la Comunidad Latina. HNC en conjunto con Takeda celebraron un evento que tuvo actividades, incluyendo un divertido juego que puso a prueba a cada uno de los participantes acerca de sus conocimientos sobre la Cultura Latinoamericana. Desde fotos de lugares famosos hasta preguntas con respuestas alternativas acerca de actores. ¡Fue definitivamente un aprendizaje que origino risas y nos proporciono momentos juntos muy agradables!

Gracias a Takeda y a todas las familias que junto con HNC participaron en honor del Mes de la Herencia Hispana.

## Retiro de la Unión Latina de HNC

6 al 8 de Noviembre del 2020



Desde el 6 al 8 de Noviembre, numerosas familias residentes de Carolina del Norte y provenientes de otros lugares del país, cuya lengua primaria es el Español, se reunieron de manera remota para celebrar el Retiro de la Unión Latina. En el transcurso de esos tres días las familias tuvieron la oportunidad de conectar con otras familias y entender de mejor manera como sobrevivir y aprender a manejar las enfermedades hemorrágicas, enteramente en Español.

El Viernes por la noche, las familias participaron en una búsqueda virtual! ¡Fue muy divertido poder ver a los participantes buscando artículos relacionados en sus propias casas! El Sábado, se les enseno a las familias como mantenerse conectados entre ellos, aun en este periodo de pandemia; así como también la importancia de saber manejar individualmente los

desordenes hemorrágicos. Luego de la sesión educacional, los invitados participaron en una clase de cocina virtual, dirigida por Flour Power Cooking Studio. El menú fue alas de pollo, vegetales asados, ¡y una salsa de calabaza de otoño y todo resulto delicioso! El Domingo las familias recibieron instrucciones de como cuidarse de la mejor manera y luego tuvieron información acerca de terapia de genes. Luego cada participante tuvo la oportunidad de abrir cajas con materiales de manualidades para pintar figuras de otoño en madera, materiales proporcionados por AR Workshop y que quedaron como un recuerdo del Retiro de la Unión Latina.

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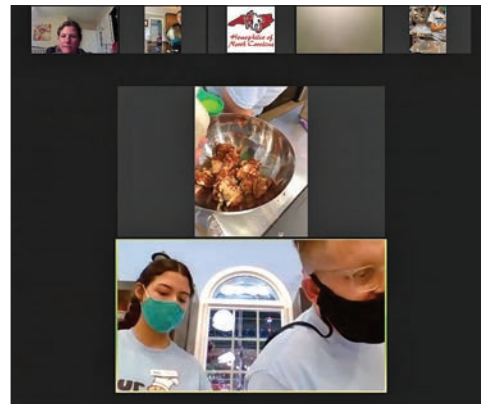


## Retiro de la Unión Latina de HNC

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Tanto el Sábado como el Domingo los participantes tuvieron la oportunidad de conocer acerca de distintas farmacéuticas, así como farmacias especializadas, quienes subsidiaron este evento.

Confiamos en que muy pronto podremos reunirnos en persona nuevamente. Pero hasta entonces, este evento nos permitió proporcionar soporte a la comunidad de habla hispana. Agradecemos a los auspiciadores y también a Colburn Keenan Foundation, que hicieron posible realizar este evento.



## Celebración de los Festivos de HNC

5 de Diciembre del 2020

¡Que gran fin de año, celebrando los próximos Festivos con Hemofilia de Carolina del Norte! (HNC por sus siglas en Ingles). Tuvimos 62 personas registradas para la presentación vía Zoom, totalizando mas de 100 personas que participaron, comparado con varias celebraciones presenciales de los Festivos en años anteriores. Después de algunos minutos durante los cuales los participantes tuvieron la oportunidad de saludar, mientras otros aun estaban registrándose para la presentación, Angie Schiavone a nombre de Full Circle Interpreting, nos explicaba como podrían escuchar la presentación en Español. Luego, Courtney Foster, quien es candidata a un doctorado de la Escuela de Psicología Pediátrica en el Departamento de Psicología de la Universidad de Carolina del Este, Como Podemos Ser Mas Resistentes Durante COVID?

Courtney nos compartió datos y trucos de como manejarnos durante estos inciertos tiempos, incluyendo mantenerse en contacto vía Zoom, o aun a través de una llamada telefónica, buscando hobbies, y realizando actividades como atención plena. Luego de la presentación de Courtney, HNC entrego el premio al Voluntario del Año, esta vez a Carol Hill. Mas información acerca de Carol, en page 4. Y para cerrar esta actividad vía Zoom, varias familias permanecieron en la llamada para decorar "Galletas de Chalecos Feos". HNC hizo llegar a cada persona que se registro, una caja con sorpresas, incluidos los ingredientes para las Galletas de Chalecos Feos, manualidades, y otros. Gracias a todos y cada uno de los que participaron en la Celebración virtual de los Festivos, y a los auspiciadores que nos ayudaron a hacer posible este evento. HNC les desea a todos Felices Fiestas y un Feliz Año Nuevo.

## Entendiendo la Transformación de Medicaid en Carolina del Norte

1 de Diciembre del 2020

Carolina del Norte tendrá una completa revisión de su Programa de Medicaid en el 2021, el cual tendrá un impacto en millones de personas y de como su cobertura medica funcionará.

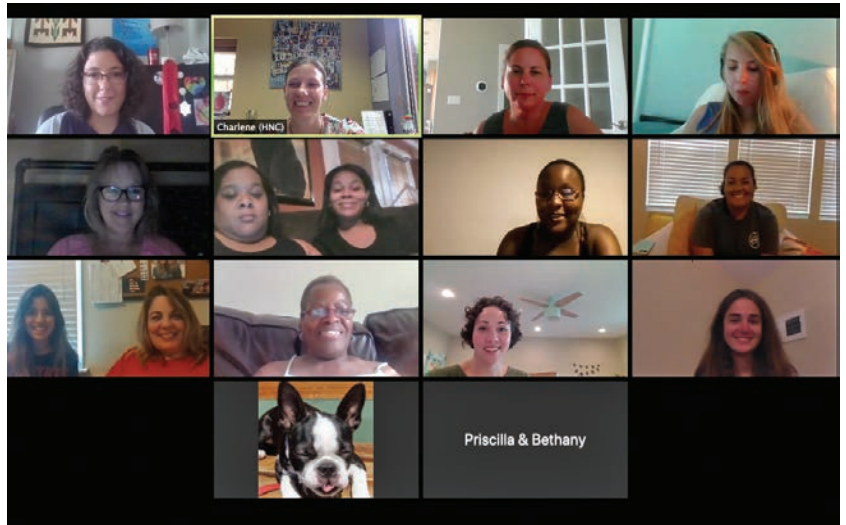
El seguro medico es critico para los pacientes que sufren de desordenes hemorrágicos, y Hemofilia del Carolina del Norte (HNC por sus siglas en Ingles) reconoce que esta revisión de Medicaid va a afectar la forma como estos individuos reciben su cobertura.

Entre los objetivos de HNC esta el informar y asegurar a los miembros de esta comunidad y proveedores, acerca de estos cambios. HNC en conjunto con el Departamento de Medicaid de Carolina del Norte, realizaron una reunión virtual. Gracias a la tecnología que Zoom ofrece, esta reunión virtual fue traducida al Español, en tiempo real. Mike Leighs el Director Representante de Asuntos de Medicaid en Carolina del Norte, presento una visión en conjunto de los cambios que la gente experimentara, así como también respondió una serie de importantes preguntas. Mike hizo una excelente presentación en detalle de los cambios, incluyendo información general y detalles específicos a la comunidad con enfermedades hemorrágicas, y también compartió algunos recursos para los pacientes.

Para más información y una copia en detalle de la reunión y copias de los cuadros compartidos en la presentación y recursos, por favor contactar HNC a [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) o bien llamando al (919) 319-0014.

## SOAR Program Update

Hemophilia of North Carolina's (HNC) SOAR Program is designed to provide support for women and girls diagnosed with a bleeding disorder. Through educational opportunities throughout the year and a private Facebook group, women affected by a bleeding disorder are provided with resources and education so that they are equipped to advocate for their healthcare needs. In addition, HNC advocates for the proper diagnosis of bleeding disorders in women and girls by exhibiting and sharing resources with other medical organizations. Though 2020 looked different in how this was done, HNC looks forward to the opportunity to advocate for women and girls through a variety of different arenas in 2021.



*Can't wait to be together in person again!*

In the coming months, HNC staff will be looking at new ways to support women in the bleeding disorders community. If you are interested in sharing your thoughts and ideas, please contact Gillian Schultz, Program Manager, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or by calling or texting her at (919) 272-6000.



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.

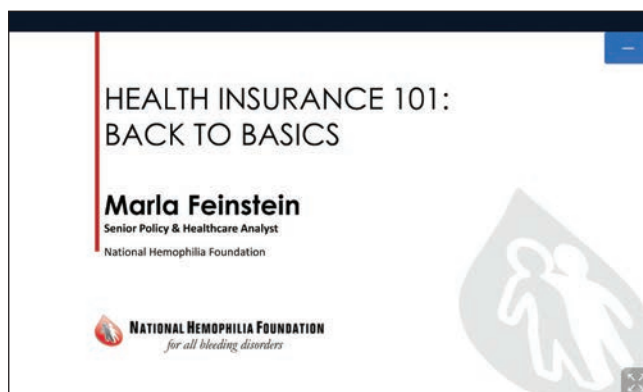
### Membership Information

For more information about SOAR, or to be added to the SOAR mailing list, please send your name and contact information, along with any questions you may have, to [soar@hemophilia-nc.org](mailto:soar@hemophilia-nc.org).

# NHF's Insurance & Reimbursement Conference

October 17, 2020

*Reprinted with permission from NHF*



From October 26th to 29th, 192 HTC social workers, nurses, and chapter leaders from 41 states took part in the National Hemophilia Foundation's (NHF's) Virtual Insurance and Reimbursement Conference— Access During Uncertain Times. The focus of this conference was understanding the impact the current pandemic has had on patient access to care and the broad regulatory and administrative changes regarding insurance and reimbursement.

The conference kicked off with NHF's policy team leading the pre-conference symposium, Insurance 101: Back to Basics. This popular symposium gave first time attendees or those looking for a refresher an overview of general health policy and insurance basics. This better prepared

attendees for the material presented over the remainder of the conference, which greatly benefited roughly half of the participants for whom this was their first time attending.

During the first session, attendees heard from NHF's federal policy advisor, Johanna Gray, who provided an update on our ongoing federal advocacy efforts, including what federal agencies are doing with respect to bleeding disorders and updates on our key advocacy issues, including access to skilled nursing facilities (SNFs) for Medicare beneficiaries, blood and product safety, the Affordable Care Act lawsuit before the Supreme Court, and more. Immediately following, Vanita Pindolia from Henry Ford Health System/Health Alliance Plan of Michigan gave an overview of the healthcare systems response to the pandemic, the costs and challenges related to managing COVID, and what are strategies to optimize costs.

On the second day attendees heard from Allison Harrison from Hemophilia Federation of America, Ayesha Azam of the Pan Foundation, Mandy Herbert of Patient Services, Inc (PSI) and Gerald Lauria from The Assistance Fund about patient assistance programs. The panelists discussed some of the resources which are available to the bleeding disorders community during the COVID-19 pandemic and how to access them. Immediately following, Kollet Koulianos, NHF's senior director of payer relations, talked about the different outreach activities that NHF is working on between payers and providers to promote the HTC model of care and ensure reimbursement. Attendees also learned more about accumulator adjustor programs and how NHF is working with payers to ensure access isn't impacted.

James Kenney of JTKENNEY, LLC, kicked off the third day of the conference discussing various payer trends and cost containment strategies. Participants were walked through processes including utilization management (UM) and prior authorization (PA), to have a more robust understanding of how they work and why they are used. In addition, attendees learned what to do to help these processes along so they do not impede access to care. The day ended with hearing from JoAnn Volk, from Georgetown's Center on Health Insurance Reforms on the challenges, current status, and changes in the private insurance market and the impact such changes could have on 2021 enrollment.

The last day focused on the states, beginning with an update from NHF's state policy team. Dillon Harp, government relations specialist, Bill Robie, government relations specialist, and Nathan Schaefer, vice president of public policy, spoke about how state governments have evolved and adapted to the new reality, and what to expect in the next legislative cycle. Charlene Cowell, executive director of Hemophilia of North Carolina, and Lynne Kinst of Hemophilia Council of California, shared their experiences with virtual advocacy. The final session concentrated on state Medicaid programs. Matt Dull, COO of Artia Solutions presented findings from the NHF Medicaid project, a project that focuses on beneficiaries in all 50 states with bleeding disorders. He highlighted the impact of COVID on enrollment and state budgets, as well as the expected changes in 2021 to program operations.

This intensive, four-day virtual workshop provided participants with the necessary tools and resources to help the community maintain access to care; this is especially important during this extended period of uncertainty. The critical role HTC staff and chapters play in helping the bleeding disorders community overcome challenges to access needed healthcare services is more important than ever.

NHF would like to thank CSL Behring, Genentech, Grifols, Hemophilia Alliance, Novo Nordisk, Pfizer, Sanofi Genzyme and Takeda for their continued support of this educational opportunity.



# Understanding Insurance Event

October 29, 2020

Health insurance can be a confusing and complicated topic, even for those who work in the field. However, it is essential to people living with bleeding disorders. Picking the right plan based on individual needs requires an understanding of the complex world of insurance. That's why Hemophilia of North Carolina was pleased to partner with Genentech in offering an *Understanding Health Insurance* event through Zoom. Attendees learned the common but often confusing lingo, differences between types of insurance, and more. It was a really educational experience for all!



# HNC Unión Latina Retreat

November 6-8, 2020



From November 6 to 8, several families from North Carolina and around the country, whose primary spoken language is Spanish, gathered remotely for the Unión Latina Retreat. Over three days, families had the opportunity to connect with one another and learn about living and managing with a bleeding disorder, entirely in Spanish.

On Friday evening, families got together for a virtual Scavenger Hunt! It was a lot of fun seeing everyone find items from around their homes! On Saturday, families learned about maintaining connections even during the pandemic, and the benefits of being empowered to manage one's bleeding disorder. Following the educational sessions, everyone participated in a virtual cooking class led by Flour Power Cooking Studio. They made chicken wings, roasted vegetables, and a fall pumpkin dip. *Continued next page*

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

## SCIENCE AND THE COMMUNITY

*come together, great things happen.*

**Genentech** | Hemophilia A  
A Member of the Roche Group

*Let's put science to work*

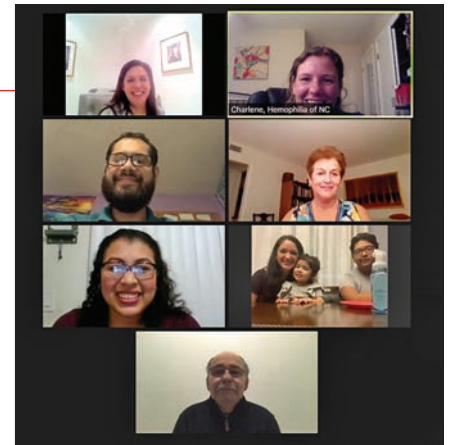
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## HNC Unión Latina Retreat *continued from previous page*

Everything looked delicious! On Sunday, families learned what they need to know in order to be advocates for their care and more about gene therapy. Then everyone opened their box of materials sent from AR Workshop and painted a fall-themed wood project as a keepsake of the Unión Latina Retreat.

On both Saturday and Sunday, attendees also had the opportunity to learn about the different manufacturers and specialty pharmacies that sponsored the event.

Hopefully, everyone will be able to get together in person soon. But until then, this event provided a great opportunity to support the Spanish-speaking community. Thank you to the sponsors and the Colburn-Keenan Foundation who made this event possible.

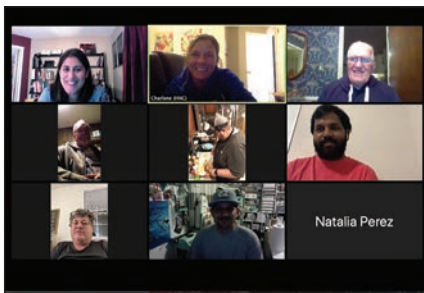


## Cooking with Chef Mike

November 18, 2020

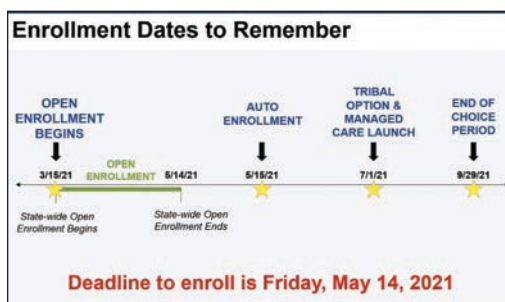
Hands down, this was one of the most delicious Zoom sessions yet! Chef Mike Hargett, who lives with severe hemophilia and is a double transplant survivor, showed Hemophilia of North Carolina (HNC) Blood Brothers how to cook a delicious and healthy BBQ meal. More specifically, they cooked a BBQ rubbed pork tenderloin sandwich with Western Carolina BBQ

sauce, apple-cabbage slaw, and pickled red onions. As if that weren't tasty enough, they added creamy broccoli salad with dried raisins, cheddar, bacon, and toasted almonds to the plate. Before the cooking began, the guys listened to a brief presentation about nutrition from UNC physical therapist Jennifer Newman. Jen provided visuals to help show exactly what a serving of popular foods would be. Some were a bit surprising, especially as the holidays approach! Thank you to Mike and Jen for donating their time and talents, and to the Hemophilia Federation of America, which makes the Blood Brotherhood program possible.



## Understanding NC Medicaid Transformation

December 1, 2020



North Carolina will have a complete overhaul of its Medicaid Program in 2021, which will affect millions of people and how their healthcare coverage works. Health insurance is critical for people with bleeding disorders, and Hemophilia of North Carolina (HNC) recognizes that Medicaid Transformation is going to change the way these individuals are covered.

As part of HNC's advocacy efforts to ensure that community members and providers are informed about the changes, HNC worked with the NC Medicaid Department to host a virtual meeting. Thanks to Zoom technology, the meeting was also interpreted into Spanish in real time. Mike Leighs, Deputy Director of Engagement for NC Medicaid, provided a thorough overview of the changes that people can expect to see as well as answering a lot of important questions. He gave an excellent presentation and provided clarity about the changes, including general information and details specific to the bleeding disorders community, as well as sharing some resources for patients.

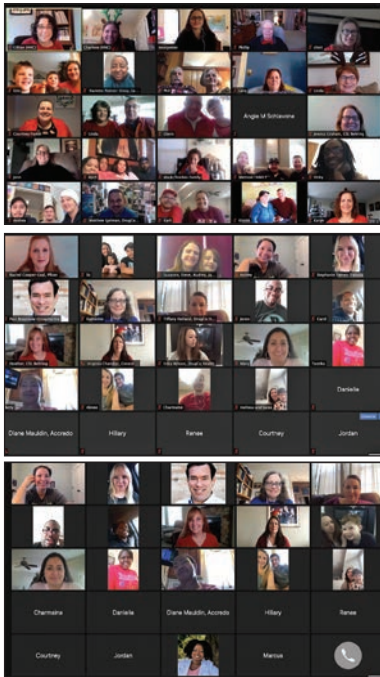
For more information and a copy of the meeting recording, presentation slides, and resources, please contact HNC at [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) or by calling (919) 319-0014.





# Holiday Celebration & Ugly Sweaters

December 5, 2020



What a great end to the year at Hemophilia of North Carolina's (HNC) Virtual Holiday Celebration! There were 62 unique sign-ins to Zoom, with over 100 people participating, rivaling many of the in-person Holiday Celebrations of past years. Following a few minutes where people had the chance to say hi while others were connecting, Angie Schiavone of Full Circle Interpreting explained how they could listen to the presentation in Spanish. Then, Courtney Foster, who is a doctoral candidate in the Pediatric School Psychology program in the Department of Psychology at East Carolina University, presented *How Can I Be More Resilient During COVID?* She shared tips and tricks on how to manage during these trying times, including staying connected with others using Zoom or even just a phone call, finding hobbies, and activities like mindfulness. Following Courtney's presentation, HNC presented the Volunteer of the Year Award to Carol Hill. You can read more about Carol on page 4. As a final activity, many families stayed on Zoom to decorate "Ugly Sweater Cookies." HNC sent everyone who registered a box of goodies, including Ugly Sweater Cookies, crafts, and more. Thank you to everyone who joined the Holiday Celebration virtually and the sponsors who helped to make the event possible. HNC wishes everyone Happy Holidays and a Happy New Year.






## Jivi® Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

▶ Dive in at [JiviExtensionStudy.com](https://JiviExtensionStudy.com)

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## In the Spring Edition

Read about the Teen FUN Day Event, the Plasma Safety Event, advocacy events, and winter virtual educational “dinners” in the Spring Edition of *The Concentrate*.

Hemophilia of North Carolina (HNC), like so many other organizations and businesses, has been bracing for the inevitable financial impact of COVID-19. From event sponsorships to Walk fundraising, the impact has the potential to significantly reduce HNC’s ability to serve the bleeding disorders community. Therefore, in addition to the individual donor recognitions listed on page 21, HNC wants to give a special note of appreciation to the companies that have continued supporting HNC’s efforts during the last few months.

### Family Retreat

#### PRESENTING SPONSORS



#### CHAMPION SPONSORS



### Raleigh Family Festival & Walk

#### PRESENTING SPONSOR



#### GOLD SPONSORS



#### SILVER SPONSOR

CVS Specialty

#### DIAMOND SPONSOR



### Retiro de la Unión Latina (Latin Union Retreat)

#### PROGRAM PARTNER



#### PREMIER SPONSORS



#### RETREAT SPONSORS



### Holiday Celebration

#### PROGRAM PARTNER



#### GOLD SPONSORS



# Revamping of HNC Programs Coming Soon

Hemophilia of North Carolina (HNC) has a variety of programs to support people with different needs in the community including:

- Blood Brotherhood – for men with a bleeding disorder
- HOPE – for families who have a child with a bleeding disorder
- SOAR – for women and girls with a bleeding disorder
- Unión Latina – for Spanish speaking community members

Based on results from the Needs Assessment, feedback from community members, and changing demographics in the community, HNC is reviewing its current programs and looking at ways to strengthen and improve the opportunities provided for people affected by bleeding disorders in North Carolina. Once the Needs Assessment is fully analyzed, HNC staff will review the information provided and will be making changes and adjustments so that YOUR needs can be fully met.

If you would like to share your thoughts, please email Gillian Schultz, HNC's Program Manager, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or call her at (919) 272-6000.



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

## HOPE Program Update

Hemophilia of North Carolina's (HNC) HOPE Program is specifically designed to meet the needs of families that have young children with a bleeding disorder. Families new to HNC as well as those that have been part of the organization are encouraged to become involved with the HOPE Program. Support is provided for families that have a child twelve and under diagnosed with a bleeding disorder, through educational opportunities, peer and emotional support, and resources.

Through educational offerings, a Parent Mentoring Program, private HOPE Facebook group, Community Connections events, and additional resources, the goal is for parents to become empowered to be able to advocate for their child's needs.

In the coming months, HNC staff will be looking at new ways to support families in the bleeding disorders community. If you are interested in sharing your thoughts and ideas, are looking to be connected with another parent through the Mentoring Program, or need anything else to support raising a child with a bleeding disorder, please contact Gillian Schultz, Program Manager, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or by calling or texting her at (919) 272-6000.

### *Recruiting Parent Mentors*

**Please contact Gillian Schultz, Program Manager,  
at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or by  
calling her at (919) 272-6000 for more information.**

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

HNC is looking to grow the Blood Brotherhood Program over the next year and encourages all men with a bleeding disorder, no matter their age, to join scheduled programs. Is there something that you would like to see HNC offer? As the community continues to age, and younger guys are experiencing better outcomes than in past generations, HNC knows that your needs are changing. 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 for activities and events, or if you have any questions about the Blood Brotherhood Program.

HNC's Blood Brotherhood Program is an extension of the Hemophilia Federation of America's (HFA) Blood Brotherhood Program. It is 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 cannot 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.hemophilafed.org](http://www.hemophilafed.org) to register.



### Unión Latina de Hemofilia

## Unión Latina Program Update

The Unión Latina Program is aimed at providing support for Spanish-speaking members of the bleeding disorders community. Through educational presentations and an annual retreat, support is provided to Spanish-speaking individuals and families entirely in Spanish.

This past fall, Hemophilia of North Carolina (HNC) held several Unión Latina events, including a Hispanic Heritage Month event and the Unión Latina Retreat, as well as provided Spanish interpretation for the Medicaid Transformation Event and the Holiday Celebration

presentation. HNC is looking forward to providing more of these opportunities in 2021.

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.



### Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at [HemDifferently.com](https://hemdifferently.com)

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

**BiOMARIN**

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**Hemophilia of North Carolina (HNC) wants to celebrate your important milestones!**

*Want to celebrate your birthday, anniversary, or event with HNC?*

**Contact us: [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org) or (919) 319-0014.**

*We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2020. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.*

*In Loving Memory of Averell Braun*

**Brenda Plassman**

*In Honor of Susan Lake*  
Carolyn Nuscher

*In Honor of Liam Joseph Grad*  
Julie Rogers

*In Honor of Preston Sykes*  
Melissa Poole

*In Honor of Kathy Otey's Grandsons*  
Wendy Merritt

*In Loving Memory of Ms. Bobbie  
Huffman, mother of Alisa Huffman,  
April Eckard, and Van Huffman*  
**Phil Poovey**

*In Loving Memory of Kasey's  
34th Birthday*  
Kevin and Melodee Frye

## Annual Giving Campaign

Asif Ansari  
Warren Ingram  
Rodney Jarvis

## Facebook Birthday Fundraisers

*Cheri's*  
Beverly Rose  
Charlene Cowell  
Cheri Clark  
Dee Bryant  
Kelly Hoots  
Kristine Maassen  
Loma Haralalka  
Lorna Rodnbusth Perry

*Keith's*  
Carmen Howard  
Chris Bentley  
Jan Parson  
Marcy Klepfer

*Susan's*  
April Eckard  
Kate Boyd  
Pat Brewer  
Phil Poovey  
Susan Lake  
Tracy Lake

*Tammy's*  
David Cummings  
Jennifer Locklear  
Wanda Burns- Ramsey

*Tracey's*  
Amber Currie  
Charita Miles  
Courtney Miles  
Crystal Vaden  
Jimmie Brandon  
Jo Renee Carr  
Kelsey Wagner  
Tracey Miles

*Thank You* 

# HFA Patient Fly-In

November 16-20, 2020

Each year, the Hemophilia Federation of America (HFA) hosts a Patient Fly-In and Congressional Reception, where a select number of community members from across the country go to Washington D.C. to meet with members of the US Congress and their staff as well as to honor members of Congress who have done extraordinary work for those with chronic and expensive diseases, including bleeding disorders. This year's event was a little different due to COVID-19, but was still aimed to advocate for the needs of the bleeding disorders community.

The week started with webinars to help prepare for the Congressional meetings. A review of HFA's policy priorities was provided on Monday evening. On Tuesday night, HFA held the Congressional Reception where it honored The Honorable Rodney Davis, US Representative from Illinois, and the Honorable Eric Swalwell, US Representative from California. Following a training on Wednesday night to prepare for the virtual meetings with legislators, two Hemophilia of North Carolina (HNC) community members connected with their legislators. Gillian Schultz, HNC Program Manager, shared her experience being a mother of a child with hemophilia, as well as her experience working with the bleeding disorders community. Jeron Hill, HNC community member, shared his experience being a young man with a hemophilia. Both shared the importance of access to quality, affordable health coverage, and the burden that is faced when that coverage is not available. Gillian and Jeron were two of sixteen community members who connected with their legislators by Zoom and conference calls.

In addition to the focus on the need for quality, affordable health coverage, participants asked for the support of H.R. 7647, a bill in the House of Representatives to bar the use of accumulator adjusters for the duration of the COVID-19 pandemic and twelve months after. Accumulator adjusters prevent the value of copay assistance programs from counting towards a consumer's out-of-pocket of expenses. An accumulator adjuster would be like having a gift card that you use to pay for something in a store, but then the store still asks you to pay the cost of what is being purchased. Essentially, this means that if an insurance company allows for accumulator adjusters, then any help that is

provided through the use of a copay card or assistance program does not apply to your deductible, copay, and/or coinsurance amount.

In addition to the meetings held on Zoom or conference calls, other community members were able to participate in a "Virtual Hill Day" using HFA's Legislative Action Center to communicate with their lawmakers by email and Twitter.



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## Advocacy Remains a Focus

Even though the political advertisements may have stopped, Hemophilia of North Carolina's (HNC) advocacy efforts are never over! Advocacy is a year-round initiative, and one that is very important to the bleeding disorders community. In addition to the recent NC Medicaid Transformation event, which is highlighted on page 16, HNC is preparing to send letters to all members about the Medicaid changes while also informing them by email and by posting on social media. With such a huge change, it is critical that anyone on Medicaid be prepared.

Additionally, the HNC advocacy committee continues to push for Medicaid expansion in NC. There will be multiple opportunities throughout 2021 for people from across the state to help amplify the importance of expanding Medicaid for those who need it most but may not currently qualify.

Stay tuned for more advocacy efforts in 2021!

# Hemophilia of North Carolina

## 2021 Calendar of Events Highlights

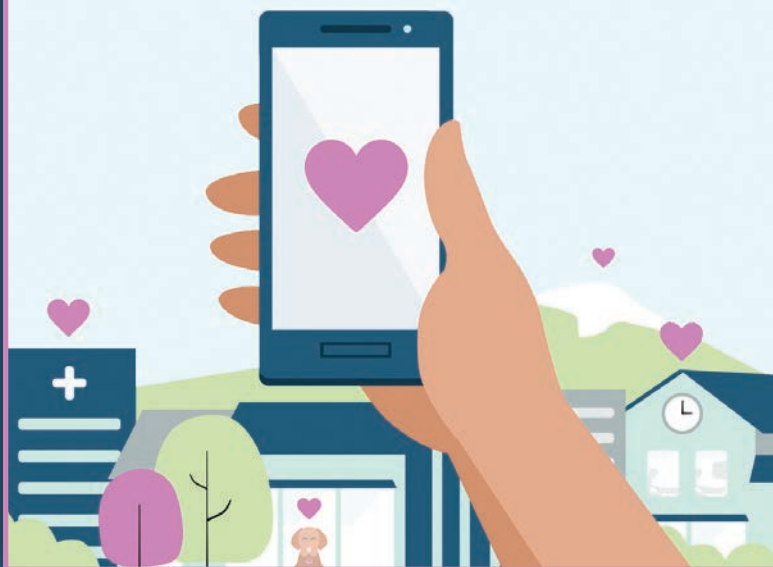


<u>March 2021</u> <i>(throughout the month)</i>	Annual Meeting - Virtual
<u>April 17, 2021</u>	Charlotte Festival & Walk - Charlotte, NC
<u>May 1, 2021</u>	Medical Symposium – Virtual
<u>July 9-11, 2021</u>	HNC Summer Conference - Lake Junaluska, NC
<u>August 7-10, 2021</u>	HNC/HSC Teen Retreat - Rock Hill, SC
<u>October 2, 2021</u>	Raleigh Festival & Walk - Morrisville, NC
<u>December 4, 2021</u>	Holiday Celebration - Greenville, NC



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HEMOPHILIA OF NORTH CAROLINA

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

(800) 990-5557 • [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)

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

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# save the dates



**Fun for the entire family!**

[hemophilia-nc.org/festival](http://hemophilia-nc.org/festival)



**Charlotte**

**Saturday, April 17, 2021**

Mint Street at 3rd St. & MLK Blvd.  
Uptown Charlotte, NC

**Morrisville**

**Saturday, October 2, 2021**

Lake Crabtree County Park  
Morrisville, NC

**Entertainment**

**Music & Games**

**Breakfast & Lunch**

**Photo Booth**

**Face Painting**

**Dog Friendly**

**And More!**

