

# THE C NCENTRATE

THE OFFICIAL NEWSLETTER FOR BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA

Spring 2022

## BIG Changes in Process



Big changes are in process for Hemophilia of North Carolina (HNC), but don't worry as it will not negatively impact any of the programs and services you love. However, you will notice that we are officially ready to transition our name, logo, and website in the coming months! So when you see "Bleeding Disorders Foundation of North Carolina" or "BDFNC," please rest assured that this is our organization. We'll be redirecting our [www.hemophilia-nc.org](http://www.hemophilia-nc.org) website to the new one for at least a year.

We can't wait to share this monumental change with you. As a reminder, this change was driven by YOU, our community

members. This community is diverse in many respects, including the types of bleeding disorders that people have. The new organization name will better represent those who we serve, so that anyone with a bleeding disorder can immediately recognize that we are here for them. So, prepare for positive changes in the months ahead!

It is possible that by the time you have read this article, we may have already changed our name to the Bleeding Disorders Foundation of North Carolina. Rest assured, everything on the following pages, whether it says Hemophilia of North Carolina or Bleeding Disorders Foundation of North Carolina, is for the same organization.

## Watch Your Insurance!

If you live in North Carolina and are on a Marketplace/ACA/Obamacare plan or on a state health plan, make sure that any copay assistance you are receiving is counting towards your out-of-pocket maximum. As of October 1, 2021, these NC insurance plans are required to accept any third-party payments (most often referred to as copay assistance and provided by pharmaceutical manufacturers) and count it towards your insurance. While this was how it had always been, in recent years the insurance companies had been implementing "Copay Accumulator Adjustment Programs" (CAAPs), which would disqualify any third-party assistance from counting.

If you think you may still be experiencing the CAAPs issue, please contact Charlene Cowell ASAP at [advocacy@hemophilia-nc.org](mailto:advocacy@hemophilia-nc.org) or (919) 319-0014.

A very special shout out to Linda Nelson, HNC community member, for testifying to the NC legislature about how CAAPs made her medicine unaffordable. Linda's testimony helped show how these insurance practices were hurting people's ability to stay healthy.

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## Save The Date

**World Hemophilia Day Celebration**  
April 25, 2022  
Virtual

**Unión Latina Event**  
April 30, 2022  
Charlotte Area

**Community Conversations**  
May 17, 2022  
Virtual

**Teen Event**  
May 21, 2022  
Raleigh, NC

**Community Conversations**  
June 21, 2022  
Virtual

**Ultra-Rare Bleeding Disorder/von Willebrand Day**  
June 26, 2022  
Chapel Hill, NC

**Summer Retreat**  
July 8-10, 2022  
Lake Junaluska, NC

**New Member Event**  
July 30, 2022  
Virtual

**NC/SC Teen Retreat**  
August 11-14, 2022  
Rock Hill, SC

**Raleigh Festival & Walk**  
October 22, 2022  
Morrisville, NC

**Holiday Celebration**  
December 3, 2022  
Greenville, NC

**Many more events coming up.**  
See page (27) for the complete list.

**BLEEDING DISORDERS FOUNDATION**   
OF NORTH CAROLINA

260 Town Hall Dr., Suite A  
Morrisville, NC 27560  
(919) 319-0014

[info@bleedingdisordersnc.org](mailto:info@bleedingdisordersnc.org)  
[www.bleedingdisordersnc.org](http://www.bleedingdisordersnc.org)

### MISSION STATEMENT

Bleeding Disorders Foundation 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

#### Bleeding Disorders Foundation of NC

(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  
www.healthcharities.org

### About This Publication

THE CONCENTRATE is the official newsletter for the Bleeding Disorders Foundation of North Carolina (BDFNC). 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 BDFNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the BDFNC office.

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

BDFNC 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  
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 (Adult Clinic): 336-713-5440  
Phone (Pediatric Clinic): 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

**Accessia Health, formerly  
Patient Services Inc. (PSI)**  
Assists persons with chronic medical illnesses  
in accessing health insurance and pharmacy  
co-payment assistance.  
1-800-366-7741  
www.accessiahealth.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

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

### VISION STATEMENT

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

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



## A MESSAGE FROM THE EXECUTIVE DIRECTOR

These last few months have been a whirlwind - in a good way! Between changing our name, getting a new website, transitioning back to in-person and hybrid events, and continuing to work on meeting our strategic plan goals, it's enough to make one's head spin. And this doesn't even scratch the surface of the many other things happening at Hemophilia of North Carolina (HNC)! We are so lucky to have an amazing staff, Gillian & Rebecca, as well as very active volunteers to help us in these important efforts. I wake up every day inspired and energized. With all these incredible changes, how could I not be energized? I believe in the mission and through phone calls, events, and emails, I am reminded by y'all that HNC is making a positive difference in your lives.

This said, I hope that you can be patient and understanding as we navigate these big changes, especially the website and new name. These two initiatives are unlike anything our staff has ever done, so while we hope there aren't any bumps in the road, we know the reality is there probably will be. Even answering our office phone with the current name will take some time and practice! But we're thrilled the day is here and hope you feel the same. Please let us know your thoughts. You can call me at (919) 319-0014 or email me at [c.cowell@bleedingdisordersnc.org](mailto:c.cowell@bleedingdisordersnc.org). I'd love to hear from you!

With appreciation,

*Charlene*

## The Man Behind the HNC Website

*By: Karyn Davis, HNC Board Member*



Have you ever wondered what goes on behind the scenes when you type [hemophilia-nc.org](http://hemophilia-nc.org) into your web browser and are transported to the Hemophilia of North Carolina (HNC) website? If you have, here's something you may want to know. Charles Register, a founding member of HNC, is the one tireless volunteer who has worked diligently to build and maintain the HNC website for many years. Every page, every event registration, every form, and every photo are at your fingertips because of Charles.

Charles's dedication to ensuring the North Carolina bleeding disorders community stays well informed about events, programs, and services takes more than just a few clicks a few times each week. It takes hours of editing, formatting, troubleshooting, attending meetings, and more to create an informative and useful website for all of us to have as a resource. As we look forward to the launch of the new Bleeding Disorders Foundation of North Carolina website, I hope you will join me in taking a moment to reflect and thank Charles for all of his work to support HNC through the years. I'm sure Charles will find new ways to support HNC's mission and vision, but for now, we can thank him for this one thing that he has done so well for so many years. Thank you, Charles!

**BLEEDING  
DISORDERS  
FOUNDATION**  
OF NORTH CAROLINA



## *A Time for Transition*

Readers may notice that *The Concentrate* is being transitioned from Hemophilia of North Carolina (HNC) to the Bleeding Disorders Foundation of North Carolina (BDFNC). It is bittersweet as staff and volunteers write their final articles using "HNC". Starting with the next edition, the newsletter will be fully transitioned to BDFNC.

Likewise, the name and logo will be transitioned on all materials, emails, and social media accounts. Make sure to check your Spam folder for emails, as it's very possible they'll get filtered there because of the new email addresses. For anyone following us on social media, no need to do anything except look for posts to start coming from BDFNC (the accounts will not change aside from the name and logo).





# Community Conversations Support Groups

Virtual Events



Hemophilia of North Carolina (HNC) continues to offer *Community Conversations* support groups on the third Tuesday of every month. Starting in March, HNC is excited to welcome community member Alisha Curtiss as the Community Conversations Group Leader. Alisha has been an active member of HNC for many years, has volunteered as a Parent Mentor, Community Leader, and has sat on numerous committees. She is the mom of two teen boys with hemophilia and has hemophilia herself. She knows the importance of community and finding a support system.

*Community Conversations* are informal Zoom meetings for people to connect and get to know each other. While there are no set agendas for each meeting, each month there is a topic of interest that allows open discussion and the opportunity to share challenges and triumphs. HNC believes that the connections made with others in the bleeding disorders community are essential in managing one's own health and well-being.

For more information about *Community Conversations*, please contact Gillian Schultz, Director of Programs, at [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) or by calling her directly at (919) 272-6000. You can also find out more by visiting the HNC website.



## World Hemophilia Day

April 17, 2022 (WHD)

April 25, 2022 (Celebratory event)

Virtual (on April 25)

Every year on April 17, the international bleeding disorders community celebrates World Hemophilia Day. The theme of this year's World Hemophilia Day is "Access for All: Partnership. Policy. Progress. *Engaging your government, integrating inherited bleeding disorders into national policy.*" By raising and bringing hemophilia and other inherited bleeding disorders to the attention of policymakers, we can increase sustainable and equitable access to care and treatment.

On April 17, visit the World Federation of Hemophilia (WFH) website to share your story and read more about others across the globe. In addition, the Wells Fargo Duke Energy Center in Charlotte will be lit up in red in observance of the day.

Then, on April 25, join Hemophilia of North Carolina (HNC) on Zoom for a virtual World Hemophilia Day celebration sponsored by Sanofi. Celebrate the connection that you share with the global bleeding disorders community as "One Family". Activities will focus on joint health, hemophilia care around the world, and global support. Information about this event is available on the HNC website, [www.hemophilia-nc.org](http://www.hemophilia-nc.org) or by contacting Gillian Schultz, Director of Programs, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org).

For more information, resources, and World Hemophilia Day tools, visit [www.wfh.org/world-hemophilia-day](http://www.wfh.org/world-hemophilia-day)

Hemophilia of North Carolina/  
Bleeding Disorders Foundation of North Carolina

### World Hemophilia Day Event

Monday, April 25, 2022  
6:30 PM  
Virtual Event on Zoom



## Unión Latina Event

April 30, 2022

Charlotte, NC

Save the date for a Unión Latina Event this spring. After a long break of in-person events, it will be so nice to be together again! Hemophilia of North Carolina (HNC) will be sharing more information about the Unión Latina Event by email, phone, text, and on our website, so stay tuned for more information.



## Teen Empowerment Event

May 21, 2022

Raleigh, NC

Hemophilia of North Carolina (HNC) is thrilled with the growth of the Teen Empowerment Program! Save the date for the next Teen Event scheduled to take place in person on May 21 at ParTee Shack in Raleigh. For those who have never heard of ParTee Shack, it is an awesome venue with three indoor mini golf courses. Each course has interactive components,

like a swing that the golfer must use while trying to get their ball in the hole! More details coming soon but for now, please mark your calendars!



## Ultra-Rare Bleeding Disorder & Von Willebrand Disease Education Day

June 26, 2022

Chapel Hill, NC

Hemophilia of North Carolina (HNC) is thrilled to be offering an educational opportunity for community members affected by bleeding disorders, including platelet disorders, ultra-rare factor deficiencies, and von Willebrand disease. With improved treatment guidance and a growing community here in North Carolina, join HNC for the first education day for this part of the community. There will be both educational and networking opportunities. More information will be available soon but for now, make sure to mark your calendar!



# Summer Community Retreat

July 8-10, 2022

Lake Junaluska, NC



For years, Hemophilia of North Carolina (HNC) has been attempting to hold an event at Lake Junaluska Conference and Retreat Center in the beautiful mountains of western NC. But for the past two years, the pandemic has put those plans on hold. So it is with great excitement that HNC is finally going to host an event there this summer!

Join HNC for the first Summer Community Retreat! This event combines the past Adult Retreat and Family Retreat into one large community event. There will be programs and activities for everyone, including kids.

More information will be available soon on the HNC website, or contact Gillian Schultz, Director of Programs, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) if you have any questions. For now, please save the date!

## Attention TEENS: Join the Carolina Crew this AUGUST!

August 11-14, 2022

Rock Hill, SC

Save the date for the annual Teen Retreat scheduled for August 11-14, 2022 at Camp Canaan in Rock Hill, SC! While the in-person retreats in the past two years were canceled because of the COVID-19 pandemic, Hemophilia of North Carolina (HNC) is looking forward to being together again this summer.

Wondering who the Teen Retreat is for? Of course, you know it's for teens. But did you know that it's for ALL teens in the community? If you are

- ages 13-18,
- diagnosed with a bleeding disorder, and/or
- the sibling or child of a person with a bleeding disorder,

then this retreat is for you!! Teens will be allowed to bring one friend or family member with them as long as that person is also a teen.

HNC, in partnership with HSC, is providing this fun, educational, and interactive weekend designed especially for teens in the community. This is a great opportunity to meet new friends, share laughs, challenge yourself, and prepare for your future. If you've never been to one of the HNC/HSC Teen Retreats, please check out the HNC Facebook page for photos.

Be on the lookout for an announcement soon. HNC will provide busing from the East Carolina University Hemophilia Treatment Center in Greenville and the HNC office in Morrisville to Rock Hill, SC.





# Art Therapy Series

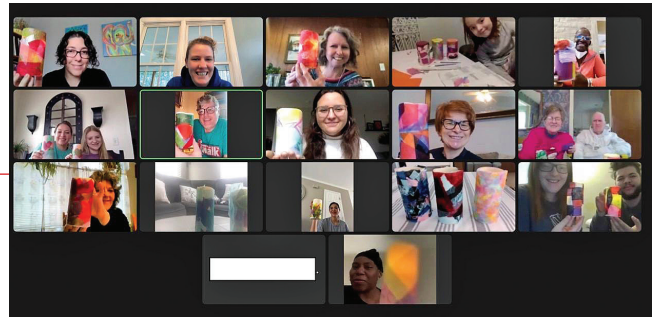
January 15 and February 26, 2022  
Virtual

As part of Hemophilia of North Carolina's (HNC) Mental Health Initiative, the value of alternative therapies for managing one's mental health was explored. One of those modalities was Art Therapy. Art Therapy uses the act of creative art making to provide emotional support. Through the creative process, individuals can learn techniques and strategies that can be used for self-care.

On January 15, community members joined Bridget Pemberton-Smith, Art Therapist and Executive Director of the Art Therapy Institute of North Carolina, to decorate candles. The importance of light, especially during the shorter winter months, was discussed, and everyone decorated an LED candle.

Then, for the second program in the series, on February 26, Bridget led everyone through a Soul Collage<sup>®</sup> session. Using just magazine clippings and a piece of cardstock, participants created individualized cards to represent a part of their personality or soul. It was amazing how different everyone's collages were. These provided a great tool for everyone to open up and share something about themselves.

HNC would like to thank the Art Therapy Institute for its collaboration on this project. If you would like to learn more about Art Therapy, you can visit the American Art Therapy Association's website at [arttherapy.org](http://arttherapy.org).



When it comes to your hemophilia A treatment

## Move beyond the threshold<sup>a</sup>

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<sup>a</sup>Trough level goal is 1% for prophylaxis.

<sup>b</sup>Compared with standard half-life products.

Discover more at [Esperoct.com](http://Esperoct.com).

### What is Esperoct<sup>®</sup>?

Esperoct<sup>®</sup> [antihemophilic factor (recombinant), glycopegylated-exei] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct<sup>®</sup> when you have surgery

- Esperoct<sup>®</sup> is not used to treat von Willebrand Disease

### IMPORTANT SAFETY INFORMATION

#### Who should not use Esperoct<sup>®</sup>?

- You should not use Esperoct<sup>®</sup> if you are allergic to factor VIII or any of the other

ingredients of Esperoct<sup>®</sup> or if you are allergic to hamster proteins

### What is the most important information I need to know about Esperoct<sup>®</sup>?

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

### What should I tell my healthcare provider before using Esperoct<sup>®</sup>?

- Before taking Esperoct<sup>®</sup>, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII
- Your body can make antibodies called "inhibitors" against Esperoct<sup>®</sup>, which may stop Esperoct<sup>®</sup> from working properly. Call your healthcare provider right

away if your bleeding does not stop after taking Esperoct<sup>®</sup>

### What are the possible side effects of Esperoct<sup>®</sup>?

- Common side effects of Esperoct<sup>®</sup> include rash or itching, and swelling, pain, rash or redness at the location of infusion

Please see Brief Summary of Prescribing Information on the following pages.



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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**esperoct<sup>®</sup>**

antihemophilic factor (recombinant),  
glycopegylated-exei





# Music Therapy Event

February 8, 2022

Virtual on Zoom

*By: Diego Mayle, Community Member*

I didn't know what music therapy was but my mom signed us up and I was willing to give it a try. I thought we were going to be talking about music and how it makes us feel. Instead, we got to do some cool activities. My favorite was drawing to the music. I remember doing this in school when I was younger.

We also got to make music with some instruments. My brother really enjoyed the egg shakers. I liked the drums the best.

My family loves to paint and we always listen to music and talk when we do. This was kind of the same thing. We had a lot of fun and I am glad we participated.



# Community Growth at New Member Gathering

February 12, 2022



Several community members new to North Carolina or new to their diagnosis joined the first-ever New Member Gathering that was held on February 12 on Zoom. Participants played a game, got to know one another, and had the opportunity to learn more about Hemophilia of North Carolina's (HNC) many programs and services.

Are you new to HNC? The next New Member Gathering will be on July 30 and will take place on Zoom. More information will be coming out this summer.

# Volunteer Training

January 22, 2022

Hemophilia of North Carolina (HNC) is excited to have launched a strengthened Volunteer Program in 2022. Volunteers have always been the backbone of HNC, and that is not changing. The strengthened Volunteer Program provides HNC's volunteers with formalized training and support.

On January 22, HNC held the first Volunteer Onboarding and Training, where a new volunteer manual was reviewed and an summary of volunteer opportunities were presented, including both in-office and remote roles.

If you would like to sign up to volunteer for HNC, please complete the Volunteer Registration Form: [hemophilia-nc.org/volunteering](https://hemophilia-nc.org/volunteering). The next Volunteer Onboarding and Training will take place on June 4.

If you have any questions, please contact Gillian Schultz, Director of Programs at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org).



# Connecting Through Yoga & Mindfulness

February 20, 2022

Morrisville, NC



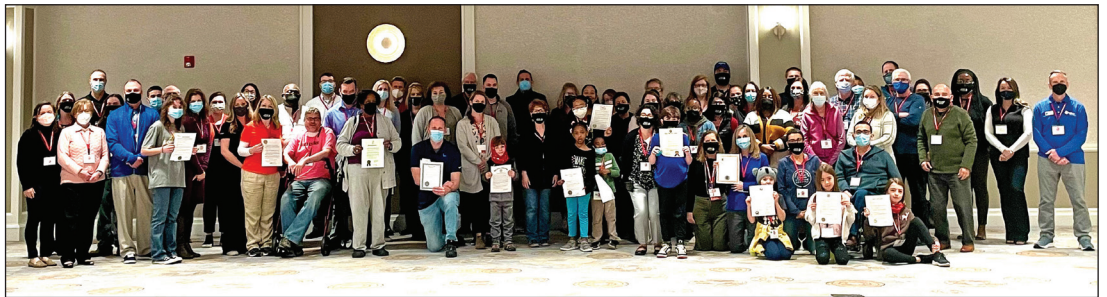
It was the perfect day for yoga with the sun shining! Everyone was in a great mood when they met at the Hemophilia of North Carolina (HNC) office to connect with one another. Fun, thoughtful introductions helped everyone get to know each other better before it was time to stretch out and learn some yoga poses! Afterward, everyone headed over to Carmen's Cuban Cafe to enjoy dinner and hear from Diane Dimon, Dr.RS, about the benefits of meditation. Diane shared many forms of meditation, recognizing that one size does not fit all when it comes to relaxing one's mind. It was the perfect way to end the day! Thank you to CSL Behring and Optum for their support of the event.

## ONE COMMUNITY Winter Conference & Medical Symposium

March 12-13, 2022

Winston-Salem, NC and Virtual

It was with great joy that Hemophilia of North Carolina (HNC) was able to hold its first large, in-person educational event since the start of the pandemic! The Winter Conference & Medical Symposium (previously called the Annual Meeting) was held as a hybrid event on March 12-13 in Winston-Salem. Almost every session was live streamed on Zoom, and there was a mix of in-person and "Zoomed In" speakers. The weekend included two days of informative educational sessions and time for networking.



As with past Annual Meetings, the Winter Conference started with the First Time Attendee Session, to prepare those who have never attended this event with an overview of what to expect over the weekend. HNC was then pleased to hear from Michael Jay Garner, who presented the keynote session, Inside a Clown Doctor's Medical Bag: How Finding the Right Tools Made All the Difference. Following lunch, there were breakout sessions about hemophilia, platelet disorders, ultra-rare factor

*Continued next page*





## Winter Conference & Medical Symposium *continued from previous page*

deficiencies, and von Willebrand disease. Everyone got to learn about the ins and outs of health insurance, a topic that both people new to the community and people who have been part of the community for many decades could appreciate, and then there were sessions about specific treatment options for hemophilia. During dinner on Saturday night, everyone participated in a fun Kahoot! game, which included general and bleeding disorders trivia.

Sunday started with presentations about complementary therapies and the importance of being connected with the community. There were also sessions for HNC's Programs, including HOPE, for families that have a child with a bleeding disorder; SOAR, for women with a bleeding disorder; Blood Brotherhood, for men with a bleeding disorder; partners/spouses of someone with a bleeding disorder; and for the Unión Latina Program. The afternoon wrapped up with a session all about feet and the importance of good footwear, mental health, and then an overview of what HNC is up to, including the highly anticipated name change to the Bleeding Disorders Foundation of North Carolina.

Attendees also had the opportunity to meet with and learn about the variety of products and services available to the bleeding disorders community during the Sponsor Vendor Visits and Industry Open House.

A Winter Conference wouldn't be complete without fun activities for the kids! There was a vibrant children's and teen track, including a painting party, science experiment to learn about blood clotting, a visit from Kaleideum (Winston-Salem children's museum), and Mad Science where the kids made slime! The teens also participated in a Scavenger Hunt around the Benton Convention Center and learned about becoming independent with a presentation from Pfizer as part of the Teen Empowerment Program.



A huge thank you to everyone who helped to make the event possible, including the volunteers, speakers, sponsors, Colburn-Keenan Foundation, Hemophilia Federation of America, and National Hemophilia Foundation.





# Charlotte Festival & Walk Raises Awareness in a Big Way

April 2, 2022  
Charlotte, NC



Thank you to everyone who made the Charlotte Family Festival & Walk for Bleeding Disorders a success! On behalf of the staff and board of directors of Hemophilia of North Carolina (HNC), we would like to express our heartfelt gratitude to the community members, volunteers, donors, sponsors, and other participants who gave their time and effort to this event.

It was so great to be back in person again. Over 305 people came out to celebrate the day with us! Fundraisers, donors, and sponsors helped us to EXCEED our fundraising goal! More than \$35,685 was raised in individual and team donations. After counting up all the donations, the community raised \$70,346, all of which supports Hemophilia of NC's many programs and services!

## **Congratulations to our winners!**

Top Team: SHARPSHARKS

Top Individual Fundraiser: Andrea Mayle

King Droplet: Jeron Hill

Queen Droplet: Amy Morrison

Junior Droplet: William Harrell

Hospital Cup: St. Jude Affiliate HTC

\* The South Cows team has asked to be excluded from the top team and individual awards.

Larry Sprinkle, WCNC Meteorologist, was back once again to help emcee the big day! Did you know? Larry has a special connection to the bleeding disorders community, having played a reporter in "The Ryan White Story"

(movie available on Netflix). Larry helped HNC announce some of the most exciting news of the day – that a megatron overlooking Uptown Charlotte was rotating facts about bleeding disorders to raise awareness AND that HNC officially launched its new website ([www.bleedingdisordersnc.org](http://www.bleedingdisordersnc.org)) and will be transitioning its name over the next few months. Larry also played a hand in having the event aired on the evening news!

There was plenty of fun at this year's Festival including spin art, tabletop games, face painting, balloon art, a photo booth, inflatable basketball hoops, posing with Sir Purr, cornhole, and music courtesy of DJ Banks. The Jumping Dreams Double Dutch team came out to get the crowd excited before everyone started lining up to walk.

*Continued next page*





# Charlotte Festival & Walk Raises Awareness in a Big Way

*continued from previous page*



Nobody left hungry with in-kind donors generously providing plenty of great treats for everyone to enjoy. Delicious ice cream (with many toppings to choose from) were donated by Marble Slab Creamery. Breakfast food included bagels from Poppy's Bagels & More, and fruit from local Food Lion and Harris Teeter stores. Starbucks donated the coffee again this year, keeping everyone caffeinated, while Pepsi donated the waters to be sure no one was dehydrated. Kai, an HNC community member, donated some

mouth-watering pizza after everyone got back from the walk! And of course, our four-legged friends enjoyed their own doggie treat bags.



A special thank you to Linda Kurtz for her continued volunteerism in the Charlotte Festival & Walk planning – from posting on community event calendars to securing in-kind donations – it is truly appreciated! HNC also wants to thank Autobell, Brandon Scott (photography), Charlotte Knights (megatron and ticket vouchers), Charlotte-Mecklenburg Police Department, Duke Energy-Mint Street Parking Garage, Grand Rental Station, Instant Imprints, Kaleideum, Michelle Hodge (Hydrojug), the Map Shop, Virginie Sirianna (photography), and the Winston-Salem Marriott.



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

**SAVE THE DATE:** Join us for the 15th Annual HNC Family Festival & Walk for Bleeding Disorders at Lake Crabtree Park in Morrisville on October 22, 2022. The 2023 Charlotte event date will be announced soon!

*Photos continued page 23*



*BDFNC appreciates the continued support of the  
Charlotte Family Festival Presenting Sponsor*

## GRIFOLS





## Fortalecer el Programa Unión Latina

Por Guillermo Sanchez, Community Member

Bleeding Disorders Foundation of North Carolina: Nuevo Nombre, Nuevos retos para el Programa de la Unión Latina.

Con el propósito de brindar servicios y programas adecuados a la gran variedad de trastornos hemorrágicos, y que además atiendan a las necesidades específicas de las familias latinas que viven en Carolina del Norte, la Fundación tiene el propósito de fortalecer el Programa de la Unión Latina para apoyar a las personas que viven con un algún trastorno hemorrágico y su familia a alcanzar y mantener una mejor calidad de vida.

Las familias Latinas con algún integrante que vive con algún trastorno hemorrágico son parte importante dentro de nuestra comunidad, por lo tanto, debemos de atender sus necesidades a través de un programa que entienda específicamente sus necesidades emocionales, económicas, y culturales.

Por lo anterior, los invitamos a ponerse en contacto con la Fundación para que conozcan nuestros programas y la forma en que pueden beneficiarse de ellos.

A demás, el Programa de la Unión Latina puede enriquecerse y crecer con la participación de las familias latinas, por ello esperamos que nos contactes y nos cuentes sobre tu trastorno hemorrágico, tu familia y tus ideas para mejorar el Programa y crecer juntos.

¡Recuerda: ¡Somos parte de una comunidad fuerte!



## Unión Latina Event

30 de abril de 2022

Charlotte, Carolina del Norte

Marque en su calendario un Evento de Unión Latina esta primavera. Hemofilia de Carolina del Norte (HNC, por sus siglas en inglés) compartirá mayor información sobre el Evento de Unión Latina por correo electrónico, teléfono, texto y en nuestro sitio web, de manera que esté atento a mayor información.

## Actualización sobre el Programa Unión Latina

¡Si su idioma principal es el español, el Programa Unión Latina de Hemofilia de Carolina del Norte (HNC, por sus siglas en inglés) es para usted! Unión Latina brinda información y recursos completamente en español a los miembros hispanohablantes de la comunidad.

¡En 2022, HNC espera volver a interactuar con miembros anteriores de la Unión Latina y además interactuar con nuevos miembros! HNC está preparando un evento en abril para la conexión mutua de los miembros de la comunidad.

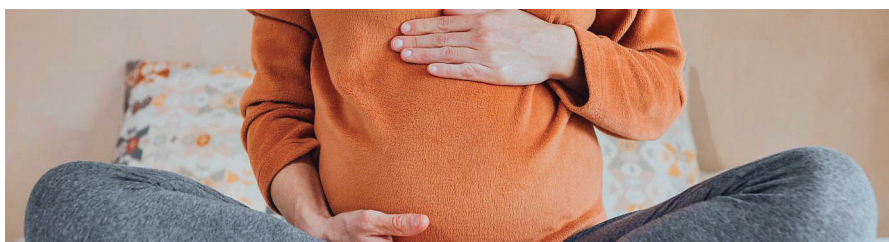
El Programa Unión Latina brinda apoyo e información a las personas y familias latinas en Carolina del Norte que sufren de trastornos hemorrágicos. La programación se ofrece en español, y la misma es posible gracias a un subsidio de Takeda. Si le gustaría mayor información, envíe un texto a Gillian Schultz, Directora de Programas, al (919) 272-6000. También puede visitar el sitio web de HNC para acceder a mayor información.





## Clinical Study and New Website to Focus on von Willebrand Disease and Pregnancy

Reprinted from National Hemophilia Foundation



*This new study was developed to increase understanding of how best to manage bleeding during delivery and the postpartum period in women with VWD.*

The onset of childbirth and the postpartum period are times when

women with von Willebrand disease (VWD) are at an increased risk for excessive bleeding, exposing them to further, and in some instances, serious complications. While there exist therapies with VWD-specific indications, it is not uncommon for these patients to still experience excessive bleeding while receiving treatment. These scenarios are challenging as there is sparse clinical data and a subsequent lack of clear guidance on the optimal management of bleeding in these particular settings.

**The von Willebrand Factor in Pregnancy (VIP) Study** was therefore developed to enhance our understanding of how best to manage bleeding during delivery and the postpartum period in women with VWD. Investigators for this prospective, multicenter trial will focus on maintaining von Willebrand factor (VWF) levels at a specific target level using VWF replacement therapy, and assessing the impact on bleeding rates during and after childbirth.

The VIP study is being stewarded by a trio of experienced principal investigators including Drs. Jill Johnsen (Bloodworks and University of Washington), Barbara Konkle (University of Washington), and Dr. Peter Kouides (Mary M. Gooley Hemophilia Center and University of Rochester). The VIP Study is currently recruiting pregnant women in the U.S. above 18 years of age with VWD of any type.

An exciting component of VIP is a new companion website [[www.vipstudy.com](http://www.vipstudy.com)], created to keep patients and healthcare professionals informed about the study. It will provide information on VIP's design, patient eligibility, and locations of participating centers. The site was officially launched on December 10th during an educational webinar that preceded the American Society of Hematology Annual Meeting.

Source: PR Newswire/The VIP Study, November 28, 2021

## Teen Day

January 8, 2022

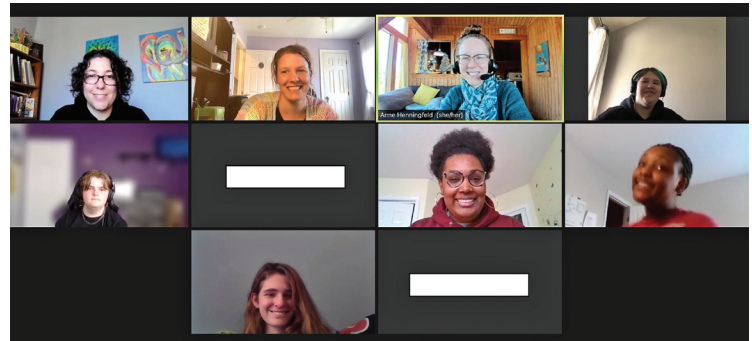
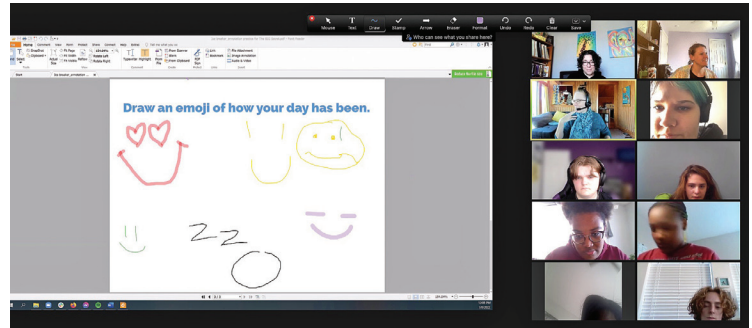
Virtual

By: Addison Dowdy

On January 8, I had the wonderful privilege of taking part in "Teen Day." The session was focused on helping high school students like me prepare for college. The first half of the session was led by Sarita Broadway with College Foundation NC. Ms. Broadway introduced the group to a website, [www.CFNC.org](http://www.CFNC.org). This site, operated by the College Foundation NC, opened some doors to me, and I know that this knowledge will help me in my junior and senior year.

The second part of the session was a fun Virtual Escape Room. The virtual room had sudokus, puzzles, and much more. It was fun getting a chance to work with other teens who are part of the bleeding disorder community like me, and I am happy that I had the chance to be a part of it.

I would like to thank Hemophilia of NC for providing these and other sessions for the bleeding disorders community.



## Bleeding Disorders Word Search

R E C M J G P U X E T A L K R  
Y C I L H R A Q R K E B U J U  
E U X K O F U A U R L K K Q F  
R V C Z A T R Q Q Y E L M D W  
Z H I M T R T Q I G T C I E L  
K G I K Q J P I G I A F T L Z  
M L L T V B K Y N M L A R H O  
Y C R O T I H Q S G P C M C A  
A I L I H P O M E H G T S N V  
C O A G U L A T I O N O M R M  
E L V O N W I L L E B R A N D  
O E Z K B D I I V E Q A X E X  
I L T V Z T V R Q G Y L M R Z  
I G N Q W W I Q I N G D C B V  
O M J W A J X Y L L P X R Q P

Looking for more fun games and quizzes for kids of different ages? Visit the National Hemophilia Foundation's Steps for Living website: <https://tinyurl.com/hemophiliagames>

clotting

coagulation

factor

family

hemophilia

htc

platelet

rare

vonwillebrand





## Blood Brotherhood Program Update

Hemophilia of North Carolina (HNC) is looking forward to offering opportunities for men to connect in person this year! The first event of the year is being planned for this spring in Greenville, NC. In addition to in-person events, HNC encourages men with a bleeding disorder to join the *Community Conversations* virtual meetings, which take place on the third Tuesday of the month on Zoom.

Beyond North Carolina, there are additional opportunities to connect with Blood Brothers from around the country by joining the Hemophilia Federation of America's (HFA) monthly Blood Brotherhood Chat on the second Monday of every month, or by joining the Blood Brotherhood Online Forum. Information about these HFA opportunities can be found on the Blood Brotherhood page of the HFA website: [www.hemophiliafed.org](http://www.hemophiliafed.org).

For more information about the Blood Brotherhood Program, or if you have ideas that you would like to share, please contact Gillian Schultz, Director of Programs, at [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) or (919) 272-6000.



## HOPE Program Update

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

You are not alone raising a child with a bleeding disorder! The Hemophilia of North Carolina (HNC) HOPE Program provides supportive programs, educational opportunities to help navigate raising a child with a bleeding disorder, and resources to help you be an advocate for your child. Not only do you not need to feel alone as a parent, but your child can connect with other children who have a bleeding disorder, helping them to feel less isolated. Whether you have an infant, toddler, preschooler, or school-aged child, find support with others at a HOPE Program event.

There are numerous opportunities throughout the year to connect with other families. HNC holds a monthly support group called *Community Conversations* so parents can share experiences and meet others in the bleeding disorders community. HNC also plans a variety of educational events throughout the year to provide you with resources and support. In addition, there is a Parent Mentoring Program to connect you one-on-one with another parent who is raising or has raised a child with a bleeding disorder. The Winter Conference & Medical Symposium, Summer Retreat, and Family Day are additional opportunities to learn and connect with other families. New in 2022, HNC will be offering New Member Gatherings to help provide additional support to those who are new in connecting with HNC.

If you have questions or would like more information about the HOPE Program, please contact Gillian Schultz, Director of Programs, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or by calling the HNC office at (919) 319-0014.

### RECRUITING PARENT MENTORS

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



## Unión Latina Program Update

If your primary language is Spanish, the Hemophilia of North Carolina (HNC) Unión Latina Program is for you! The Unión Latina provides education and resources to Spanish-speaking community members entirely in Spanish.

In 2022, HNC is hoping to re-engage with past members of the Unión Latina and engage with new members as well! HNC is planning an event in April to connect members of the community with each other.

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. If you would like more information, please text Gillian Schultz, Director of Programs, at (919) 272-6000. You may also visit the HNC website for more information.





# Strengthening the Unión Latina Program

By: Guillermo Sanchez, Community Member



**Bleeding Disorders Foundation of North Carolina: New Name, New Changes for the Unión Latina Program.** With the purpose of providing adequate services and programs for a great variety of bleeding disorders, while also attending to the specific needs of Latino families living in North Carolina, Hemophilia of North Carolina (HNC) aims to strengthen the Unión Latina Program to support people living with a bleeding disorder and their families to achieve and maintain a better quality of life.

Latino families who have a member of their family living with a bleeding disorder are an important part of our community, therefore, we must address their needs with a program that specifically understands their emotional, economic, and cultural needs.

We invite you to contact with HNC to learn about our programs and how you can benefit from them.

In addition, we really believe that the Unión Latina Program can be enriched and grow with the participation of Latino families, so we hope you will contact us and tell us about your bleeding disorder, your family, and your ideas to improve the Program and grow together.

Remember: We are part of a strong community!

## SOAR Program Update

Women and girls with bleeding disorders face unique challenges. Hemophilia of North Carolina's (HNC) SOAR Program is dedicated to helping women and girls overcome those challenges. Specific events are planned to teach women how to advocate for themselves, to provide resources and education about bleeding disorders, and to provide a community that understands.

In February, HNC hosted a women's yoga event in Morrisville. Women had the opportunity to connect with one another during the event. HNC is looking forward to more in-person events later this year. The session *"Carry the Burden No More: Modern Perspectives on 'Carriers' and Women with Bleeding Disorders"* was presented by Dr. Rachael Davis from ECU at the Winter Conference & Medical Symposium. Look forward to additional programming at the Ultra-Rare Bleeding Disorders & von Willebrand Disease Education Day this June, at the Summer Community Retreat in July, and at the Blood Brotherhood and SOAR Weekend in the fall. HNC also hosts a monthly *Community Conversations* support group that provides the opportunity to connect with others who share similar experiences.

As part of the SOAR Program, HNC raises awareness about bleeding disorders in the general public and medical community. HNC is looking forward to participating in a variety of medical conferences in 2022 to raise awareness about women with bleeding disorders. These conferences are vital in furnishing resources to medical providers who may not be aware of the signs and symptoms of bleeding disorders in women and girls.

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, and 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 they may SOAR to their full potential.

Please contact Gillian Schultz, HNC's Director of Programs, for more information about the SOAR Program at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or by calling the HNC Office at (919) 319-0014.





# Teen Empowerment Program



Hemophilia of North Carolina (HNC) is thrilled with the kick-off of the **new** Teen Empowerment Program! The first event was held on January 8. Teens from across North Carolina joined the program where they learned about preparing for college and scholarships. They then participated in a virtual Escape Room. It was great to see all the teens participate! The Teen Track at the Winter Conference & Medical Symposium provided the second opportunity for teens this year. They painted, completed a scavenger hunt, and learned more about transitioning to adulthood. Additional programs are being planned for later this year, including the combined Teen Retreat with HNC's neighbors in South Carolina.

The Teen Empowerment Program is a new program that started just this year. This program will provide multiple opportunities throughout the year for teens to connect with each other. While today's teens with a bleeding disorder are suffering fewer complications from their bleeding disorder than past generations, they still have unique needs. This program will provide an outlet just for them. And HNC also knows that teens who are not diagnosed with a bleeding disorder but have a sibling or a parent with a bleeding disorder also need support. So this program is for them, too.

Thank you to Pfizer for being a Sophomore Sponsor for the Teen Empowerment Program. For more information, please contact Gillian Schultz, Director of Programs, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or by calling her directly at (919) 272-6000.

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Not an actual patient.





## Mental Health Initiative

Over the past two years, Hemophilia of North Carolina (HNC) has been a leader in the bleeding disorders community when it comes to learning about and addressing mental health needs in the bleeding disorders community. On March 1, HNC wrapped up the collection phase of the mental health survey. The information that was collected is being used to determine what your needs are when it comes to the mental health of those diagnosed with a bleeding disorder. With your help, nearly 300 surveys were collected, which will provide valuable data. The Department of Social Impact at the University of North Carolina Wilmington is currently analyzing the results and will present them later this spring. That information will be used to plan future programming, develop mental health resources, and see how HNC can advocate to remove barriers to care. As a leader, HNC has shared the survey with other bleeding disorders chapters across the country so that they can continue this important initiative in their areas.



As with many chronic conditions, the stress of managing a bleeding disorder can lead to emotional distress and other challenges. HNC is committed to moving the conversation about mental health in the bleeding disorders community from talking about it to DOING something about it. The Mental Health Initiative brings that talk to action to support the bleeding disorders community.

*If you're interested in sharing your thoughts or have ideas, consider joining the HNC Mental Health Task Force, which meets quarterly.* Contact Gillian Schultz, Director of Programs, at [gillian.schultz@hemophilia-nc.org](mailto:gillian.schultz@hemophilia-nc.org) or by calling the HNC office at (919) 319-0014 to find out more.

## What is NCABBD? More Alphabet Soup?

By: Kathy Register, HNC Board Member and Community Member



No! These letters stand for the North Carolina Advisory Board for Bleeding Disorders (NCABBD). This is a committee of representatives from all of the North Carolina Hemophilia Treatment Centers (HTCs), the Bleeding Disorders Foundation of NC (that's us--formerly HNC, now BDFNC—more ABC's), and consumers. NCABBD has been meeting for years—it was created over a decade ago in order to keep open the lines of communication between the bleeding disorders community and providers. Members find the board extremely valuable. The

NCABBD looks at issues past, present, and future that could affect our lives: politics, money, healthcare, family, lifestyles, opportunities, employment, and more. We exchange important information to help carry out our respective missions.

During these difficult years of COVID-19, the committee held hands by sharing stories, knowledge, and COVID policies and strategies. All parties were able to benefit greatly by staying in touch and learning what was and wasn't working for consumers and providers. BDFNC served to broadcast the information learned from the advisory board.

Institutions represented: Hemophilia Treatment Center of Levine Cancer Institute and Levine Children's, University of NC Harold R. Roberts Hemophilia and Thrombosis Center, Wake Forest Baptist Hospital Hemophilia Treatment Center, The St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital, the East Carolina University Hemophilia Treatment Center, and of course BDFNC.

The next meeting, using Zoom, will be April 22, 2022.

Anyone interested in becoming a member of this advisory board should contact Steven Humes at [steven.humes@hemophilia-nc.org](mailto:steven.humes@hemophilia-nc.org).



## Bleeding Disorders Foundation of North Carolina (BDFNC) wants to celebrate your important milestones!

*Would you like to receive a card in the mail and celebrate your birthday, anniversary, or event with BDFNC?*

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

## Dr. Paulette Bryant...More Than a Physician

*By: Austin Caldwell and LaQuenta Caldwell-Moody*



There are so many things that we could say about Dr. Paulette Bryant and what she means to our family, but that would take far too long. As we reflect on the time that we spent with Dr. Bryant at Blume Pediatric Hematology/Oncology Clinic, now St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital, my mind keeps going back to the first time we met her. We were very anxious because we didn't know what to expect, but that all changed as soon as she entered the room. Her bright and welcoming smile entered first and then we heard her sweet voice. "Hi, I'm Dr. Bryant and you must be Austin," she said. At that moment my anxieties went away almost instantly. It was something about her presence that made us feel comfortable, at ease, and yes, safe. All these feelings were new to us because we had never had them at Austin's hematology visits before.

Dr. Bryant took her time with us that day as she went over all the things she needed us to know and answered all the questions we had for her. She was very attentive to Austin and was eager to learn all about him (if you know Austin then you know he was all about that because he loves being the center of attention!). As time went on, Austin became a regular fixture at the clinic, and he was always excited to see Dr. Bryant when he had an appointment even when he wasn't feeling well. There was something about her that made him feel as if everything was going to be alright. Her kind and compassionate spirit resonated with us.

Austin was under the care of Dr. Bryant for 15 years, from kindergarten to his freshman year of college. During that time, our relationship was formed, and she became more than his doctor. She became an honorary family member. She has been there for some of our highest highs and our lowest lows. She has prayed with us, for us, and over us. She cares about Austin as a person, not just a patient, and always wanted the best for him. Getting to know Dr. Bryant has been an absolute pleasure. We often tell people that she is our angel on earth. We will be forever in her debt for all that she has done for our family. She has always been honest with us, compassionate, present (day or night) and, most of all, loving, and for that we are forever grateful. Congratulations on your retirement and thank you for being more than a physician!



# Fran Spratley Retires from UNC

By: Jen Newman, MSPT, UNC Hemophilia Treatment Center



The UNC Hemophilia Treatment Center (HTC) would like to announce the retirement of Fran Spratley in December 2021. Fran was UNC's first full-time program manager starting in Feb 2017, and she dedicated over 20 years to the UNC healthcare system working as a nurse in various roles. Fran's work at the UNC HTC primarily focused on program development and management, but what her staff will remember her for the most are her kindness and constant support. Fran is now enjoying her retirement with her husband, their pets, and extended family. We wish her well with her next adventures and hope she remains in touch with the bleeding disorders community, which will so greatly miss her.

## 2022 Friends of BDFNC

*We gratefully acknowledge the individuals who generously donated to BDFNC during the past quarter of 2022  
We extend a sincere thank you to our supporters, some of who have contributed several times during this period.*

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# MAX FEINSTEIN SHARES HIS WORLD

## ON THE NEW HEMOPHILIA-INSPIRED CONCEPT ALBUM *REDEFINE*

### OUT EVERYWHERE **MARCH 25<sup>TH</sup>**

#### IN HONOR OF **BLEEDING DISORDER AWARENESS MONTH**



Whether on stage or on record, **MAX FEINSTEIN** is bent on spilling his guts while encouraging others to do the same. The Jersey City songwriter's "progressive grunge" sensibilities and chameleonic voice combine to create a thoughtful and immediate brand of rock that celebrates vulnerability.

While repairing an elbow heavily damaged by hemophilia, Max was forced to confront the ways in which

the rare bleeding disorder had impacted his mental health. It was during this process that he began to redefine his relationship with his body and mind.

Full of righteous guitars and theatrical vocals, Feinstein's third collection of music, *REDEFINE*, is an emotional rollercoaster of self-talk and self-determination that transcends its chronic illness origins.

#### FOR FANS OF

Paul McCartney, Mike Patton, Ween, Steven Wilson, King Gizzard & the Lizard Wizard, Mastodon, The Mars Volta, Frank Zappa, Primus, working through some stuff, blowing off steam

#### "FEINSTEIN DOES NOT PLAY A ROLE HERE."

From what I can hear, this is a piece of the puzzle that he is. This honesty cannot be staged; these outbursts of passion and feeling are real."

—KMS REVIEWS

"An aesthetic unlike anything we've heard, with a unique vocal timbre and a frenetic interpretation that sounds great through the complex guitar riffs and a dose of psychedelia."

—BOTECO INDIE

"The message couldn't be clearer: Don't hide behind your affliction; use it to inspire yourself and others."

—JIM TESTA, *THE JERSEY JOURNAL*

"This is an impressive amount of damage. Someone with this degree of elbow damage typically wouldn't be able to play guitar like this."

—SIDDHANT MEHTA, MD

"An epic soundscape that is every bit as complex, vulnerable, creative, and honest as the masterful musician that molded it."

—YACK! MAGAZINE





# Charlotte Festival & Walk Raises Awareness in a Big Way

photos continued from page 12



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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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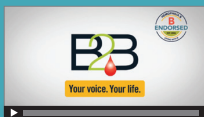
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# Advocacy Needs to Continue, Even During Easy Times

By: Joe MacDonald

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We find ourselves in a delightful spot regarding hemophilia.

My youngest boy's last internal bleeding episode occurred nearly eight years ago. Using prophylactic treatment, we're managing his bleeding disorder well. My older son, who struggled with breakthrough bleeding episodes despite using a recombinant factor VIII product, now finds a happy balance between addressing his personal and medical needs.

Thanks to Hemlibra (emicizumab-kxwh), coping with my boys' medical issues is easier than ever. Gone are the days when three weekly intravenous infusions was the norm in our house. Now my sons do a subcutaneous injection into their thighs

once every other week. As a result, both of my stinky boys appear healthy, and breakthrough bleeds no longer rear their ugly head. The boys are experiencing a level of normalcy that was unheard of for people with hemophilia only a few years ago.

So what are we to do with our extra time, given the progress of hemophilia treatment?

The answer is that we can't forget our past, but we must also keep our eyes open to the future. More treatment developments are possible. I've heard a simple nose spray that helps prevent joint and muscle bleeds is in the works. What was a pipe dream 10 years ago is now our reality.

## Advocacy and education for the community

We must also remember to take care of our community. Advocacy may come easier when things are difficult because we stand to benefit from the changes that we're seeking. That becomes our focus. But we must remember to continue to lobby for the benefit of the entire bleeding disorders community.

By continuing to participate in advocacy, we offer hope to those who have been newly diagnosed and those who continue to struggle with the effects of their disease. After working so hard to seek out what is best for my boys, I can now work toward the betterment of many children's lives.

And we must continue to educate others about bleeding disorders. If we want people to stand up for what is right in the treatment of hemophilia, we must teach our sons and daughters how to share their needs with the people they interact with. Understanding comes with knowledge.

I hope to instill in my sons that even when things are better for us, standing up for others is still important. I am very grateful for the MacDonald boys' season of calm waters. But I don't want them to get complacent. Our roles as advocates remain as crucial as they were during difficult times. Many people depend on and can benefit from our advocacy and efforts to help others better understand this disease.

*Our work is far from over as we look beyond our personal needs and into our community.*



# NC Advocates Went to DC, Virtually

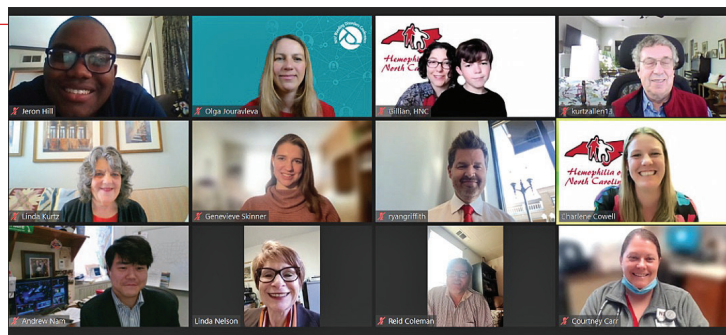
March 1-2, 2022

There were no cars or train rides to get to the National Hemophilia Foundation's (NHF's) annual Washington Days event this year, but advocates were still able to make their mark on Washington, DC. Thanks to technology, North Carolina advocates could still meet with their U.S. Senators and Representatives from the comfort of their own homes. With eleven advocates from around the state and six appointments, it was a busy and productive day filled with virtual meetings!

The "asks" included:

- Help Ensure Lower Patient (HELP) Copays Act - HR 5801
  - Advocates asked Representatives to co-sponsor HR 5801, and for Senators to introduce a companion bill.
  - The HELP Copays Act (HR 5801) clarifies the Affordable Care Act's definition for cost sharing to ensure payments made "by or on behalf of" patients count. It also closes an essential health benefit (EHB) loophole, making any covered item or service part of the EHB package, so that all cost sharing counts.
  - While North Carolina has passed a law banning Copay Accumulator Adjustment Programs (CAAPs), this only covers people on NC Marketplace plans and NC State Health plans. A federal law is needed to protect others like those on private employer plans.
- Continued funding and support for federal programs that support the bleeding disorders community:
  - **National Institutes of Health (NIH):** Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
  - **Centers for Disease Control and Prevention (CDC):** Funds Hemophilia Treatment Center (HTC) surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
  - **Health Resources and Services Administration (HRSA):** Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as PT and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all of their patients.

We need your voice to ensure our policymakers are aware of the importance of these issues for the bleeding disorders community. Interested in learning more about Washington Days, the asks, or how you can get involved? Please contact Charlene Cowell, HNC Executive Director, at [charlene.cowell@hemophilia-nc.org](mailto:charlene.cowell@hemophilia-nc.org).



NC advocates meet with Andrew from Sen. Tillis' office



NC Rep. Foxx meets with NC advocates



NC Advocates thank Ashley from Rep. Ross' office for their support of HR 5801





# Bleeding Disorders Foundation of North Carolina

## 2022 Calendar of Events Highlights

<b><u>April 30, 2022</u></b>	<u>Unión Latina Event - Charlotte Area</u>	<b><u>September 20, 2022</u></b>	<u>Community Conversations - Virtual</u>
<b><u>May 17, 2022</u></b>	<u>Community Conversations - Virtual</u>	<b><u>October 8, 2022</u></b>	<u>Family Day &amp; New Members Event - Location TBD</u>
<b><u>May 21, 2022</u></b>	<u>Teen Day Raleigh, NC</u>	<b><u>October 18, 2022</u></b>	<u>Community Conversations - Virtual</u>
<b><u>June 21, 2022</u></b>	<u>Community Conversations - Virtual</u>	<b><u>October 22, 2022</u></b>	<u>Raleigh Festival &amp; Walk - Morrisville, NC</u>
<b><u>June 26, 2022</u></b>	<u>VWD/Ultra-rare Bleeding Disorders Day - Chapel Hill, NC</u>	<b><u>October 29, 2022</u></b>	<u>Unión Latina Event - Location TBD</u>
<b><u>July 19, 2022</u></b>	<u>Community Conversations - Virtual</u>	<b><u>November 5, 2022</u></b>	<u>Blood Brotherhood Event - Location TBD</u>
<b><u>July 30, 2022</u></b>	<u>New Members Event - Virtual</u>	<b><u>November 15, 2022</u></b>	<u>Community Conversations - Virtual</u>
<b><u>August 11-14, 2022</u></b>	<u>Teen Retreat Rock Hill, SC</u>	<b><u>November 19, 2022</u></b>	<u>Teen Event - Location TBD</u>
<b><u>August 16, 2022</u></b>	<u>Community Conversations - Virtual</u>	<b><u>December 3, 2022</u></b>	<u>Holiday Celebration/ Unión Latina - Greenville, NC</u>
<b><u>August 20, 2022</u></b>	<u>Women's Event - Location TBD</u>	<b><u>December 13, 2022</u></b>	<u>Community Conversations - Virtual</u>
<b><u>September 17-18, 2022</u></b>	<u>SOAR (women)/Blood Brotherhood (adult men) Weekend - Location TBD</u>		

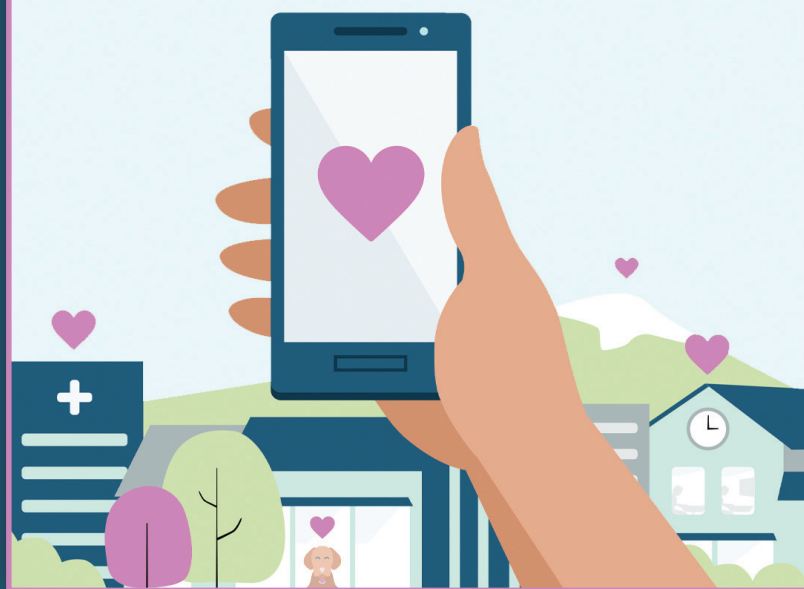
\* We are providing the year's tentative calendar of events early this year so members can save the dates. Events will be added throughout the year and the dates/locations may change. All event details will be sent via email and text as soon as they are confirmed. Please make sure you are getting the information. Email BDFNC at [events@hemophilia-nc.org](mailto:events@hemophilia-nc.org) or call (919) 319-0014 to be added to the email and/or text groups.





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