

THE NCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Summer 2023

BDFNC is Growing!

As the Bleeding Disorders Foundation of North Carolina (BDFNC) continues to expand and develop programs and services for the community, it's important that the staff grow with it.

BDFNC is excited to announce two new additions to the team. Filling newly created positions are Genevieve Skinner, who joined as BDFNC Advocacy Director, and Victoria "Vic" Campos, who came on board as the Events & Outreach Coordinator.

Genevieve Skinner has joined the Bleeding Disorders Foundation of NC as our Advocacy Director. She is an undergraduate student in Washington D.C. at American University. She is majoring in the interdisciplinary studies of Communications, Legal Institutions, Economics and Government in the School of Public Affairs. She is also studying dance, continuing a lifelong commitment to the art.

Continued page 4

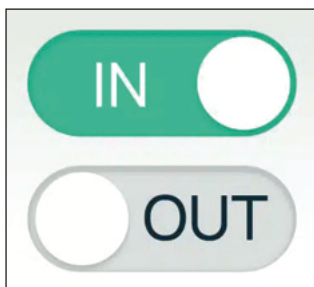


Genevieve Skinner



Vic Campos

Opt In to Get Newsletter at Home



Do you enjoy receiving this newsletter delivered directly to your home, or would you prefer reading this newsletter online?

Contact the BDFNC office to OPT IN to home delivery of *The Concentrate* by December 1 if you want to continue to receive your copy of *The Concentrate* delivered by mail to your home address. **Only members who OPT IN to receiving this newsletter by mail before December 1 will continue to receive *The Concentrate* by mail in 2024.** If you don't OPT IN you will receive a link to read

the newsletter online through a downloadable version of *The Concentrate* on the BDFNC website.

By informing the Bleeding Disorders Foundation of North Carolina (BDFNC) of your preference, you can help BDFNC conserve valuable resources by providing home delivery only to those who select it.

To OPT IN, please do one of the following:

- Update your membership application on the BDFNC website (www.bleedingdisordersnc.org/membership)

and confirm your communication preferences,

- Send an email to

info@bleedingdisordersnc.org,

- Text BDFNC at (919) 271-4171

with your name and address,

- Call the BDFNC office at (919) 319-0014.

In this Edition:

UPCOMING EVENTS	Page 4
RECENT EVENTS	Page 8
SUPLEMENTO DE LA UNIÓN LATINA	Page 10
SOAR SUPPLEMENT	Page 12

Save The Date

Summer Community Retreat

July 7-9, 2023

Morehead City, NC

NC/SC Teen Retreat

August 10-13, 2023

Rock Hill, SC

NHF Conference

August 17-19, 2023

Baltimore, MD

Welcome to BDFNC

August 26, 2023

Virtual

Blood Brotherhood & SOAR Weekend

September 22-24, 2023

Pine Knoll Shores, NC

Unión Latina Event

September 30, 2023

Charlotte, NC

Raleigh Festival & Walk

October 14, 2023

Morrisville, NC

HOPE Family Day

November 4, 2023

Charlotte, NC

Holiday Celebration

December 2, 2023

Gastonia, NC

Many more events coming up.

See page (23) 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
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)

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

National Hemophilia Foundation

(888) 463-6643
www.hemophilia.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 Health Hemophilia Treatment Center

435 Clinic Drive
Module F
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

Novant Health Center for Bleeding Disorders

125 Queens Road, Suite 600
Charlotte, NC 28204
Phone: (980) 302-6600

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.

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.



FROM THE BDFNC OFFICE

More than two years ago, the Bleeding Disorders Foundation of North Carolina (BDFNC) began its Mental Health Initiative. Driven by the ongoing but often private talk about how people with bleeding disorders are suffering from depression, anxiety, and substance abuse, along with the unsettling realization that patients with bleeding disorders have been denied access to inpatient behavioral health treatment because of their bleeding disorder, the Mental Health Initiative was started to learn more about these issues and begin developing ways to actively deal with them.



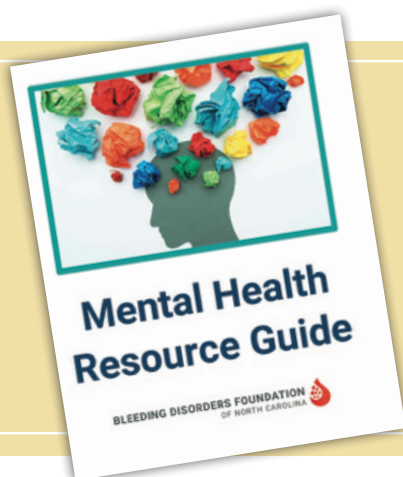
Through the first-of-its-kind survey of patients with a bleeding disorder in North Carolina, we learned that more than one third of patients have or are currently dealing with mental health issues and the complications that affect the mental health of patients with bleeding disorders, including hospitalizations and pain. This survey has since been translated into Spanish, and will soon be distributed to the Spanish-speaking community. We are also looking to distribute a similar survey to parents and caregivers.

To address the issue of inpatient mental health care, I am part of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC). BD SUMHAC is made up of members from the National Hemophilia Foundation, the Hemophilia Federation of America, Hemophilia Treatment Center (HTC) providers, chapter staff, and community members. The mission of BD SUMHAC is to ensure that patients with a bleeding disorder can access appropriate substance use disorder and mental health treatment facilities. BD SUMHAC is trying to learn more about the regulations and guidelines that govern inpatient and residential behavioral health facilities here in North Carolina. **This is where I am asking for YOUR help.** We can use the expertise of people who work in or are knowledgeable about the behavioral health system here in North Carolina. If you work in the mental health field, the NC Medicaid department, or just have an interest in helping, please let me know. It is through a team of dedicated individuals that we will be able to make changes.

And if you are interested in learning more about BD SUMHAC, or you or a loved one have been denied access to inpatient mental health or substance use treatment, please contact me. I can be reached by email at g.schultz@bleedingdisordersnc.org or by calling me directly at (919) 272-6000.

Best wishes,

Gillian



Did you know that BDFNC has an entire webpage dedicated to mental health resources, as well as a Mental Health Resource Guide booklet? These can be accessed from the BDFNC website: <https://bleedingdisordersnc.org/resources/mental-health/>

If you'd like a copy of the booklet, please email Gillian at g.schultz@bleedingdisordersnc.org.



BDFNC is Growing! continued from page 1

Originally from Wake Forest, NC, Genevieve has been a part of the BDFNC community for as long as she can remember, coming to walks and the annual conference with her mom. She first got involved with BDFNC due to her mother's factor I deficiency. Since then, she has worked on issues that affect the bleeding disorders community at the national level while interning with the policy division of the National Hemophilia Foundation. She has also interned for the Bleeding Disorders Foundation of NC for two summers and volunteered for many years before that, even attending her first Advocacy Days when she was 15. Genevieve enjoys the legislative process and is proud to be a part of it on behalf of BDFNC.

Vic (Victoria) Campos recently began her career with BDFNC in June. Vic is originally from San Antonio, Texas, and is fluent in Spanish. She was introduced to this organization by a former supervisor and is passionate about learning more about bleeding disorders. Vic has her undergraduate degree in Psychology with minors in Social Work and Nonprofit Studies from NC State University and she is currently in her second and final year of her Master of Social Work degree at NC State University. Vic spends her free time with her husband and their dog Mookie, going on adventures to different states, and playing board games (Yahtzee is their current favorite).

Event Attendance Policy

The Bleeding Disorders Foundation of North Carolina (BDFNC) is pleased to offer all events and activities (except fundraisers) free of charge for your participation. While they are free for you to attend, there are significant costs associated with events. To help ensure that resources are used in the most efficient way possible, BDFNC established the *Event Registration and Attendance Policy*. This policy outlines what happens when you do not show up for an event, as well as how registrations are handled by BDFNC. Please let us know if you are unable to attend an event for which you have registered, so we can be good stewards of the money that has been raised and donated to fund these events.

You can read the Event Registration and Attendance Policy in full on the BDFNC website: bleedingdisordersnc.org/event-registration-and-attendance-policy.

See you at an event soon!

Summer Community Retreat

July 7-9, 2023

Morehead City, NC

By the time all the fun at the Summer Community Retreat takes place, this edition of *The Concentrate* will already be in production. Read all about it in the fall edition.



Attention TEENS: Join the Carolina Crew this AUGUST!

August 10-13, 2023

Rock Hill, SC

Registration is open for the annual Teen Retreat, scheduled for August 10-13, 2023 at Camp Canaan in Rock Hill, SC!

Wondering who can go to the Teen Retreat? Of course, you know it's for teens. But did you know that it's for ALL teens in the community, ages 13-18?

- Teens diagnosed with a bleeding disorder
- Siblings of someone with a bleeding disorder
- Children of someone with a bleeding disorder



Teens will be allowed to bring one friend or family member with them as long as that person is also a teen.

The Bleeding Disorders Foundation of North Carolina (BDFNC) will once again partner with the Bleeding Disorders Association of South Carolina (BDASC) to provide this fun, educational, and interactive weekend designed for the specific needs of 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 NC/SC Teen Retreats, please check out the BDFNC Facebook page for photos.

Visit the BDFNC website for more information.



Welcome New Community Members

August 26, 2023

Virtual Event

Now that you have been connected with the Bleeding Disorders Foundation of North Carolina (BDFNC), you may be wondering about the programs and services that are available to you. Join Gillian Schultz, BDFNC's Director of Programs, and also mom of a son with hemophilia, for "Welcome to BDFNC!" on August 26 at 10:00 AM on Zoom.

Gillian will review all BDFNC programs and services, discuss how you can get involved, and how BDFNC can support you. Navigating the world of bleeding disorders can be challenging. BDFNC strives to provide you with the resources to help you, and to connect you with a community that understands.

Registration will be available on the BDFNC website.



A Weekend for Men and Women Diagnosed with a Bleeding Disorder

September 22-24, 2023

Pine Knoll Shores, NC



The Bleeding Disorders Foundation of North Carolina (BDFNC) will be returning to the beloved Trinity Center for the Blood Brotherhood and SOAR Weekend this September. There will be three days and two nights of connection and community for adults (and their partners/spouses) diagnosed with a bleeding disorder. There will be plenty of time to learn and socialize with other community members. The community connections that you will make have been found to be so important when living with a bleeding disorder.

More information and registration will be available on the BDFNC website later this summer.

Unión Latina Event in Charlotte

September 30, 2023

Charlotte, NC

Save the date for a Unión Latina event on September 30, 2023. This event will provide time to network with other Spanish-speaking individuals and families affected by bleeding disorders. These events are a great opportunity to learn more about bleeding disorders, as well as to connect with others in the community. Presentations and resources provided are in Spanish. More information will be available on the BDFNC website later this summer. Anyone interested in learning more about BDFNC's Unión Latina events can send an email to Gillian at g.schultz@bleedingdisordersnc.org or text her at (919) 272-6000.



Raleigh Festival & Walk for Bleeding Disorders

October 14, 2023

Morrisville, NC



It's almost time for the 16th annual Raleigh Family Festival & Walk for Bleeding Disorders! This exciting event will be on October 14 at Lake Crabtree Park in Morrisville. In addition to being a fun-filled few hours, it's also an important fundraiser for the Bleeding Disorders Foundation of North Carolina (BDFNC) and one of the best ways to raise awareness among the general public.

The Festival & Walk is BDFNC's largest fundraiser, with 100% of all proceeds supporting BDFNC's mission of advocacy, education, promotion of research, and delivery of supportive programs and services. This year's Raleigh fundraising goal is \$100,000, with a goal of \$35,000 coming from individual and team fundraising.



More information about the event will be available on the BDFNC website soon. In the meantime, please save the date and tell your friends and family!

HOPE Family Day at the Great Wolf Lodge

November 4, 2023
Concord, NC



Save the date for the HOPE Family Day on November 4 at the Great Wolf Lodge in Concord. This will be a single-day event. Priority registration will be for families who have a child twelve or under who is diagnosed with a bleeding disorder. There will be a presentation, lunch, and a visit to the waterpark.

The HOPE Program is the Bleeding Disorders Foundation of North Carolina's (BDFNC's) program to support families with children diagnosed with a bleeding disorder. More information and registration will be available later this year on BDFNC's website.

Bring in the Holidays with BDFNC

December 2, 2023
Gastonia, NC

While you are probably sweating off this summer's heat, save the date for the Bleeding Disorders Foundation of North Carolina (BDFNC) Holiday Celebration on December 2 in Gastonia. Bring some holiday cheer as BDFNC celebrates 2023, the holiday season, and you. This event is always a popular one, with activities for people of all ages as well as gifts for all the kids in attendance. More information will be coming this fall.



Community Conversations

Third Tuesday of Each Month



The Bleeding Disorders Foundation of North Carolina (BDFNC) knows how important personal connections are for people affected by bleeding disorders. One way that BDFNC provides this support is through a monthly, virtual meet-up called Community Conversations. Always held on the third Tuesday of the month at 7:00 pm, these informal meetings are facilitated by longtime community member Alisha Curtiss. Alisha is the mom of two teen boys with hemophilia and is diagnosed with hemophilia herself. Each month, she leads a conversation. Community Conversations are meant to be FOR YOU, about topics that are relevant to what you deal with.

Whether you want to think of it as a support group or just a monthly chat with fellow community members is up to you, but whatever you think, BDFNC hopes that it provides you with the support and community that you are looking for. More information can be found on the BDFNC website or by emailing Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org.



Charlotte Festival & Walk – A Success!

April 22, 2023

Charlotte, NC



Morning storms did not stop the Bleeding Disorders Foundation of North Carolina (BDFNC) from hosting an amazing Family Festival & Walk for Bleeding Disorders in Charlotte this past April. While the sky opened up during the early morning setup, the rain cleared out, and even blue skies were seen during the event itself. In all, more than \$61,000 was raised to support BDFNC programs and services! There were 21 teams, and about 250 individuals braved the rain to come out on April 22.

Congratulations to the winners of this year's awards:

- Top Fundraising Team: WillPower
- Most Enthusiastic First-Time Fundraiser: Avery Miller
- Most Individual Donors: Jeron Hill
- Top Fundraiser Under 18: William Hodges
- Team with the Most Active Fundraisers: SHARPSHARKS
- Best Team T-shirt: Team Diego and Team G-Man
- Hospital Cup: Novant HTC



BDFNC is already planning for next year's Charlotte Festival & Walk. Save the date for April 27, 2024. The event location will be the same, but there will be a new walk route next year.

Medicaid Unwinding 101

May 2, 2023

Virtual

Have you heard people talking about "Medicaid Unwinding?" Regardless of whether you or your family is on Medicaid, this is a significant event that everyone should be aware of. As part of educating the community about this topic, the Bleeding Disorders Foundation of North Carolina (BDFNC) held a virtual event to provide a 101 on what is going on with Medicaid Unwinding. Attendees received a thorough overview, and some resources, as well as an opportunity to ask questions. BDFNC will continue to provide information to the community.

To learn more, please contact the BDFNC office for information.

Blood Brothers Get Together for Fishing & Connections

May 6, 2023

Morrisville, NC

It was a beautiful day for the Blood Brotherhood Fishing & Connections event at Lake Crabtree County Park. Guys with bleeding disorders had an opportunity to catch some fish, share stories, and enjoy the day together. Even though the lake was catch-and-release, attendees are pretty sure more than one fish was caught throughout the day! More events are being planned for the Blood Brotherhood Program, so stay tuned for more fun events.



Advocates Rocked It at Advocacy Days

May 17-18, 2023

Raleigh, NC

On May 18, several members of the Bleeding Disorders Foundation of North Carolina (BDFNC) went to the North Carolina Capitol to advocate for issues important to the bleeding disorders community.

After advocating for more than a decade about the importance of Medicaid expansion, advocates were excited to go to the legislature this year to thank their representatives and senators for approving Medicaid expansion. With the expansion of Medicaid, there is a lower risk of someone with a bleeding disorder falling into the “coverage gap.” This can prevent long-term disability and potentially death for members of the bleeding disorders community and help reduce the strain on the healthcare system. Advocates also discussed with their legislators and their staff the importance of all Medicaid Managed Care Organizations ensuring that all Hemophilia Treatment Centers (HTCs) are in network.



BDFNC meets with Sen. Rachel Hunt

Advocates found the experience to be “fulfilling” and “empowering,” and were excited that “legislators recognized us as the ‘group in red.’” A first-time advocate even said, “the process was much easier than I thought it would be, as the staff of BDFNC prepared me for what to expect the night before meeting with legislators.” If you are interested in becoming an advocate, email advocacy@bleedingdisordersnc.org to join the monthly advocacy



BDFNC meets with Rep. Julie von Haefen

call. No prior experience needed! Your story is important. As an advocate said, “They won’t know anything about us if we don’t tell them.”

Reframe Your Mindset

May 22, 2023

Charlotte, NC



Twenty-eight community members came out to Maggiano’s Little Italy for dinner and an educational program on May 22 in Charlotte. Virginia Chandler, Genentech Clinical Nurse Educator, presented “Reframe Your Mindset,” which explored how to examine scenarios and think about them in different ways to be more optimistic.

It was great seeing so many community members together for a great dinner. Thank you to Genentech for sponsoring this event.



Actualización del Programa Unión Latina

Es importante que las personas que viven con un trastorno hemorrágico encuentren una comunidad con otras personas que también padecen un trastorno hemorrágico. Cuando su idioma principal es el español, la importancia de esto aumenta ya que es importante no solo encontrar personas que entiendan su afección de salud sino también su cultura e idioma. El Programa Unión Latina de la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) brinda oportunidades para involucrarse y participar en diferentes actividades para que usted y su familia puedan informarse y educarse sobre los trastornos hemorrágicos, así como para brindar recursos para que puedan recibir tratamiento médico.

La Unión Latina está dirigida por el miembro de la comunidad Guillermo Sánchez, quien siempre está dispuesto a comunicarse con usted y hablar sobre sus experiencias. BDFNC espera hacer crecer la Unión Latina a lo largo de 2023. Si desea obtener más información o participar, comuníquese con Gillian Schultz, Directora de Programas, al correo electrónico events@bleedingdisordersnc.org.

¡BDFNC está creciendo!

A medida que la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) continúa expandiéndose y desarrollando programas y servicios para la comunidad, es importante que el personal crezca con la fundación.

BDFNC se complace en anunciar dos nuevas incorporaciones al equipo. Genevieve Skinner, quien se unió como Directora de Apoyo de BDFNC, y Victoria “Vic” Campos, quien se incorporó como Coordinadora de Eventos y Difusión, ocuparon estos puestos recién creados.

Genevieve Skinner se unió a la Fundación de Trastornos Hemorrágicos de Carolina del Norte como nuestra Directora de Apoyo. Es una estudiante de licenciatura en Washington, D.C., en la American University. Se está especializando en los estudios interdisciplinarios de Comunicaciones, Instituciones Jurídicas, Economía y Gobierno en la Escuela de Asuntos Públicos. También está estudiando danza, continuando con su compromiso de por vida con el arte.

Originaria de Wake Forest, N.C., Genevieve ha sido parte de la comunidad de BDFNC desde que tiene memoria, asistiendo a caminatas y a la conferencia anual con su madre. Primero se involucró con BDFNC debido a la deficiencia de factor I de su madre. Desde entonces, ha trabajado en temas que afectan a la comunidad de trastornos hemorrágicos a nivel nacional mientras realizaba una pasantía en la división de políticas de la Fundación Nacional de Hemofilia. También realizó una pasantía para la Fundación de Trastornos Hemorrágicos de Carolina del Norte durante dos veranos y fue voluntaria durante muchos años antes de eso, incluso asistió a sus primeros Días de Apoyo cuando tenía 15 años. Genevieve disfruta del proceso legislativo y se enorgullece de ser parte de él en nombre de BDFNC.

Vic (Victoria) Campos recientemente comenzó su carrera con BDFNC en junio. Vic es originaria de San Antonio, Texas, y habla español con fluidez. Un antiguo supervisor la presentó a esta organización y le apasiona aprender más sobre los trastornos hemorrágicos. Vic cuenta con una licenciatura en Psicología con especialización en Trabajo Social y Estudios sin Fines de Lucro de la NC State University y actualmente está en su segundo y último año de su Maestría en Trabajo Social en la NC State University. Vic pasa su tiempo libre con su esposo y su perro Mookie, yendo a aventuras a diferentes estados y jugando juegos de mesa (Yahtzee es su favorito actualmente).



Genevieve Skinner



Vic Campos

Miembros de Unión Latina van a Greenville

24 de junio de 2023
Greenville, NC



Los miembros de la comunidad Unión Latina tuvieron una tarde divertida en Captain Jack's Miniature Golf en Greenville, NC. Además del minigolf, los participantes tuvieron la oportunidad de presentarse y conocerse.

Yinell Núñez, educadora de salud bilingüe de Takeda, inauguró el evento con un rompehielos interactivo que hizo reír a todos. Los asistentes tenían que lanzarse una pelota por la sala mientras decían el nombre de la persona. Para la última ronda, se estaban lanzando cuatro bolas y todos sabían los nombres de los demás.

Una vez que todos dejaron de reírse con este juego, Yinell presentó el tema de la resiliencia. Manejar el estrés es un aspecto importante de nuestra vida cotidiana. Esta presentación abordó algunas de las causas comunes del estrés y proporcionó algunos ejemplos de cómo adaptarse y manejar mejor la adversidad. Como presentación interactiva, los participantes exploraron lo que significa ser resiliente y aprendieron algunas habilidades asociadas, además de obtener consejos y herramientas para llevar un estilo de vida saludable.

Después del helado, ¡todos probaron suerte

en el minigolf! Este campo de 18 hoyos bajo techo es único y brindó otra oportunidad para las risas y el compañerismo. ¡Fue un día fantástico!



Managing Bleeding Disorders in Pregnancy Requires Early Diagnosis, Multidisciplinary Care

September 27, 2022

By: Rose McNulty

Reprinted from AJMC

Pregnant patients with inherited bleeding disorders face an elevated risk of life-threatening bleeding during pregnancy, delivery, and the postpartum period, making the identification and management of these disorders crucial to the mother and newborn's health. A recent review details current knowledge on mitigating the risk for carrying mothers with hemophilia or von Willebrand disease (VWD) and their children.

Although healthy women experience changes to the hemostatic system throughout pregnancy, childbirth, and the postpartum period that support coagulation to minimize bleeding, these changes might not fully protect patients with hemophilia or VWD. Understanding the inheritance patterns of bleeding disorders and being aware of normal levels of procoagulant and anticoagulant factors in newborns is another key aspect of management.

Hemophilia is characterized by low levels of coagulant factors VIII or IX, and factor VIII in particular increases throughout pregnancy. Although the increase is normally sufficient in healthy women, the increase is inconsistent between women with hemophilia and may not be enough to prevent postpartum bleeding. Treatment by a multidisciplinary team at a care center affiliated with a hemophilia treatment center (HTC) is the ideal scenario for this patient group to reduce the risk of complications. Contextual information about the mother's family and prepregnancy counseling on the potential for genetic transmission would ideally be in place at the HTC.

To assure sufficient levels of coagulant factors are present at delivery, factor levels should be checked early in pregnancy and at least at 28 to 34 weeks of pregnancy.

Desmopressin (DDAVP) or factor replacement therapy is recommended for patients whose factor levels are lower than 50% by week 34 of pregnancy, although factor replacement is the first choice if needed due to the potential risk of neonatal or maternal hyponatremia with DDAVP. The factor level target should be 100% to 150%.

Continued next page



Managing Bleeding Disorders in Pregnancy Requires Early Diagnosis, Multidisciplinary Care *continued from previous page*

Determining the gender of the fetus is also important, as males carry a 50% risk of inheriting the disease and being at risk of neonatal bleeding while females have a 50% chance of being carriers with mildly low factor levels and little risk of neonatal bleeding. Chorionic villus sampling (CVS) or amniocentesis to evaluate fetal DNA is suggested for mothers of male fetuses. At birth, intracranial hemorrhage is the greatest concern for a newborn with hemophilia.

VWD is a more heterogeneous condition than hemophilia, although some management aspects are similar. During pregnancy, von Willebrand factor (VWF) levels increase to mitigate bleeding at delivery, but there is significant variation in VWF levels in expectant mothers with VWD. Those with type 1 VWD tend to show bleeding profile improvement throughout pregnancy as factor levels increase. Those with type 2 VWD show an increase in defective endogenous VWF, but not in VW activity. In women with type 3 VWD, the most severe form, both VWF and factor VIII typically remain low during pregnancy. Factor replacement therapy can help compensate for the lack of natural factor level increases.

As in hemophilia, target factor levels should be a minimum of 50%, targeting 100% to 150% at delivery. Factor replacement therapy with VWF containing plasma-derived factor VIII concentrate has been the most used intervention, although recombinant VWF may be more effective, the study authors note. To manage the risk of postpartum hemorrhage, prophylaxis with antifibrinolytics is recommended, and postpartum tranexamic acid is recommended when the patient's bleeding score is high or there is a history of postpartum hemorrhage. As with hemophilia, DDAVP is another treatment option but carries concerns of maternal hyponatremia.

With hemophilia and VWD, the safety of neuraxial anesthesia has been called into question. Although it is still debated, experts agree that it should not be administered when factor activity is below 50%. In newborns, the greatest concern regarding bleeding complications is for those with type 2 or 3 VWD.

Overall, the review emphasizes the importance of early and accurate diagnosis of bleeding disorders in pregnant women and the fetuses they carry. Additionally, appropriate treatment for insufficient factor levels is crucial to uneventful pregnancy and birth. Treatment by a multidisciplinary care team and ideally involving an HTC are both key to improving the likelihood of a safe delivery for mothers and newborns.

Reference: Janbain M, Kouides P. Managing pregnant women with hemophilia and von Willebrand disease: How do we provide optimum care and prevent complications? *Int J Womens Health*. 2022;14:1307-1313. doi:10.2147/IJWH.S273043

Article can be found here:

<https://www.ajmc.com/view/managing-bleeding-disorders-in-pregnancy-requires-early-diagnosis-multidisciplinary-care>



Attention SOAR Community Members: Make sure to save the date for the 2023 SOAR & Blood Brotherhood Weekend, taking place September 22-24 in Pine Knoll Shores, NC. This weekend, held in the beautiful Outer Banks, will offer an opportunity for women to network and learn about issues affecting females with bleeding disorders.

SUPPORTING ALL OF THE BLEEDING DISORDERS COMMUNITY

Ultra-Rare Bleeding Disorders & Von Willebrand Disease Education Day

June 3, 2023

Chapel Hill, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) hosted the second Ultra-Rare Bleeding Disorders & Von Willebrand Disease Education Day on June 3 at the Friday Center in Chapel Hill. Since changing the name of the organization from Hemophilia of North Carolina to the Bleeding Disorders Foundation of North Carolina, the staff has been working hard to ensure that all bleeding disorders are provided with education and resources. While that can be challenging since ultra-rare bleeding disorders range from 1 in 300,000 to 1 in 2 million depending on the diagnosis, what can be seen are the similarities between each bleeding disorder. And while von Willebrand Disease (VWD) affects up to 1 in 100 individuals, with mild symptoms for many affected, people with VWD are underdiagnosed.



Offered as a hybrid event, close to 30 people joined BDFNC to learn and connect. Starting with an interactive game, attendees got to compete to find out who knew the most about bleeding disorders. There were breakout sessions for ultra-rare bleeding disorders and VWD, as well as sessions on how to manage pain and provide input on what kind of programs would be



beneficial for those affected. An interactive session after lunch kept everyone engaged where they could see that while their bleeding disorders might not be the same, they experience similar situations and are all resilient. The day concluded with a short overview of self-advocacy.

One participant said that they “enjoyed all the information and were thankful for the VWD programs and focus on the 2021 [Medical and Scientific Advisory Council VWD Guidelines] update.” Another person said, “It’s incredibly valuable to meet others with similar struggles.”

BDFNC will continue to work on ways to support people affected by all bleeding disorders in the future, and it looks forward to hosting this event again in 2024.

Unión Latina Members Go to Greenville

June 24, 2023

Greenville, NC

Unión Latina community members had a fun afternoon at Captain Jack’s Miniature Golf in Greenville, NC. In addition to the mini golf, participants had an opportunity to learn and meet one another.

Yinell Nunez, Takeda Bilingual Health Educator, kicked off the event with an interactive ice breaker that had everyone laughing! Attendees had to toss a ball around the room to one another while calling out the person’s name. By the last round, four balls were being tossed around and everyone knew each other’s names.

Once everyone stopped laughing from the game, Yinell presented the on the topic of resilience. Managing stress is an important aspect of our everyday lives. This presentation discussed some of the common causes of stress and provide some examples of how to better adapt and manage adversity. As an interactive presentation, participants explored what it means to be resilient and learn some associated skills, as well as gained tips and tools for living a healthy lifestyle.

After ice cream, everyone tried their hand at some mini golf! This indoor, 18-hole course is unique and provided another chance for laughter and comradery. It was a fantastic day!





Blood Brotherhood Program Update

The Bleeding Disorders Foundation of North Carolina (BDFNC) knows the importance of making connections so that you don't feel isolated. The Blood Brotherhood Program does just that – it connects men with bleeding disorders to share experiences and camaraderie.

In 2023, BDFNC is looking to strengthen the Blood Brotherhood Program. Whether you have been part of the North Carolina bleeding disorders community for years, are new to North Carolina, or you are a young adult, BDFNC hopes that you will participate in 2023.

Following this spring's Blood Brotherhood event in Morrisville, other opportunities for Blood Brothers to connect this year will be at the Summer Community Retreat, the Blood Brotherhood & SOAR Weekend, a Blood Brotherhood Event late in the fall, and during Community Conversations Support Group meetings.

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.

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@bleedingdisordersnc.org.



HOPE Program Update

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

Have you seen the HOPE logo and wondered what it is? The Bleeding Disorders Foundation of North Carolina (BDFNC) HOPE Program provides support for families who have a child diagnosed with a bleeding disorder. Most programs are geared towards families with children under twelve.

In 2023, BDFNC is looking forward to providing additional resources for families, whether they have a newly diagnosed child with a bleeding disorder or they have been part of the community for longer. Infusion support, daycare and school resources, what activities are safe for children with a bleeding disorder, unique needs of undiagnosed siblings, and more are some of the topics and/or resources that BDFNC is planning to provide.

While it is still summer, you might already be planning for your child to go back to school this fall. If you are looking for resources for sending your child with a bleeding disorder to school, BDFNC has a Back to School Toolkit. Contact BDFNC to get a copy.

If you are the parent of a child with a bleeding disorder, you know the importance of making connections with other parents. Join the BDFNC HOPE Facebook group by contacting Gillian Schultz, Director of Programs. You can also read more about the HOPE Program, including Gillian's experience raising a now 12-year-old with hemophilia on the BDFNC website.

The mission of HOPE is to improve the quality of life for families of children with a bleeding disorder, so they may HOPE to lead a fulfilling life.

If you have questions or would like more information about the HOPE Program, please contact Gillian at events@bleedingdisordersnc.org or by calling the BDFNC office at (919) 319-0014.



Unión Latina Program Update

It is important that people who live with a bleeding disorder find community with others also affected by a bleeding disorder. When your primary language is Spanish, the importance of this is increased since it is important not only to find people to understand your health condition but also your culture and language. The Bleeding Disorders Foundation of North Carolina (BDFNC) Unión Latina Program provides opportunities to get involved and participate in different activities so that you and your family can become informed and educated about bleeding disorders, as well as to provide resources so that you can receive appropriate medical treatment.

The Unión Latina is led by community member Guillermo Sanchez, who is always willing to reach out to you and talk about your experiences. BDFNC looks forward to growing the Unión Latina throughout 2023. If you would like more information or to get involved, contact Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org.



SOAR Program Update

The Bleeding Disorders Foundation of North Carolina (BDFNC) SOAR Program is 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.

While fall may seem far away, BDFNC is starting to gear up for exhibiting at a number of conferences held each fall to raise awareness about women and girls with bleeding disorders. The North Carolina Nurses Association and the School Nurse Association of North Carolina annual conferences are two events where we focus our awareness and outreach on women and girls with bleeding disorders.

BDFNC hopes to connect with women with bleeding disorders at the upcoming Summer Community Retreat in July and Blood Brotherhood and SOAR Weekend in September. In addition, to connect with other women diagnosed with a bleeding disorder, request access to the private SOAR Facebook group.

BDFNC would also love to hear from YOU, about your story as a woman with a bleeding disorder, in order to share experiences so other women don't have to feel so alone. Email Gillian Schultz, Director of Programs, to request access to the Facebook group or with your personal story at events@bleedingdisordersnc.org.

Teen Empowerment Program



The Bleeding Disorders Foundation of North Carolina (BDFNC) realizes that teens have unique needs as they are growing up, becoming independent, and learning to manage their bleeding disorder on their own. BDFNC also recognizes that ALL teens in the bleeding disorders community can benefit from supportive programs, regardless if they are the person in the household with a bleeding disorder. The Teen Empowerment Program supports all teens impacted by a bleeding disorder.

BDFNC is preparing for the Teen Retreat along with the Bleeding Disorders Association of South Carolina. This annual event brings together teens from North and South Carolina for four days of team building and relationship building. BDFNC is also planning to have a couple of smaller teen events later this year.

For more information about the Teen Empowerment Program, please contact Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org or by calling/texting (919) 272-6000.

A Program for Spouses, Partners, and Caregivers

Nick Henry, who is the partner of someone with a bleeding disorder, is helping BDFNC to create a program specifically for spouses, partners, and caregivers in order to provide support and resources. Interested in learning more or getting involved? Reach out to Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org or (919) 319-0014 and she can connect you with Nick.



Mental Health Initiative

The Bleeding Disorders Foundation of North Carolina (BDFNC) continues to prioritize the importance of mental health among those affected by bleeding disorders. BDFNC 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.

Please help BDFNC normalize the conversation about mental health by sharing your story. While talking about physical health and mental health should not be different, there is still a stigma about sharing mental health stories. Help BDFNC change this. You can share your story (either with or without your name) here: <https://www.surveymonkey.com/r/WRB6GTH>.

BDFNC has published a Mental Health Resource Guide to provide resources for individuals in managing their mental health. If you would like a copy, please contact BDFNC at events@bleedingdisordersnc.org so that we can send it to you. Next steps for BDFNC are to continue the research into how bleeding disorders affect a person's mental health and to distribute its mental health survey in Spanish and for caregivers.

Finally, if you read the "From the Office" article written by Gillian Schultz, Director of Programs, there is a national coalition that is looking for community involvement. The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) includes members from across the country who all unite on one thing: Getting community members the mental health/substance use disorder treatment they need when they need it most. You can learn more about BD SUMHAC on their website: www.bdsunhac.org. If you are interested in getting involved, contact Gillian.

To learn more about BDFNC's mental health initiative, BD SUMHAC, or if you'd like to get involved, please contact Gillian at events@bleedingdisordersnc.org or by calling/texting her at (919) 272-6000.

ALTUVIIIIO™ 
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

NOW APPROVED

Looking for information? Your CoRe can help!



Connect with
Xaviette Pointer-Kincy
xaviette.pointer-kincy@sanofi.com
857-259-2447



Learn more at
ALTUVIIIIO.com or by
scanning the QR code

ALTUVIIIIO™ 
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

sanofi



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

Board Member Ellen Kearney earned her PhD in Human Resources, and her daughter graduated from high school and is attending UNC Charlotte in the fall!



Happy 2nd Birthday, Nickte Almendra and Kimberly Almendra!



Congratulations, Destiny Young!
Graduated from Myers Park High School, June 2023
Going to NC Central in the fall to study Pre-Med



Happy birthday to Jamie McNeill and thank you for all of your advocacy on behalf of the bleeding disorders community!



Are you celebrating a birthday, graduation, anniversary, birth, or something else? If you'd like for BDFNC to announce your special day, contact us at info@bleedingdisordersnc.org.

2023 Friends of BDFNC

We gratefully acknowledge the individuals who generously donated to BDFNC during the past quarter of 2023. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

Employee Giving Programs (various)

April Lindsey Evans
Dan & SJ Cox

General Donations

Carrie Regler
Sue & Allen Heafner
Linda & Allen Kurtz
Dr. Randy & Cathy Lambe
Dr. Sara Miller and Dr. David Howell

Facebook Fundraisers

Cristal Avina
Semiko Bennett
Andrea Nicole Benzie
Kristin Britt
Curtiss Reid Coleman
Charlene Cowell
Renee Holder
Sandy Rainier Kerr
April Lindsey-Evans
Megan Niemyer Moore
Ashley Emory Siler
Josiah Willis

If interested in learning more about the different ways individuals and businesses can make a difference in the lives of people with bleeding disorders, please visit bleedingdisordersnc.org/ways-to-give/ or contact Charlene at c.cowell@bleedingdisordersnc.org. We truly appreciate it!



North Carolina DHHS Secretary Dr. Mandy Cohen Appointed as CDC Director



President Biden has selected Dr. Mandy Cohen to be the next director of the Centers for Disease Control and Prevention (CDC). Dr. Cohen served as the North Carolina Secretary of Health and Human Services (DHHS) for five years. In those five years, she led North Carolina through the COVID-19 pandemic, spearheaded the Opioid Action Plan alongside Governor Cooper, and helped pass North Carolina Medicaid Expansion. Dr. Cohen is an internal medicine physician and has held senior positions at the Centers for Medicare and Medicaid Services (CMS).

How Medicaid Unwinding Affects You

A graphic with a dark blue background and white text. The main text reads "MAKE SURE MEDICAID HAS YOUR CURRENT CONTACT INFORMATION". Below this, it says "UPDATE INFO / LEARN MORE AT: tinyurl.com/NCmedicaidcontactinfo". At the bottom, there is the NCDHHS logo and the text "NCDHHS NC Medicaid Division of Health Benefits".

If you or a family member are currently enrolled in Medicaid or NC Health Choice for Children (North Carolina's Children's Health Insurance Program – CHIP), you may need to take steps to find out if you can continue your coverage. During the COVID-19 health emergency, eligibility reviews were paused. However, they have resumed. This means that you could lose your Medicaid or NC Health Coverage. **Make sure North Carolina has your current mail address, phone number, email, and other contact information, and check your email.** The Medicaid department will contact you about your coverage.

You can check and/or update your contact information and learn more here: <https://tinyurl.com/NCmedicaidcontactinfo>

If you are no longer eligible for coverage, you may be able to purchase a health insurance plan through the Health Insurance Marketplace (www.healthcare.gov).



Supplies of Critical Nasal Spray for Hemophilia A, von Willebrand Disease Restored, but Patients and Coverage Recede

Apr 25, 2023

By: Tony Hagen

Reprint from *Managed Healthcare Executive*

Nearly three years after Ferring Pharmaceuticals suspended production of nasal sprays that boost blood clotting in people with Type 1 von Willebrand disease and hemophilia A, it remains unclear if — or when — the company will resume production.

The production was suspended due to a packaging seal problem that led to evaporation and potentially dangerously high concentrations of the active ingredient, desmopressin.

Desmopressin is a synthetic form of vasopressin, a naturally occurring hormone with a wide range of effects that influence blood pressure, blood volume, urination and kidney function. As it turns out, increasing the levels of von Willebrand factor and factor VIII, the clotting factor that people with hemophilia A are short on, is also in vasopressin's bag of tricks and therefore desmopressin's. Desmopressin is the active ingredient in DDAVP nasal spray and Stimate. The two brand-names tend to get used interchangeably, although Stimate is actually a higher-concentration product.

Patients who previously used DDAVP nasal spray or Stimate have been prescribed clotting factor instead, which is more costly and requires intravenous infusion. In addition, clotting factor can lead to inhibitor development in patients with hemophilia A, adding to the difficulty and cost of care.

To bridge the gap, the Hemophilia Alliance, a trade association for many of the federally funded hemophilia treatment centers, turned to STAQ Pharma, a 503B outsourcing facility, which was able to put desmopressin into production in 2021 in the Stimate-level concentrations that after the FDA declared desmopressin a drug in short supply, which is a prerequisite for outsourcing approval.

"Since the July 2020 recall, many patients who relied on (desmopressin acetate) for bleeding control have experienced serious hardship, including worsening health condition. Desmopressin acetate nasal spray has been an important therapeutic solution for these patients for management of bleeding complications and to facilitate surgical procedures and has been a first-line therapy for more than 25 years," members of the Hemophilia Alliance wrote in a letter to payers urging them to cover the STAQ Pharma product.

STAQ Pharma is producing the drug for a wholesale cost of about \$400 per vial, with roughly 6 actualizations, or uses, which is \$80 less than the original Ferring cost, according to Joe Pugliese, president and CEO of the Hemophilia Alliance.

Still, it has been difficult to get payers to reimburse for this product, he said.

"We've talked to the FDA several times about what we would have to do to get an abbreviated New Drug Application," which would give the STAQ Pharma drug generic status and potentially improve the argument for payer coverage.

"Those conversations with the FDA have not been going quickly, which means that reimbursement and distribution are challenging at times. Support from pharmacy benefit managers has been mixed. Of course, hemophilia treatment centers and the smaller home care companies around the country have been purchasing the product and making it available to patients with good results," Pugliese said.

The uncertainty and interruption in supply has affected the size of the market for this drug despite its advantages over intravenous clotting factor.

"Some people moved to subcutaneous desmopressin acetate. Some people have moved to factor concentrates," Pugliese said. However, about 2,000 vials of the STAQ Pharma nasal spray have been shipped since 2021. "Getting the word out and then getting the patients connected with the product have been slow, but we continue to grow every month," Pugliese said.

Advocates for patients with hemophilia are also interested in STAQ Pharma producing supplies of another product for bleeding control called Amicar (aminocaproic acid), which Acorn Pharmaceuticals discontinued because of its Chapter 7 bankruptcy, announced in February 2023. There are other suppliers of this product, though, so the FDA may not want to add it to the drug shortage list.

Continued next page



Supplies of Critical Nasal Spray for Hemophilia A, von Willebrand Disease Restored, but Patients and Coverage Recede

continued from previous page

“If at some point in time we find that bleeding disorder patients couldn’t get access to this product, we’d probably go back to the FDA,” Pugliese said.

Article can be found here: <https://www.managedhealthcareexecutive.com/view/supplies-of-critical-nasal-spray-for-hemophilia-a-von-willebrand-disease-restored-but-patients-and-coverage-recede>

Inequities in Thrombosis and Hemostasis Lab Testing the Focus of Illustrated Review

June 14, 2023

Reprinted from the National Hemophilia Foundation

A new illustrated review published in the journal *Research and Practice in Thrombosis and Haemostasis* makes the case that many established reference intervals (RIs) used to interpret the results of laboratory tests are biased and highly problematic. This is significant as RIs are central to the process for determining whether any given lab results are deemed normal or abnormal via predetermined ranges.

Authors of the review posit that RIs such as those utilized in thrombosis and hemostasis, are based on structural and deeply rooted inequities such as systemic racism and sexism. They argue that this dynamic has perpetuated a cycle in hematology whereby heavy menstrual bleeding (HMB) linked to conditions like anemia or iron deficiency are “inappropriately” normalized in women, and especially in Black women. In addition, women with von Willebrand disease (VWD) will, in many instances suffer from HMB and other complications, for many years before receiving a diagnosis – this is a result of normalization and under-assessment on the part of some healthcare providers. This is further complicated by the complexities of interpreting labs associated with von Willebrand factor (VWF), which should be conducted in wider and more inclusive context that includes estrogen status, recent stress, blood type, among other variables.

Citing several research case studies, the authors detail many of the current RIs used to assess a number of hematologic conditions and highlights particular disparities, including those used for sex-based hemoglobin, race-based hemoglobin, heavy menstrual bleeding, iron deficiency and coagulopathy. It also includes a review on the impact of both sex and race in our common understanding of VWF.

The review culminates in a series of action items including a call to remove race-based RIs and reevaluate sex-based ones rooted in weak evidence based on a high risk of bias; use broad population based data sets to prioritize and track quality indicators in health in equity-deserving groups to reduce health disparities; foster and fund inclusive health research via recruitment of diverse participants to promote generalizability of research findings; prioritize research areas of extreme health disparity, particularly at vulnerable intersections of social identity such as pregnancy research among Black women and those living with sickle cell disease.

“We must actively unlearn dogmatic medical beliefs and learn anew with updated data and understanding,” emphasized the authors. The full review “Laboratory-based Inequity in Thrombosis and Hemostasis: Review of the Evidence,” is currently available online, including in PDF.

Citation

Merz LE, Siad FM, Creary M, Sholzberg M, Weyand AC. Laboratory-based inequity in thrombosis and hemostasis: review of the evidence. *Res Pract Thromb Haemost*. 2023 Mar 15;7(2):100117. doi: 10.1016/j.rpth.2023.100117. PMID: 37063772; PMCID: PMC10099330.

Disclaimer: NHF provides periodic synopses of articles published in peer reviewed journals, the purpose of which is to highlight papers that cover a wide range of topics and speak to a broad spectrum of the inherited blood disorders community. Topics include shared decision making, gene therapy, health equity, and more. NHF hopes you find this content to be informative and engaging.

Any questions about the articles featured here should be directed to the publishing journal and/or the study authors. This content is for general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or HTC before pursuing any course of treatment.



2024 Washington Days: Join Us!

March 6-8, 2024
Washington, D.C.

If you are interested in getting involved in advocacy, save the date for next spring (March 6-8, 2024), when you can travel to Washington D.C. and talk to our nation's lawmakers about issues that are important to the bleeding disorders community. Every year the National Hemophilia Foundation



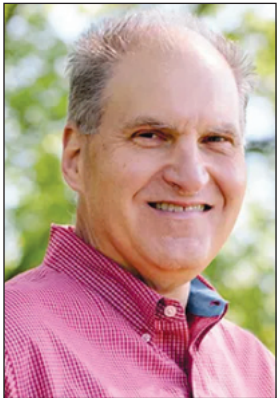
(NHF) hosts "Washington Days" for advocates from around the country to meet each other and their lawmakers. The Bleeding Disorders Foundation of North Carolina (BDFNC) provides travel grants to NC community members who want to participate. No experience is needed and NHF and BDFNC provide lots of guidance. It is important that BDFNC members from all over North Carolina come because lawmakers want to talk to you, their constituents. If you are interested in joining the team for "Washington Days" or getting involved in advocacy in other ways, email Genevieve at advocacy@bleedingdisordersnc.org.



Announcement from NHF CEO and President

May 26, 2023

Reprinted from the National Hemophilia Foundation



Dear National Hemophilia Foundation Community, Staff and Friends,

It is with mixed emotions that I want to inform you that I have decided to step down from my leadership position as President and CEO at the end of this year. Earlier this week, I informed the NHF Board of Directors of my decision and asked them to initiate a search for the next leader of the organization.

In the past three and a half years we have made substantial advancements towards the vision of a world without inheritable blood disorders by striving to meet our mission focused on research, education, and advocacy to ensure that people and families with inherited blood disorders may thrive.

I am particularly proud of the collaborative effort to bring the research state of the science to fruition and the publication of excellent manuscripts that articulate not only the gaps in care, but positive areas for continued collaborative research to close these gaps for people living with inherited bleeding disorders. Now, we as a community, are on the journey to build a sustainable research infrastructure to execute the most important

science to enhance the health and wellbeing of people living with inheritable bleeding disorders.

Pathway to Cures is another initiative that I am very proud of. P2C holds the promise to catalyze innovation towards the vision of cures for inherited blood disorders and bring the community steps closer to equitable outcomes for all who share in the bloodsisterhood and brotherhood.

The work that NHF has done to improve access to care through policy and payer work, increase educational opportunities for those living with inherited blood and bleeding disorders, their families and loved ones and the healthcare professionals who provide care is also an area of great pride. The strength and vitality of the chapter community continues to grow and evolve to meet the needs of the community.

I consider it a great privilege and honor to serve this community and organization as it's President and Chief Executive Officer since 2020 and thank you all for your trust and support during my tenure. During this time, we have planted the seeds that I am hopeful will sprout into the vision of a world without inherited blood disorders. I believe this is the right time for a new leader to continue the journey. I may be leaving my office but not the community as I intend to continue to work towards the vision of a world without inheritable blood disorders, but as a volunteer. Last, but certainly not least, I look forward to your participation and support at the Bleeding Disorders Conference in August and the Red Tie Soiree in October.

Yours truly,
Dr. Len Valentino

Announcement can be found here: <https://www.hemophilia.org/news/announcement-from-nhf-ceo-and-president>

Bleeding Disorders Foundation of North Carolina

2023 Calendar of Events Highlights



July 7-9, 2023

Summer Community Retreat -
Morehead City, NC

August 10-13, 2023

NC/SC Teen Retreat - Rock Hill, SC

August 17-19, 2023

NHF Bleeding Disorders Conference -
Baltimore, MD

August 26, 2023

Welcome to BDFNC - Virtual

September 22-24, 2023

Blood Brotherhood & SOAR Weekend -
Pine Knoll Shores, NC

September 30, 2023

Unión Latina Event - Charlotte, NC

October 14, 2023

Raleigh Festival & Walk - Morrisville, NC

November 4, 2023

HOPE Family Day - Concord, NC

December 2, 2023

Holiday Celebration - Gastonia, NC

April 27, 2024

Charlotte Festival & Walk - Charlotte, NC

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 most up to date information. Email BDFNC at events@bleedingdisordersnc.org or call (919) 319-0014 to be added to the email and/or text groups.



Talk to your doctor and see if
ADVATE® is right for you.


ADVATE
[Antihemophilic Factor (Recombinant)]

For more information, please visit AdvateRealLife.com

Copyright © 2020 Takeda Pharmaceutical Company Limited. 300 Shire Way, Lexington, MA 02421. 1-800-828-2088. All rights reserved. TAKEDA and the TAKEDA logo are trademarks or registered trademarks of Takeda Pharmaceutical Company Limited. ADVATE is a registered trademark of Baxalta Incorporated, a Takeda company. US-ADV-0119v1.0 05/20

Not an actual patient.



**BLEEDING
DISORDERS
FOUNDATION**
OF NORTH CAROLINA



**BLEEDING DISORDERS FOUNDATION
OF NORTH CAROLINA**

260 Town Hall Dr., Suite A

Morrisville, NC 27560

info@bleedingdisordersnc.org

www.bleedingdisordersnc.org

NONPROFIT ORG

U.S. POSTAGE

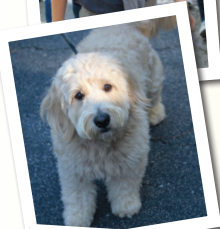
PAID

CARY NC 27511

PERMIT NO. 830

Change Service Requested

mark your calendars!



RALEIGH

Saturday, October 14, 2023

Lake Crabtree County Park
Morrisville, NC



**Entertainment • Music & Games
Breakfast & Lunch
Photo Booth • Face Painting
Dog Friendly • And More!**



Fun for the entire family!
bleedingdisordersnc.org/festival