

# THE NCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Summer 2024

## Raleigh Festival & Walk for Bleeding Disorders is Back Again!

November 2, 2024  
Morrisville, NC



Get ready for the 17th annual Raleigh Family Festival & Walk for Bleeding Disorders—it's going to be a blast!



Picture this: Lake Crabtree Park in Morrisville transformed into a hub of excitement and community spirit. There will be fun activities galore and a walk that's not just a stroll, but a show of solidarity for the bleeding disorders community!

Mark your calendars because on that day, you're not just having a good time—you're making a difference. This event is fun for all ages and the Bleeding Disorders Foundation of *Continued page 6*

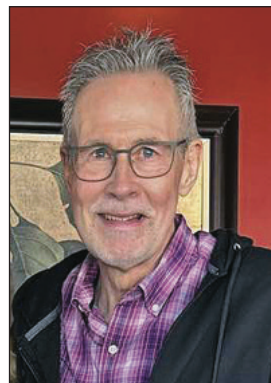
## BDFNC Presidency Transition

By: Charlene Cowell, BDFNC Executive Director

We are very excited to announce a transition of Board President for the Bleeding Disorders Foundation of North Carolina (BDFNC) in July 2024. The importance of the role of Board President can not be overstated. It is critical in the organization's success and advancement, including responsibilities such as organizing meetings, overseeing business affairs, representing BDFNC to outside parties, and planning for the perpetuation of leadership. The Board President works hand in hand with the Executive Director and the Board of Directors to fulfill BDFNC's mission and vision through successfully executing the strategic plan to help build a bright future for BDFNC.

Steve Humes, MM, MPH, has served as Board President since July 2019. Throughout his leadership, we have formed integral committees, undergone an extensive strategic plan process, strengthened the organization's policies, and so much more. Steve will continue to serve on the BDFNC Board of Directors for an additional term of two years. We thank Steve for his time, commitment, passion, and invaluable contributions to BDFNC during his term.

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### Save The Date

#### Summer Community Retreat

August 2-4, 2024  
Lake Junaluska, NC

#### Infusion Workshop

August 10, 2024  
Cornelius, NC

#### Navigating School with a Bleeding Disorder

August 20, 2024  
Virtual

#### Education Dinner

August 22, 2024  
Raleigh, NC

#### Physical Therapy Event

August 31, 2024  
Hendersonville, NC

#### Unión Latina Weekend

September 7-8, 2024  
Winston-Salem, NC

#### Raleigh Family Festival & Walk for Bleeding Disorders

November 2, 2024  
Morrisville, NC

#### Blood Brotherhood & SOAR Weekend

November 15-17, 2024  
Wilmington, NC

#### Holiday Celebration

December 7, 2024  
Chapel Hill, NC

Many more events coming up.

BLEEDING  
DISORDERS  
FOUNDATION  
OF NORTH CAROLINA



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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 Bleeding Disorders 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 Bleeding Disorders 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.hemob.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 Bleeding Disorders 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.*



## BDFNC Presidency Transition *continued from page 1*



We welcome Karyn Davis as the new Board President effective July 1, 2024. Karyn has served on the Board of Directors for the past two years and was an integral part of the staff of BDFNC from 2015 to 2020 as Operations Manager. Her familiarity with the organization and exposure from a variety of positions she's held will provide valuable insight and leadership as we continue the success of BDFNC and support the members of the bleeding disorders community. Congratulations, Karyn, and thank you for continuing to share your time and talent!

### A NOTE FROM BDFNC'S NEW PRESIDENT, KARYN DAVIS:

*I am honored to continue to serve the bleeding disorders community of North Carolina in this new role. Steve Humes' knowledge and oversight over the past four years were fundamental to BDFNC's ability to successfully navigate through the pandemic and post-pandemic years and continue to provide supportive programs and services despite the obstacles. As BDFNC looks to the future, I hope I am equally up to the task. I am thankful for the opportunity to be a part of this diverse community and will do my best to support BDFNC's mission and vision.*

## It's Not Goodbye - It's See You Later

By: Victoria (Vic) Gioia

Dear Bleeding Disorders Foundation of North Carolina (BDFNC) Community,

It is with a heavy heart that I announce my departure from my role as the Events and Outreach Coordinator. This decision did not come lightly, and I will deeply miss being in this role.

As a military child, I moved around every few years and had to say many "goodbyes." A phrase one friend once told me that has always stayed with me is, "It's Not Goodbye - It's See You Later." Although I will no longer be in this role, I will still be an active volunteer. You will be able to see me at future events and volunteering at the office in my spare time. You will definitely see me in the future!

As I transition out of this role, I want to express my deepest gratitude to each of you. Thank you for your kindness, your warmth, and for welcoming me into this community. Thank you for the memories we've created, as I will forever cherish them. As I step into the next chapter of my life, I carry with me the lessons I've learned and the memories I've made over the last year in this role.

It has been an honor and a privilege to be a part of this community and each community member will always hold a special place in my heart. See you all later!

With care,  
Victoria (Vic) Gioia



## No es adiós, es hasta luego

Por: Victoria (Vic) Gioia

Queridos miembros de la comunidad de la Bleeding Disorders Foundation of North Carolina (BDFNC),

Con gran pena les anuncio que dejo mis obligaciones como la Events and Outreach Coordinator. Esta decisión no ha sido tomada a la ligera y voy a extrañar mucho mi trabajo.

Como hija de militares, me movía cada pocos años y tenía que decir muchas «despedidas».

Una frase que un amigo me dijo una vez y que siempre me ha acompañado es «No es adiós, es hasta luego». Aunque ya no voy a ocupar este puesto, seguiré siendo una voluntaria activa. Podrán verme en futuros y como voluntaria en la oficina en mi tiempo libre. ¡Definitivamente nos veremos en el futuro!

Al dejar este puesto, quiero expresar mi más profunda gratitud a cada uno de ustedes.

Gracias por su amabilidad, su cariño y por acogerme en esta comunidad. Gracias por los recuerdos que hemos creado, que guardaré para siempre. Al entrar en el próximo capítulo de mi vida, llevo conmigo las lecciones que he aprendido y los recuerdos que he creado durante el último año en este puesto.

Ha sido un honor y un privilegio ser parte de esta comunidad y cada miembro de la comunidad siempre tendrá un lugar especial en mi corazón. ¡Nos vemos más tarde!

Con cariño,  
Victoria (Vic) Gioia





# Adventure Awaits at the NC/SC Teen Retreat!

July 18-21, 2024  
Parkton, NC

Read all about this year's NC/SC Teen Retreat in the Fall Edition of *The Concentrate!* Teens impacted by a bleeding disorder were invited to spend four days together for amazing activities to build leadership skills, spark curiosity, and provide life-long friendships.

The Teen Retreat is for all teens in the bleeding disorders community, including those diagnosed with a bleeding disorder, their siblings, and children of parents with a bleeding disorder.



# A Weekend Getaway in the NC Mountains: Summer Community Retreat

August 2-4, 2024  
Lake Junaluska, NC

Heading back to the North Carolina mountains, the Bleeding Disorders Foundation of North Carolina (BDFNC) is excited to be returning to the Lake Junaluska Conference & Retreat Center for the 2024 Summer Retreat. There will be programs and activities for the entire bleeding disorders community to get together, connect, learn, and have fun! Whether you have been part of the community for years or are new, this event provides a great opportunity to get connected and find out firsthand how BDFNC is able to support you. More information about the Summer Community Retreat is available on BDFNC's website.

# Unión Latina Event

July 27, 2024  
Asheville, NC



Spanish-speaking community members are invited to a summer day at the North Carolina Arboretum to learn and explore the beauty of western North Carolina. This summer's Unión Latina event will include an educational program about the best ways to stay active with a bleeding disorder, lunch, and a visit to the beautiful gardens and trails at the NC Arboretum. The NC Arboretum features miles of hiking trails, acres of cultivated gardens, and hundreds of native plant species. Transportation assistance is available and registration is required. More information is available on the BDFNC website.



# Heading to the NC Mountains: Physical Therapy Event

August 31, 2024  
Hendersonville, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) is partnering with two amazing physical therapists, Jennifer Newman and Ruth Mulvany, to bring some educational topics to the mountains. While the specific topics are still being determined, there will be two sessions happening simultaneously: one for adults with bleeding disorders and another for children with bleeding disorders. More information is available on the BDFNC website.



# Infusion and Injection Workshop

August 10, 2024  
Cornelius, NC



Being able to self-infuse or self-inject your bleeding disorder treatment makes life with a bleeding disorder easier to manage. This community is taught from an early age the benefits of self-infusion/injection and how to administer these treatments at home and on the go. The Bleeding Disorders Foundation of North Carolina (BDFNC) plans to host several self-infusion/injection workshops across the state to provide community members the opportunity to learn and practice self-infusion or injection and hear strategies about overcoming fear of needles among an audience that understands.

Join BDFNC at a workshop in Cornelius (a suburb of Charlotte) to learn, practice, and perfect your infusion or injection skills. Whether you are new to self-infusion or just want to brush up on your skills, you are welcome to register. All ages and skill levels are welcome. Providers from the St. Jude Affiliate Clinic and Novant Health Center for Bleeding Disorders, and nurses from InfuCare RX will be on hand to assist with this program.

Thank you to Octapharma and InfuCare RX for sponsoring this event.

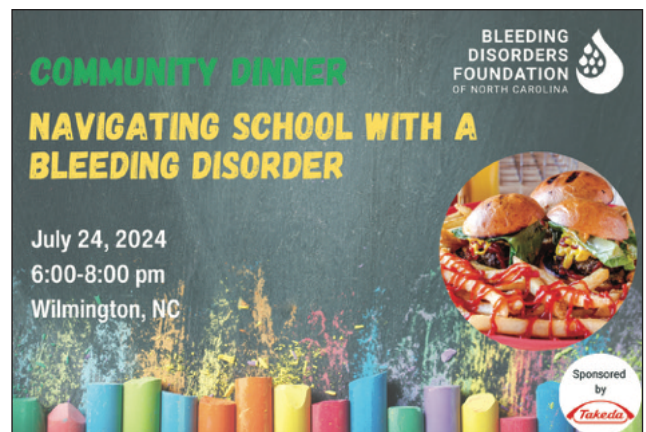


# Community Dinner to Prepare for Back-to-School

July 24, 2024  
Wilmington, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) is pleased to invite you to a Community Education Dinner in Wilmington. There will be dinner, time to make connections, and an educational presentation. Learn how students, parents, family members, and school staff can work together to provide a positive learning environment for students with a bleeding disorder - from preschool to college. You can find more information and register for the event on the BDFNC website.

\*\* BDFNC will also host the same presentation virtually on August 20 if you're unable to make it to Wilmington.



# Unión Latina Weekend

September 7-8, 2024  
Winston-Salem, NC

Join the Bleeding Disorders Foundation of North Carolina (BDFNC) for a weekend that will build community and provide resources and education, specifically for the Spanish-speaking bleeding disorders community. All presentations and information will be presented and available to you in Spanish. There will be fun sessions, supportive programs, and activities for kids. Hotel accommodations, travel assistance, and all meals are provided at no cost. More information will be available on the BDFNC website later this summer.



## *Raleigh Festival & Walk for Bleeding Disorders is Back Again!*

*continued from page 1*



North Carolina's biggest fundraiser of the year. Every dollar raised supports crucial advocacy, education, and research efforts, plus vital programs and services.

So, gather your crew, form those teams, and spread the word! We've set our sights high with a goal of \$100,000, and with your help, we're going to smash it!

Stay tuned for more details coming soon on the BDFNC website this summer. Until then, save the date, rally your friends, and get ready to make memories that matter!



## A Weekend to Build Supportive Connections for Men and Women

November 15-17, 2024  
Wilmington, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) looks forward to a weekend event to build supportive connections for men and women with bleeding disorders. The Blood Brotherhood & SOAR Weekend brings everyone together for education, camaraderie, and fun. In addition to amazing opportunities to build brotherhood for men with bleeding disorders in the Blood Brothers track, BDFNC is partnering with the CHES Foundation LadyBugs Program for an enhanced SOAR track. More information about this partnership will be coming soon.

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





# Ring in the Holiday Season with BDFNC

December 7, 2024  
Chapel Hill, NC

While you are probably sweating from this summer's heat, save the date for the Bleeding Disorders Foundation of North Carolina (BDFNC) Holiday Celebration on December 7 in Chapel Hill, NC. Bring some holiday cheer as BDFNC celebrates 2024, the holiday season, and you. More information will be coming this fall.



# Community Conversations: Blood Brother Chat

March 19, 2024

By: Guillermo Sanchez, BDFNC Board Member

Hello Blood Brothers!

In the last Blood Brothers chat we had a really interesting and inspiring stories about friendship. The chat was held virtually and our amazing guest (and hopefully permanent virtual member): Wayne Cook, current President of the Coalition for Hemophilia B, talked about how the Blood Brother program was created as a way to offer a safe place to improve the health and quality of life of men living with a bleeding disorder through sharing, learning, and advocating for themselves. And yes, the initial idea started from a man who wanted to share what living with a bleeding disorder was with people who could understand him.

Over time, the Blood Brotherhood has gone through various changes all with the sole purpose of continuing to provide a safe space where men with bleeding disorders can come together and advance towards a common goal: Have the best life.

The Bleeding Disorder Foundation of North Carolina (BDFNC) is also reshaping its own Blood Brotherhood Program, with more opportunities to meet virtually, so all the brothers from across the state can join the conversation. Please visit the BDFNC website so you don't miss the next one.

# Community Gathers in Asheville

March 28, 2024  
Asheville, NC



About a dozen community members from western North Carolina gathered for food, good conversation, and a presentation geared towards helping attendees get on the path to financial success. It was a great evening to learn more about saving for the future, and that even small steps make a big difference over time. Everyone had a great time and new connections were made. The Bleeding Disorders Foundation of North Carolina looks forward to going back to western North Carolina this summer.





# Community Conversations

April 16, 2024

By Alisha Curtiss, Community Member

The April Community Conversation focused on ultra-rare factor deficiencies and platelet disorders. Gillian opened the discussion with questions about how to expand education and service to the group. There were open conversations about unique barriers faced by participants to be further discussed at upcoming events focused on emerging treatments. The group shared their experiences including treatment barriers and diagnostic barriers due to the rarity of their bleeding disorders.



# World Hemophilia Day Event

April 17, 2024

Raleigh, NC

Thank you to everyone who attended the World Hemophilia Day event at The Westin in Raleigh, NC! Sanofi led their “One Family Program” where attendees learned about the past, the present, and the future of bleeding disorders. After the presentation, attendees made time capsules and shared their wishes for the future of the bleeding disorders community. This event brought together community members who all had different bleeding disorders and celebrated each one. This event was a heartwarming way to celebrate World Hemophilia Day and bring community members together.



# Blood Brothers Pizza in the Park

April 20, 2024

By: Guillermo Sanchez, BDFNC Board Member

Can you imagine a Saturday afternoon in a nice shelter eating pizza and playing dominoes while you held a great conversation with other men with a bleeding disorder? That just happened at our last Blood Brothers reunion!

Even when virtual reunions offer the opportunity to participate from different places across the state, it's really nice for blood brothers to connect in person throughout the year. A huge welcoming hug or handshake may be the only thing someone needs to feel part of the community.

In discussions exclusively among men with bleeding disorders, conversations can branch in various directions, ultimately leading to valuable insights and learning. Everybody goes home as a different person, with a little bit of new knowledge from someone else – a piece of advice, an anecdote, etc.

Come to the next in-person reunion and be ready to have fun, get a hug, eat something nice, and above all, be prepared to share and learn.



# Charlotte Festival: A FUNdraising Success

April 27, 2024  
Charlotte, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) Charlotte Family Festival & Walk for Bleeding Disorders was a smashing success! The community raised \$57,515, just under the goal of \$60,000. Around 200 community members, family, and friends came together to celebrate the bleeding disorders community and take part in a 5K Walk in support of BDFNC. While this year featured a number of changes, including an earlier start time and new walk route, along with the PanCan Walk taking place adjacent to the event, the Walk of Hope taking place inside Truist Field, and a huge concert taking place later in the day at Bank of America Stadium, the Family Festival & Walk for Bleeding Disorder went on without a hitch!



Attendees enjoyed face painting, balloon twisting, crafts, games, chair massages, cotton candy, ice cream, coffee, breakfast and lunch, visits with event sponsors, a fantastic DJ, and great performances from Zumba with Gee and Dancing Dreams *Continued next page*





# Charlotte Festival: A FUNdraising Success

*continued from previous page*

Double Dutch! Larry Sprinkle, meteorologist with WCNC was the emcee once again and helped to build the excitement of the crowd.

BDFNC would like to acknowledge the many volunteers, both total strangers and close family and friends, who helped to make the day a huge success. Thanks also goes out to all the sponsors, participants, donors, and other supporters.

Congratulations to this year's fundraising winners:

- Top Fundraising Team:** SHARPSHARKS
- Second Place Fundraising Team:** Novant HTC
- Third Place Fundraising Team:** Team Diego
- Most Enthusiastic First-Time Fundraiser:** Tara Brown
- Team with the Most Individual Donors:** SHARPSHARKS
- Biggest Team:** Team Diego
- Top Fundraiser Under 18:** Reuben Screpetis
- Volunteer Extraordinaire:** Daniel Gougherty
- Hospital Cup:** Novant HTC

Couldn't make it to Charlotte? You have an opportunity to fundraise for the Raleigh Family Festival & Walk for Bleeding Disorders, taking place on November 2 at Lake Crabtree Park in Morrisville. **While a new location for the Charlotte Family Festival & Walk is still being finalized, save the date for April 26, 2025.**



## GRAND CLUB

*The Grand Club recognizes teams that have raised at least \$1,000 for the Family Festival & Walk for Bleeding Disorders.*

- SHARPSHARKS - Team Captains: Linda Kurtz and Gillian Schultz
- Novant HTC - Team Captain: Allison Rector
- Team Diego - Team Captain: Andrea Mayle
- George's Trailblazers - Team Captain: Charlene Cowell
- Team G-Man - Team Captain: Jaime Odom
- Team Hill - Team Captain: Jeron Hill
- Charlie's Troopers - Team Captain: Kate Stotz

## SILVER SUPPORTER FUNDRAISERS

*Individuals who have raised at least \$500 for the Family Festival & Walk for Bleeding Disorders.*

- Charlene Cowell
- Jeron Hill
- Matthew Jester
- Linda Kurtz
- Andrea Mayle
- Gillian Schultz

## BRONZE BENEFACTORS

*Those who have donated at least \$250 for the Family Festival & Walk for Bleeding Disorders.*

- |                             |  |
|-----------------------------|--|
| Paulette Bryant             | Nick Mayle                             |
| Charlene Cowell & John Prim | David Miller                           |
| Susan & Charles Cowell      | Teri Moore                             |
| Daniel Gougherty            | Phil Poovey                            |
| Jeron Hill                  | Anna Rettew                            |
| Wayne P. Huckel             | Rose Baptist Church,<br>North Rose, NY |
| Matthew Jester              | Wayne & Susan Schultz                  |
| Allen & Linda Kurtz         |  |
| Andrea Mayle                |  |





# Growing Community One Family at a Time: HOPE Family Day

May 18, 2024  
Raleigh, NC



It was great to see so many new community members and young families at the HOPE Family Day at the Marbles Kids Museum in Raleigh. The afternoon began with children and their families making crafts and playing games. Then pizza was delivered for lunch! Lucia Opara, the social worker at the UNC Hemophilia Treatment Center, gave a presentation about how to manage needle phobia for infusions and injections. She gave lots of helpful tips and tricks, and then everyone had a good conversation about their experiences and what has worked for them. Following all the activities, everyone went into Marbles Kids Museum to enjoy the hands-on activities and exhibits.



# Mental Health Matters: Film Screening and Dinner

May 30, 2024  
Greensboro, NC

When you hear about living with a bleeding disorder, you probably think about physical challenges and obstacles to overcome. Doctor and hospital visits, bleeds, and infusions are probably common images that come to mind. But what about mental obstacles? Like other chronic conditions, the prevalence of mental health disorders is higher among people with bleeding disorders. This is especially true for depression and anxiety. But it is only within the past few years that the bleeding disorders community has really started talking about the impact bleeding disorders have on your mental health.

The Bleeding Disorders Foundation of North Carolina (BDFNC) was pleased to partner with Sanofi to bring the film, *Let's Talk*, to North Carolina. Produced by Believe Limited, the film shares the experiences of five community members and how they have had to manage their mental health. From stories of losing friends to AIDS, the feelings of getting diagnosed, and the challenges of managing limitations with a bleeding disorder, nothing was off-limits in the film.

Following the film screening, Debbie de la Riva and Hanna Beary from Believe Limited facilitated a talk-back, where attendees very openly discussed the film and their personal circumstances with mental health. If the event hadn't needed to wrap up, the conversation could have gone on for much longer.

Interested in seeing the film? You can stream it from the comfort of your home. Visit [letstalkmh.com/](http://letstalkmh.com/) to see the film and for resources.

BDFNC also has a webpage with helpful information, including a link to the BDFNC Mental Health Resource Guide: [bleedingdisordersnc.org/resources/mental-health/](http://bleedingdisordersnc.org/resources/mental-health/)



## Unión Latina Noticias

By: *Guillermo Sanchez, BDFNC Board Member and Volunteer Unión Latina Program Coordinator*

Las familias latinas han participado con entusiasmo, no solo en los eventos que se ofrecen en español, sino en todas las demás actividades ofrecidas para todos los miembros de la comunidad de desórdenes sanguíneos en Carolina del Norte. Desde los programas educativos y las Conversaciones Comunitarias de la Unión Latina hasta el Festival Familiar y la Caminata en Charlotte.

El sentimiento entre las familias latinas es siempre el mismo: Calidez y comprensión por parte de toda la comunidad de desórdenes sanguíneos. Una de las mamás de las familias latinas dijo: “Cuando nos mudamos a Carolina del Norte en busca de una vida mejor para mis hijos, pensé que enfrentaríamos solos todos los desafíos que los desórdenes sanguíneos traen a las familias, pero en contra de todas nuestras creencias, hemos encontrado un equipo que lucha y exige junto a nosotros el acceso al tratamiento para todas las personas sin importar raza, país de origen o idioma.

Las familias latinas han adquirido un gran número de habilidades para afrontar mejor los desafíos diarios de vivir con trastornos hemorrágicos.

Las Familias Latinas agradecemos todo el apoyo que nos ha brindado la Fundación y la Comunidad de Desórdenes Sanguíneos en general. Estamos listos para retribuir a esta gran comunidad.

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## Evento de Unión Latina

27 de julio de 2024

Asheville, Carolina del Norte (NC)

Los miembros de la comunidad de habla hispana están invitados a un día de verano en el Arboreto de Carolina del Norte para aprender y explorar la belleza de la parte del oeste de Carolina del Norte. El evento Unión Latina de este verano incluirá un programa educativo sobre las mejores maneras de mantenerse activo con un trastorno hemorrágico, un almuerzo y una visita a los hermosos jardines y senderos del Arboreto de Carolina del Norte. El Arboreto de Carolina del Norte cuenta con millas de rutas de senderismo, acres de jardines cultivados y cientos de especies de plantas nativas. Se proporciona asistencia de transporte y es necesario registrarse. Más información se encuentra disponible en el sitio web de BDFNC

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## Iniciativa de Salud Mental

La Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) continúa derribando barreras en lo que respecta a la salud mental y los trastornos hemorrágicos. En mayo, la BDFNC organizó la proyección de una película con Believe Limited, patrocinada por Sanofi, sobre la salud mental en la comunidad de trastornos hemorrágicos. La película generó una gran conversación sobre el continuo estigma que existe sobre la salud mental y las conexiones entre los trastornos hemorrágicos y la salud mental.

A finales de este año, la BDFNC administrará la encuesta de salud mental realizada a finales de 2021 y principios de 2022, en español, para que la perspectiva de la comunidad latina pueda incluirse en el análisis de los resultados. Usted puede leer sobre la encuesta inicial en la página de recursos de salud mental de la BDFNC: [bleedingdisordersnc.org/resources/mental-health/](https://bleedingdisordersnc.org/resources/mental-health/). Más detalles sobre la encuesta en español serán publicados este año más adelante.

BDFNC también continúa abogando por el acceso equitativo al tratamiento de salud conductual para pacientes hospitalizados (incluidos los trastornos de salud mental y uso de sustancias) para pacientes con trastornos hemorrágicos. Se sabe que a los pacientes con trastornos hemorrágicos se les niega la colocación en cama porque tienen un trastorno hemorrágico. El año pasado, la BDFNC tuvo conocimiento de dos pacientes que experimentaron estas negaciones, y otros han enfrentado los mismos problemas en los últimos años. Con la ayuda de la Coalición de Acceso a la Salud Mental y Uso de Sustancias para

*Continúa en la página siguiente*



## **Iniciativa de Salud Mental** *continuación de la página anterior*

Trastornos Hemorrágicos (BD SUMHAC), un equipo de miembros de la comunidad de Carolina del Norte, proveedores de HTC y personal de la BDFNC se ha estado reuniendo con diferentes organizaciones para obtener más información sobre las regulaciones y orientaciones que puedan influir en las admisiones a instalaciones específicas. Usted puede obtener más información sobre el trabajo de BD SUMHAC en [www.bdsumhac.org](http://www.bdsumhac.org) o comunicarse con Gillian en [gschultz@bleedingdisordersnc.org](mailto:gschultz@bleedingdisordersnc.org). Debido al tremendo trabajo de BD SUMHAC y otras organizaciones de apoyo, la Sección 504 de la Ley de Rehabilitación se actualizó recientemente para aclarar que las instalaciones médicas están incluidas en esta ley. Usted puede leer más sobre esta noticia en la p. 24.

## **Fin de Semana Unión Latina**

7-8 de septiembre de 2024

Winston-Salem, Carolina del Norte (NC)

Únase a la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) durante un fin de semana que construirá una comunidad y brindará recursos y educación,



específicamente a la comunidad de habla hispana

con trastornos hemorrágicos. Todas las presentaciones e información serán presentadas y estarán disponibles para usted en español. Habrá actividades divertidas, programas de apoyo y programas para niños. El alojamiento en hotel, la asistencia en el viaje y todas las comidas se proporcionan sin costo alguno para usted. Habrá más información disponible en el sitio web de BDFNC a finales de este verano.



## **Festival de Raleigh y Caminata para los Trastornos Hemorrágicos**

2 de noviembre de 2024

Morrisville, Carolina del Norte (NC)

¡Ya casi es el momento del 17º Festival Familiar Anual de Raleigh y Caminata por los Trastornos Hemorrágicos! Una vez más, el evento se llevará a cabo en el parque de Lake Crabtree en Morrisville. Habrá actividades muy divertidas y una caminata entretenida para mostrar la fortaleza de la comunidad de trastornos hemorrágicos. Lo más importante es la recaudación más grande de fondos para la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC). El cien por ciento de todos los fondos recaudados respaldan la misión de defensa, educación, promoción de la investigación y prestación de programas y servicios de apoyo de BDFNC. Al formar equipos y compartir información sobre el evento con su familia, amigos y redes personales, la BDFNC cuenta con USTED para ayudar a recaudar \$100.000 y sabe que usted puede hacerlo.

Más información sobre el evento estará disponible en el sitio web de BDFNC este verano. Mientras tanto, ¡por favor reserva la fecha y cuénteselo a sus amigos y familiares!





## Adverse Pregnancy Outcomes More Common in Women With Inherited Bleeding Disorders

By: Vicki Moore, PhD

Reprinted from *Hematology Advisor*

Higher risks of postpartum hemorrhage (PPH) and other adverse pregnancy outcomes were demonstrated in women with inherited bleeding disorders, in comparison with the general population, in a recent study based in Alberta, Canada. Study findings were reported in the journal *Haemophilia*.

The study was a retrospective, population-based, cohort study based on data obtained from the Alberta Pregnancy Birth Cohort for the years of 2010 to 2018 and including women who experienced pregnancy associated with live birth in a hospital. Individuals were assigned to either of 2 groups based on the presence or absence of an inherited bleeding disorder, such as von Willebrand disease (VWD), hemophilia A, or hemophilia B. Odds of developing PPH or certain other pregnancy outcomes were compared between the 2 groups.

The study population included 311,330 women, with a total of 454,400 pregnancies that involved live births. The mean age of the mothers was 29.6 years. Within this population, there were 80 women who had VWD, 11 women who had hemophilia A, and 2 women with hemophilia B.

Over the study period, the rate of PPH did not show a significant change overall ( $P = .35$ ). In 2010, this rate was 10.13 per 100 deliveries (95% CI, 10.10-10.16) and in 2018, the rate was 10.72 (95% CI, 10.69-10.75).

However, significant differences were observed in the rates of PPH based on the presence of any of the evaluated bleeding disorders. Women with bleeding disorders had a significantly higher odds of developing PPH, compared to women without bleeding disorders (odds ratio [OR], 2.3; 95% CI, 1.5-3.6).

Antepartum hemorrhage and red cell transfusion were also significantly more likely in women with bleeding disorders in this analysis. In women with an inherited bleeding disorder, the OR for antepartum hemorrhage was 2.9 (95% CI, 1.5-5.9), compared with not having a bleeding disorder. The OR for red cell transfusion was 2.8 (95% CI, 1.1-7.0) in this comparison.

*Continued next page*

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## *Adverse Pregnancy Outcomes More Common in Women With Inherited Bleeding Disorders* continued from previous page

The study investigators also found that third-trimester von Willebrand factor levels were evaluated in 50.0% of pregnancies in women with VWD. Third-trimester factor VIII activity was measured in 47.1% of pregnancies in women with hemophilia A.

The study investigators concluded that PPH occurred at a stable rate in Alberta between 2010 and 2018, but women with inherited bleeding disorders were at greater risk of experiencing PPH and antepartum hemorrhage during pregnancy. The investigators also considered hemostasis workup to be suboptimal during the third trimester for women with bleeding disorders in this study.

“Further study is required to identify factors associated with delayed diagnosis and inadequate haemostasis workup to help ensure early identification and management of underlying bleeding disorders,” the investigators wrote in their report.

*Disclosures: Some authors have declared affiliations with or received grant support from the pharmaceutical industry. Please refer to the original study for a full list of disclosures.*

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## **National Bleeding Disorders Foundation Victory for Women: Ask the Experts**

May 16, 2019

*Reprinted from Hematology Advisor*

***Factor IX- Severe runs in my family and I was diagnosed with FIX mild. What concerns should I have for getting pregnant. Risks to me or to my child that may or may not have hemophilia or bad. (My family has both)***

Hemophilia B (FX IX) occurs in 1 in 25,000 boys. The severity type is associated with the inherited variant and does not change per generation. Of course there is some difficulty in measuring levels particularly if it is between <1% and 1% which takes a high quality lab to consistently discriminate between those levels. If your father has hemophilia B, then you are an obligate carrier, meaning you definitely carry the genetic variant on the X chromosome while having a normal FIX gene on the other unaffected X chromosome. The risks of bleeding during pregnancy is related to the FIX level and most carriers (based on studies) with levels >60% during pregnancy have little pathologic bleeding. The bleeding tendency is more variable when <60%. Additionally FIX does not rise during pregnancy (it may rise 5% or so) and thus what your factor level is in the first trimester will be the same at the time of delivery. So if you are a carrier then your son has a 50/50 chance of having hemophilia B (mild) and the risk of bleeding in the newborn period is small for mild deficiency, with a very low risk of bleeding in the head. If you have a daughter she has a 50/50 chance of being a carrier and only in extremely rare situations would her level be low enough to lead to bleeding. The bottom line is you should go to an adult hematologist at your local HTC to get a birth plan in place.



# Advocates Raise Awareness for Bleeding Disorders

June 4-5, 2024  
Raleigh, NC

On June 5, North Carolina bleeding disorder advocates visited the North Carolina Legislature to speak with their representatives about issues important to this community. Several first-time advocates joined this year!



*BDFNC Advocates meet with Sen. Sawyer*

After a training dinner on the evening of June 4, advocates were prepped and ready to speak with their legislators about the issue of prior authorization. Prior authorization is the process in which health insurers determine whether or not they will approve coverage for a treatment plan or prescription drug. The current prior authorization process gets in the way of quality and timely treatment by creating access to care problems. HB 649, in the North Carolina Legislature, is a bill that, if passed, would help solve these problems. Many of the legislators our group met with agreed that the current prior authorization process is causing problems for patients and needs to be changed.

Advocates found this experience to be rewarding and plan to come back next year. If you are interested in becoming an advocate, email [advocacy@bleedingdisordersnc.org](mailto:advocacy@bleedingdisordersnc.org). No prior experience needed! Your story is important.



*The advocacy group at the BDFNC tent*



*Staff from the National Bleeding Disorders Foundation joined us!*

# Ultra-Rare Bleeding Disorders and von Willebrand Disease Community Education Day

June 8, 2024  
Chapel Hill, NC



The Bleeding Disorders Foundation of North Carolina (BDFNC) has been growing its programming for people with platelet disorders, ultra-rare factor deficiencies, and von Willebrand disease (VWD). On June 8, the 3rd Annual Ultra-Rare and VWD Community Education Day was held at the UNC Friday Center, and on Zoom for those who could not attend in person. The event provided valuable education and provided support among a smaller portion of the BDFNC community. Sessions included *Genetic Counseling for VWD & Rare Bleeding Disorders*, *Nosebleeds: How to Prevent & Control*, *Battle of the Bruises: Tape for the Win* (session about using kinesiology tape), *Management of Platelet Disorders & Ultra-Rare Factor Deficiencies*, *Von Willebrand Disease: Modern Therapy Landscape*, and *Advocating in the ER*.

To wrap up the day, attendees participated in a hands-on workshop to learn more about Kintsugi. Kintsugi is a Japanese art form. Instead of throwing away broken pottery, it is repaired with lacquer dusted with powdered gold, making the new piece repaired and sometimes even more beautiful than before.





# Advocacy Program Fights for Access to Care!



This spring and summer, the Bleeding Disorders Foundation of North Carolina (BDFNC) Advocacy Program has been focusing on patient access to care. Both prior authorization and step therapy are programs implemented by insurers that can block patient access to care. BDFNC is working closely with the Fair Health NC Coalition (FHNC) on the issue of step therapy. This is a program in which patients may be asked to ‘fail first’ on a different medication before the medication prescribed by their doctor is approved. North Carolina passed a law in 2020 that was meant to streamline step therapy and have insurers provide an easily accessible exemption process. However, patients are still burdened by step therapy. BDFNC and FHNC are working to help patients and providers contact the NC Department of Insurance if they are experiencing issues with the step therapy process.

Prior authorization is a process in which health insurers determine whether or not they will approve coverage for a treatment plan or prescription drug. The current prior authorization process can lead to delays in care and diminish the quality of treatment. Advocates visited the NC legislature in June to speak with their representatives about this issue. HB 649 is a bill in the legislature that, if passed, would help solve these problems. Advocates spoke with legislators about their experiences with prior authorization and why it is important to pass this bill.

Members of the community speaking up about issues that affect them is an important part of advocacy here at BDFNC. If you are interested in getting more involved with advocacy, please email [advocacy@bleedingdisordersnc.org](mailto:advocacy@bleedingdisordersnc.org) to join BDFNC’s monthly advocacy call!

## BLOOD BROTHERS

### Blood Brothers Program Update

Be part of the Blood Brothers program! The Bleeding Disorders Foundation of North Carolina (BDFNC) is looking to strengthen its long-standing program through a variety of events throughout the year. BDFNC knows that times have changed and the activities needed to provide support to men with bleeding disorders are different than 15 years ago. BDFNC wants your input to learn what your needs are. Please let BDFNC know what kinds of activities you’d like to see.

Whether you are a young man just out of college or you are planning for retirement, the Blood Brothers Program is for you!

For more information about the Blood Brothers Program, or if you have ideas that you would like to share, please contact Gillian, Director of Programs, at [g.schultz@bleedingdisordersnc.org](mailto:g.schultz@bleedingdisordersnc.org).

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- Help
- Opportunity
- Partnership
- Empowerment

## How BDFNC Supports Parents of Children Diagnosed with a Bleeding Disorder

# HOPE Program Update

*By: Gillian Schultz, Director of Programs*

When your child is diagnosed with a serious condition, like a bleeding disorder, it is normal to feel overwhelmed and scared. Whether the diagnosis comes out of the blue, or even if you have a history of bleeding disorders in your family, once your child receives the diagnosis, it changes everything. As parents, we want the best for our kids and for them to be happy, healthy, and successful. While having a bleeding disorder adds obstacles to achieving those goals, the Bleeding Disorders Foundation of North Carolina (BDFNC) can help you and your child to overcome barriers and achieve those milestones.

The HOPE Program is for parents and caregivers of children diagnosed with a bleeding disorder. Through education, resources, and by facilitating social connections, BDFNC provides you with the tools to be empowered and take control of your child's bleeding disorder. When my son was an infant and toddler, the resources I received through the HOPE Program helped ease some of my fears and provided me with a community that understood what we were dealing with. While my friends who had children without a bleeding disorder could sympathize with my concerns about bleeds and injuries, it was only the community of other parents of children with a bleeding disorder who could really understand what it was like!

While times have changed and treatments for hemophilia have improved, that doesn't mean you don't have those same worries and fears. If your child has a bleeding disorder without the same effective treatments as hemophilia, you might have other fears too. Our kids still have to deal with frequent medical appointments, frequent blood tests, infusions and/or injections. We have to teach them how to safely participate in common activities like bike riding and participating in sports, manage school accommodations and health plans in school, and how to maintain a safe and healthy lifestyle. BDFNC encourages you to connect with us for events and activities for families to help normalize these experiences and where you can relate with others who are experiencing similar circumstances.

What are some resources that you'd like? Do you have an educational topic you'd like to learn more about? An activity you'd like us to do? Reach out and let us know! We want to ensure that we're providing you with the support that you need. BDFNC also has a private Facebook group just for parents of children with bleeding disorders. If you'd like to be added, let me know. Email, call, or text me to let us know what you need. I can be reached at [g.schultz@bleedingdisordersnc.org](mailto:g.schultz@bleedingdisordersnc.org) or directly at (919) 272-6000.

## Unión Latina de Hemofilia

## Unión Latina Update

*By: Guillermo Sanchez, BDFNC Board Member and Volunteer Unión Latina Program Coordinator*

The Latino Families have been participating with enthusiasm in not just the Spanish language events planned for them but in all other activities offered for all the members of the bleeding disorders community in North Carolina. From the Latin Union Community Conversation and education programs to the Family Festival and Walk in Charlotte, families have been active.

The feeling among Latino families is always the same: There is a warmth and understanding from the entire bleeding disorders community. One of the moms of the Latino families said: "When we moved to NC looking for better quality of life for my sons, I thought we would be alone facing all the challenges that living with a bleeding disorder brings to families, but we have found a team that fights and demand alongside us for the access to treatment for everyone regardless race, country of origin or language."

The Latino Families have acquired a broad range of skills to better cope with the day-to-day challenges of living with bleeding disorders through this organization. All the Latino families appreciate the wide range of support that the Bleeding Disorders Foundation of North Carolina has offered and are ready to give back to this great community.





## Bleeding Disorders Affect Women Too SOAR Program Update

Bleeding disorders don't affect just men; Women and girls with bleeding disorders face unique challenges. The Bleeding Disorders Foundation of North Carolina (BDFNC) SOAR Program is dedicated to supporting women and girls to overcome those challenges and raising awareness about women with bleeding disorders.

BDFNC will be partnering with the CHES Foundation Ladybugs Program to bring an enhanced women's track to the Blood Brotherhood and SOAR Weekend this November in Wilmington. More details will be announced later this summer. BDFNC also encourages women to connect at the Summer Community Retreat in August.

SOAR is a program of BDFNC 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 they may SOAR to their full potential.

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

## Teen Empowerment Program



The Bleeding Disorders Foundation of North Carolina (BDFNC) knows that teens with bleeding disorders have unique needs. Between navigating school, getting a job, beginning to date, applying for college, and managing a bleeding disorder, there's a lot to figure out. Teen Empowerment Program activities are meant to help you develop leadership skills, learn about managing adult responsibilities, and become independent in managing your bleeding disorder.

As a teen, what do you need or want? BDFNC does not want to just hold events to say that there was a Teen Event. Are you interested in virtual events? In-person events? Are there any

topics that you'd like to know more about? This is your program, so help to make things happen that are relevant to you! Please complete this short survey to help BDFNC make the Teen Empowerment Program meaningful to you: [forms.gle/PD6SYCZt8qK6KPbR6](https://forms.gle/PD6SYCZt8qK6KPbR6)

For more information about the Teen Empowerment Program, please contact Gillian, Director of Programs, at [g.schultz@bleedingdisordersnc.org](mailto:g.schultz@bleedingdisordersnc.org) or by calling (919) 319-0014.

# TEENS

Help Us to Plan  
Programs for YOU!

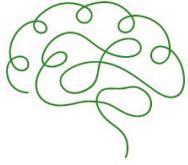







# Mental Health Initiative

MENTAL HEALTH



INITIATIVE

The Bleeding Disorders Foundation of North Carolina (BDFNC) continues to break down barriers when it comes to mental health and bleeding disorders. In May, BDFNC hosted a film screening with Believe Limited, sponsored by Sanofi, about mental health in the bleeding disorders community. The film sparked a great conversation about the continued stigma that exists about mental health, and the connections between bleeding disorders and mental health.

Later this year, BDFNC will be administering the mental health survey conducted in late 2021 into early 2022, in Spanish, so that the perspective of the Latino community can be included in the analysis of results. You can read about the initial survey on BDFNC's Mental Health Resource Page: [bleedingdisordersnc.org/resources/mental-health/](http://bleedingdisordersnc.org/resources/mental-health/). More details about the Spanish survey will be coming later this year.

BDFNC also continues to advocate for equitable access to inpatient behavioral health treatment (including mental health and substance use disorders) for patients with bleeding disorders. It is known that patients with bleeding disorders are denied a bed placement because they have a bleeding disorder. In the past year, BDFNC has been made aware of two patients experiencing these denials, and others have faced the same issues in past years. With the help of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), a team of North Carolina community members, HTC providers, and BDFNC staff has been meeting with different organizations to learn more about any regulations and guidelines that may influence specific facility admissions. You can learn more about the work of BD SUMHAC at [www.bdsumhac.org](http://www.bdsumhac.org) or reach out to Gillian at [gschultz@bleedingdisordersnc.org](mailto:gschultz@bleedingdisordersnc.org). Because of the tremendous work of BD SUMHAC and other advocacy organizations, Section 504 of the Rehabilitation Act was recently updated to clarify that medical facilities are included in this law. You can read more about this news on p. 24.

## The North Carolina Bleeding Disorders Community Has Lots to Celebrate!



*Congratulations!*

Nick Henry graduated Rowan Cabarrus Community College with an Associate in Applied Science in Automotive Systems Technology Degree! Go Nick!



*Congrats*

Congratulations to Ash Dewaine who graduated from Farmville Central High School and was accepted into PCC!

The logo for the Bleeding Disorders Foundation of North Carolina, featuring a red blood drop icon and the text "BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA".

WE WANT TO CELEBRATE YOU!

Are you celebrating a birthday, graduation, anniversary, birth, big stick, or something else? If you'd like for BDFNC to announce your special day, let us know!

A QR code located in the bottom right corner of the celebratory graphic.

## 2024 Friends of BDFNC

*We gratefully acknowledge the individuals who generously donated to BDFNC during the past quarter of 2024. 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  
Isaac Mayle  
Shashi Ranjan  
Brent White

### *In honor of Charles and Kathy Register*

Carolyn Davidson  
Marie Hammond  
Dr. Randolph and Mrs. Catherine Lambe

### *In honor of Mary Hugh Dotson Cartledge*

Chuck Cartledge

### *In Memory of Kevin Transou*

Rush & Associates

### *General Donations*

Karyn and Kyle Davis  
Sue and Allen Heafner  
Linda and Allen Kurtz  
Rick and Sue Makrickas

### *In honor of Charles Register and Tom Watts*

Bret and Janet Stolp

### *In honor of Halle Patrick*

Mary-Jane Patrick

### *George D. McCoy Education Scholarship*

Anonymous Donor  
Phillip Poovey

### *Community Health Charities*

Anonymous Donors

### *In honor of Jen Newman, Physical Therapist extraordinaire, UNC HTC*

Charles and Kathy Register

### *Facebook Fundraisers*

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Charlene Cowell  
Linda Doane  
Daniel Gougherty  
Chelsie Angel Neal  
Myron

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*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/](https://bleedingdisordersnc.org/ways-to-give/) or contact Charlene at [c.cowell@bleedingdisordersnc.org](mailto:c.cowell@bleedingdisordersnc.org). We truly appreciate it!*

# Share Your Time Volunteers Needed

The Bleeding Disorders Foundation of North Carolina (BDFNC) couldn't offer all that it does without the help of dedicated volunteers who give their time and talents. If you have been thinking about volunteering, reach out to BDFNC. Anyone can help, both at the BDFNC office in Morrisville or from your home. BDFNC is specifically looking for volunteers who are currently able to help with event mailings and event preparations at the office in Morrisville.



**Sign up to volunteer today:  
[bleedingdisordersnc.org/volunteer](http://bleedingdisordersnc.org/volunteer)**

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# Hemophilia A vs. B: What's the Difference?

*Much is the same when it comes to hemophilia A and B, but a few key differences change how common—and how treatable—they are.*

By: Michael Hickey

Posted: February 28, 2022

Reprinted from the National Bleeding Disorders Foundation

There are some key differences between hemophilia A and hemophilia B. Read on to see how they differ in terms of genetics, prevalence, effect on the body and courses of treatment.

## The Differences Between Hemophilia A and B

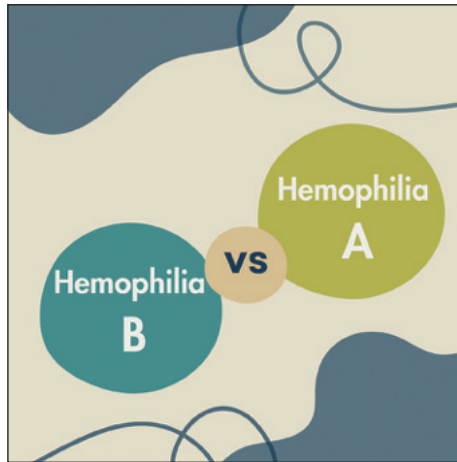
Both types of hemophilia are the result of mutations in the genes that encode coagulation factors—proteins in the blood that help control bleeding. However, the affected proteins are different: Type A, known as classic hemophilia, is caused by a deficiency of factor VIII, one of the proteins that helps blood to form clots. Hemophilia B is caused by a deficiency of factor IX. Severe cases occur in 35% of people with hemophilia B and 45% of people with hemophilia A.

On a genetic level, things look a bit different, too: According to the journal *Haematologica*, the factor VIII gene is located at the end of the long arm of the X chromosome, while the factor IX gene is also on the long arm but closer to the centromere. Additionally, the factor VIII gene is relatively large and structurally complex (26 exons), while the factor IX gene is much smaller and structurally simpler, containing only eight exons (exons are a segment of a DNA or RNA molecule containing information coding for a protein or peptide sequence).

The journal article also states that point mutations, deletions, insertions and rearrangements have been found in factor VIII and IX, but not at the same frequency. Gross genetic abnormalities account for about 7% of hemophilia B cases, while gene rearrangements account for almost half of severe hemophilia A cases, with intron 22 inversion being the most common defect.

## Hemophilia Prevalence

Hemophilia A is much more common than hemophilia B. The Centers for Disease Control and Prevention reports the estimated prevalence of hemophilia in the United States is 12 cases per 100,000 males for hemophilia A and 3.7 cases per 100,000 males for hemophilia B. Additionally, the estimated incidence of hemophilia among U.S. births is 1 in 5,617 male births for hemophilia A and 1 in 19,283 male births



for hemophilia B. (There are far fewer studies on hemophilia in women, but it's estimated that women make up about 1% of all people with moderate or severe hemophilia.)

## Hemophilia Symptoms

About 20% of people who have severe hemophilia A might develop an inhibitor. This is much less common in hemophilia B, occurring in less than 3% of cases. Hemophilia A and hemophilia B have been considered clinically indistinguishable. Yet according to a report, there's some evidence that severe deficiency in factor IX is clinically milder than

severe factor VIII deficiency, which would make type B less clinically severe than type A. The report points to studies that found:

- Severe gene mutations were less prevalent in severe hemophilia B compared with severe hemophilia A.
- The risk of undergoing a joint replacement was three times higher among people with severe hemophilia A.
- People with severe hemophilia B bled less frequently than those with hemophilia A.
- People with severe hemophilia B used about 20% less factor concentrate than those with hemophilia A.
- A significantly higher proportion of people with severe hemophilia A needed regular prophylaxis compared with those with severe hemophilia B.

## Hemophilia Treatment

Hemophilia A needs to be treated with factor VIII and hemophilia B with factor IX replacement. Since inhibitors are more common among people with hemophilia A, the effectiveness of certain treatments does vary between A and B. Immune tolerance induction, used to bring down the level of the inhibitor and enable factor replacement to begin working again, is successful in about 70% of people with hemophilia A and 30% of those with hemophilia B.

Source:

<https://hemaware.org/bleeding-disorders-z/hemophilia-a-vs-b-whats-the-difference>



# New Federal Rule Strengthening Protections Against Disability Discrimination

May 14, 2024

By: BD SUMHAC, HFA, and NBDF

May 10, 2024 - The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), National Bleeding Disorders Foundation (NBDF), and Hemophilia Federation of America (HFA), are pleased to share that after advocacy from the bleeding disorders community, the U.S. Department of Health and Human Services (HHS), through its Office for Civil Rights (OCR), finalized a new rule that will increase equity and access to behavioral health facilities for people with bleeding disorders.

The new rule, entitled *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*, clarifies that the protections afforded to people with disabilities (including people with bleeding disorders) under Section 504 of the Rehabilitation Act of 1973 (Section 504) apply to medical settings. Importantly for the bleeding disorders community, it clarifies that medical providers (including behavioral health facilities) must conduct an individualized inquiry in order to make the determination whether the facility can meet the person's needs, and that they cannot deny access based solely on the presence of a diagnosis, such as a bleeding disorder.

BD SUMHAC, which includes HFA and NBDF as key coalition members, is pleased that HHS responded to their public comments and included strong language in the final rule that will increase equity and access for the bleeding disorders community. The rule states, "In the vast majority of circumstances, where medically indicated care depends on the specific clinical circumstances of the patient seeking treatment, [medical providers] must engage in an individualized inquiry when determining eligibility for treatment." In other words, a facility must conduct an individualized inquiry and talk with the individual's care team (and learn about the bleeding disorder and person's needs) to determine whether they could accommodate that specific individual.

According to a national survey conducted in 2022, people with bleeding disorders are often denied access to inpatient and residential mental health and substance use treatment because of their bleeding disorder. BD SUMHAC's mission is to address this issue and increase equity and access to inpatient and residential treatment facilities for all people with bleeding disorders. In talking with providers whose patients had been denied access to appropriate treatment because of their condition, BD SUMHAC found that facilities are often uneducated about bleeding disorders and have significant misconceptions, bias, and stereotypes about the needs of people with bleeding disorders. Yet, rather than taking the time to learn more about the needs of the specific individual requesting access, facilities often deny people with bleeding disorders on the basis that the condition is too "medically complex." BD SUMHAC looks forward to working with OCR to ensure the appropriate enforcement of this newly released clarification of Section 504.

The public comments submitted to HHS from BD SUMHAC, NBDF, and HFA can be found here:  
[drive.google.com/file/d/15wZFTKYreNrYFEOSdvSrx-mPJCGOvsEU/view](https://drive.google.com/file/d/15wZFTKYreNrYFEOSdvSrx-mPJCGOvsEU/view)

The press release from HHS announcing the new rule can be found here:  
[www.hhs.gov/about/news/2024/05/01/hhs-finalizes-rule-strengthening-protections-against-disability-discrimination.html](https://www.hhs.gov/about/news/2024/05/01/hhs-finalizes-rule-strengthening-protections-against-disability-discrimination.html)

The final rule may be viewed or downloaded here:  
[www.federalregister.gov/public-inspection/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial](https://www.federalregister.gov/public-inspection/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial)

A fact sheet on the rule is available here:  
[www.hhs.gov/civil-rights/for-individuals/disability/section-504-rehabilitation-act-of-1973/part-84-final-rule-fact-sheet/index.html](https://www.hhs.gov/civil-rights/for-individuals/disability/section-504-rehabilitation-act-of-1973/part-84-final-rule-fact-sheet/index.html)

## Thank you to our Advocates and Champions!

This win would not have been possible without the tremendous advocacy of many members of the bleeding disorders community. Over 50 BD SUMHAC advocates met with Members of Congress in Washington D.C. as part of both the Hemophilia Federation of America's Fly-In and the National Bleeding Disorders Foundation's Washington Days to garner their support for this effort. As a result of the community's advocacy, Senator Ed Markey (MA) and Congressman Joe Courtney (CT) agreed to lead a sign-on letter to HHS echoing

*Continued next page*



## New Federal Rule Strengthening Protections Against Disability Discrimination *continued from previous page*

BD SUMHAC's public comments to HHS. Congressman Carbajal (CA), Congressman Lynch (MA), Congressman Tonko (NY) also joined them in amplifying our efforts. We are grateful for their support!

### About BD SUMHAC

Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) is a national, multi-stakeholder advocacy coalition which includes both NBDF, HFA, local bleeding disorder organizations, bleeding disorders clinicians from hemophilia treatment centers, and community members. The mission of BD SUMHAC is to advocate for access to appropriate substance use disorder and mental health treatment facilities for all individuals with BD with a focus on inpatient and residential facilities. BD SUMHAC is not a mental health or substance use disorder treatment organization and does not offer behavioral health treatment or recommendations, but it does support providers in getting people with BD the access they need.

## National Bleeding Disorders Foundation Announces Transition from Hemophilia.org to Bleeding.org

April 16, 2024

*Reprinted from the National Bleeding Disorders Foundation*

The National Bleeding Disorders Foundation (NBDF) is proud to announce its transition from the website hemophilia.org to a new, more inclusive domain: Bleeding.org. This change, taking place on Tuesday, April 23, 2024, is a part of the Foundation's ongoing commitment to serving the diverse needs of the inherited blood and bleeding disorders community.

"This website transition is a bold leap for our community," said Philip Gattone, President and CEO of NBDF.

"This new URL allows us to be more inclusive and better represent the full

spectrum of bleeding disorders, including hemophilia, von Willebrand disease, and other rare conditions. By using a more inclusive domain, we hope to reach a wider audience and provide more comprehensive resources and support to all who need it."

The transition to Bleeding.org follows a recent name change from the National Hemophilia Foundation (NHF) to the National Bleeding Disorders Foundation (NBDF) in August 2023. In addition to the new name, the National Bleeding Disorders Foundation unveiled a new visual identity and logo intended to represent a wide range of inheritable blood and bleeding disorders, as well as a new tagline: "Innovate | Educate | Advocate."

Jay Patel, NBDF's Senior Director of Online Marketing, says, "As the National Bleeding Disorder Foundation continues to roll out our new name and identity, we remind community members to stay connected, join the newsletter community, and add www.bleeding.org to your safe email list to continue receiving our resources and updates."





# Understanding Pharmacy Benefit Managers (PBMs) and Their Challenges

In the complex landscape of healthcare, Pharmacy Benefit Managers (PBMs) play a crucial yet often misunderstood role. These entities act as intermediaries between insurance companies, pharmacies, and drug manufacturers, aiming to streamline prescription drug benefits and costs. While their purpose is to negotiate better prices and manage drug benefits efficiently, PBMs have faced scrutiny and criticism for several reasons.

## What Do PBMs Do?

PBMs administer prescription drug plans for insurance companies, employers, and Medicare Part D plans. They negotiate prices with drug manufacturers, establish networks of pharmacies, and process claims from pharmacies. They also develop formularies, which are lists of drugs covered under a particular plan, and negotiate rebates and discounts from drug manufacturers.

## Challenges and Criticisms

Despite their intended role in controlling costs and improving access to medications, PBMs have come under fire for several practices:

1. **Lack of Transparency:** One of the most significant criticisms against PBMs is their lack of transparency in pricing and rebate negotiations. The complex nature of their contracts with drug manufacturers often results in undisclosed rebates and discounts, making it difficult to determine the actual cost of drugs.
2. **Impact on Drug Pricing:** While PBMs negotiate lower prices for insurers and employers, these savings do not always translate to lower costs for consumers at the pharmacy counter. High deductibles, copayments, and coinsurance can still result in significant out-of-pocket expenses for patients.
3. **Network Restrictions:** PBMs often establish preferred pharmacy networks, limiting where patients can fill their prescriptions. This can be particularly challenging for patients in rural or underserved areas who may not have convenient access to a preferred pharmacy.
4. **Formulary Limitations:** Formularies created by PBMs may not always include all medications or the most effective treatments for certain conditions. Patients and healthcare providers may face restrictions or require prior authorization for medications not included on the formulary.
5. **Consolidation and Market Power:** The consolidation of PBMs has raised concerns about their market power and ability to negotiate favorable terms with drug manufacturers and pharmacies. Critics argue that this consolidation may lead to reduced competition and higher prices.

## Efforts for Reform

In response to these challenges, there have been calls for increased transparency in PBM practices. Some states have enacted legislation requiring PBMs to disclose rebate information and pricing details to consumers and employers. Additionally, efforts are ongoing to reform rebate structures and ensure that savings negotiated by PBMs are passed on to consumers.

## Learn more

There has been a growing number of articles written about the challenges with PBMs, including one from the National Bleeding Disorders Foundation (NBDF). Contact the Bleeding Disorders Foundation of North Carolina at [advocacy@bleedingdisordersnc.org](mailto:advocacy@bleedingdisordersnc.org) if you'd like more information about PBMs.



*NBDF article about a bleeding disorders community member's experience with a PBM.*



*The New York Times article.*



# Bleeding Disorders Foundation of North Carolina

## 2024 Calendar of Events Highlights



### July 18-21, 2024

NC/SC Teen Retreat - Parkton, NC

### July 24, 2024

Community Dinner - Wilmington, NC

### July 27, 2024

Unión Latina - Asheville, NC

### August 2-4, 2024

Summer Community Retreat - Lake Junaluska, NC

### August 10, 2024

Infusion Workshop - Cornelius, NC

### August 20, 2024

Navigating School with a Bleeding Disorder - Virtual

### August 22, 2024

Education Dinner - Raleigh, NC

### August 31, 2024

Physical Therapy Event - Hendersonville, NC

### September 7-8, 2024

Unión Latina Event - Winston-Salem, NC

### November 2, 2024

Raleigh Family Festival & Walk for Bleeding Disorders - Morrisville, NC

### November 15-17, 2024

Blood Brotherhood & SOAR Weekend - Wilmington, NC

### December 7, 2024

Holiday Celebration - Chapel Hill, 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](mailto:events@bleedingdisordersnc.org) or call (919) 319-0014 to be added to the email and/or text groups.

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