THE CONCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Winter 2023-24

Spotlight on Dedication: Celebrating BDFNC's Exceptional Volunteers of 2023

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

While normally there is one volunteer award, BDFNC staff felt that in 2023 we must acknowledge two individuals. BDFNC is happy to announce that the 2023 Volunteer of the Year awardees are Alisha Curtiss and Guillermo Sanchez. *Continued page 4*

Coming to a City Block this Spring: Charlotte Festival & Walk

April 27, 2024
Charlotte, NC

Save the date for the 2024 Charlotte Family Festival & Walk for Bleeding Disorders! On April 27, the Bleeding Disorders Foundation of North Carolina (BDFNC) will be celebrating the 10th Annual Charlotte Festival & Walk on the streets of Uptown Charlotte! The Festival & Walk culminates months of your fundraising with a fun block party! There will be a new walk route this year, along with plenty of activities for the entire family.

The Family Festival & Walk is BDFNC's largest fundraiser, which includes an event in the spring in Charlotte and in the fall in Raleigh. Funds raised provide the foundation of all BDFNC programs and services available, including:

- Advocacy to ensure access to lifesaving bleeding disorder treatments
- Education
- Community building opportunities
- Emotional support
- Programs for men, women, teens, families, and in Spanish

Continued page 5

In this Edition:

Save The Date

Community Dinner
February 2, 2024
Raleigh

Unión Latina Event
February 10, 2024
Greenville, NC

Community Dinner (*tentative*)
February 15, 2024
Winston-Salem, NC

Community Medical Symposium & Annual Meeting
March 15-17, 2024
Charlotte, NC

Blood Brothers Community Chat
March 19, 2024
Virtual

Community Conversations
April 16, 2024
Virtual

World Hemophilia Day
April 17, 2024

Charlotte Family Festival & Walk for Bleeding Disorders
April 27, 2024
Charlotte, NC

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

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA

260 Town Hall Dr., Suite A
Morrisville, NC 27560
(919) 319-0014
info@bleedingdisordersnc.org
www.bleedingdisordersnc.org

BDFNC RESOURCE CENTER

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 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.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.

Brittany: A Heartfelt Farewell to a Dedicated Board Member

It is with both gratitude and a touch of sadness that we bid farewell to Brittany Gabriel, who has been an invaluable member of our board of directors. Brittany joined us as a non-voting board member for a one-year term through Duke University's Sanford School of Public Policy Board Leadership Initiative.

Over the last year, Brittany has brought a unique perspective, unwavering commitment, and positive energy to every initiative. As part of her time serving the organization, Brittany created multiple educational materials about bleeding disorders that are being used to raise awareness among the general public. These materials have already made their debut at various medical conferences at which the Bleeding Disorders Foundation of North Carolina (BDFNC) has exhibited.

As Brittany embarks on a new chapter, she takes with her our deepest appreciation and warmest regards. While she may no longer be with us in an official capacity, her influence and guidance will continue to resonate within our organization.

As she finishes her one-year commitment, the BDFNC Board and staff extend our heartfelt thanks to Brittany for her dedication, passion, and support. We are grateful for the time Brittany invested in furthering our cause and making a lasting impact on our mission.

Please join us in expressing our sincerest gratitude to Brittany for her service and wishing her all the best in her future endeavors.

~ Charlene, Executive Director

The Future Depends on You

Any good nonprofit organization provides value to the community it serves by listening to community feedback. One way that an organization can gather community feedback is through a needs assessment.

Every few years, the Bleeding Disorders Foundation of North Carolina (BDFNC) does a needs assessment to ensure that the programs and services that are offered meet your needs. Currently, BDFNC has four needs assessment surveys open to gather your opinions about different services offered to you.

- Communications
- Programs
- Community Assistance
- Teens and Young Adults (to be completed by community members ages 13-29 only)

For each survey that you complete, you will be given the opportunity to enter into a prize drawing for a $25 Amazon gift card. If you complete the Communications, Programs, and Community Assistance surveys, you will be entered into an additional prize drawing.

Please take time to complete each of the needs assessment surveys by visiting bleedingdisordersnc.org/updates and clicking on each link. Each survey will take less than 10 minutes to complete, and most will only take five minutes. Your responses are anonymous. At the end of the survey, you will be provided a link to another website (you will need to copy and paste it into your browser) to enter into a drawing for a $25 Amazon gift card.

Thank you for taking the time to help guide the future of BDFNC!

Spotlight on Dedication: Celebrating BDFNC's Exceptional Volunteers of 2023

continued from page 1

Guillermo Sanchez

Guillermo and his family have been extremely active since joining BDFNC in 2007. Guillermo is always a friendly face, whether at an in-person or virtual event. After joining BDFNC, Guillermo began immersing himself in every possible activity, from events to committees. Guillermo is responsible for spearheading the creation of BDFNC's Unión Latina Program in 2008. Guillermo and his family lived outside the US for a few years but as soon as they were back in North Carolina, they picked right back up in their volunteer efforts and attend almost every BDFNC event across the state!

Alisha Curtiss

Alisha has been leading BDFNC's monthly Community Conversations virtual meet-up events for almost two years now! This online resource provides an opportunity for anyone from the North Carolina bleeding disorders community to come together to gain support. She is always ready to lead a conversation based on the needs of the attendees or research a specific topic so she can facilitate an informal conversation with participants each month. Alisha has also been a Community Leader and Parent Mentor for BDFNC. As a woman with hemophilia B and a mom of two sons with the same condition, Alisha's openness to share her experiences has been beneficial to everyone she's connected with, especially newer community members.

One Bleeding Disorders Community

As you hear and read about upcoming Bleeding Disorders Foundation of North Carolina (BDFNC) events in 2024, hopefully, you will notice a theme. Many of the events planned in 2024 will have the word "*community*" as part of the event's name:

- *Community* Medical Symposium
- Summer *Community* Retreat
- *Community* Dinners
- *Community* Conversations
- Ultra-Rare Bleeding Disorders & von Willebrand Disease *Community* Day

While there are so many challenges to being affected by a bleeding disorder, you also become a part of the bleeding disorders community. This means you have connections and support through thick and thin. BDFNC members often tell us that they feel embraced and welcomed into an extended family and that attending events can feel like a family reunion.

BDFNC hopes that you will feel included in the bleeding disorders community, and wants you to know that you don't have to go it alone. If you haven't connected with the community before, that's okay! Register for an event and connect with other people living with bleeding disorders. If you used to come out, but haven't because of the pandemic or other life circumstances, you are always welcome back! And if you have been a regular at BDFNC events, please welcome new community members with open arms.

Unión Latina Event in Greenville

February 10, 2024
Greenville, NC

Save the date for a Unión Latina event in Greenville! This event is an amazing opportunity to get to know other Spanish-speaking members of the bleeding disorders community. This is a great time to learn more about bleeding disorders, especially since the presentation and resources will be in Spanish! More information will be available on the BDFNC website in January. Anyone interested in learning more about BDFNC's Unión Latina events can send an email to Victoria (Vic) Gioia at v.gioia@bleedingdisordersnc.org or call/text her at (919) 462-6220.

Community Medical Symposium

March 15-17, 2024
Charlotte, NC

Save the date to join the Bleeding Disorders Foundation of North Carolina (BDFNC) at the 2024 Community Medical Symposium. Whether you call it the Annual Meeting, Winter Conference, or Consumer/Community Medical Symposium, this is the largest and most attended educational event of the year. This year's theme of "*Building Community Resources*" will provide you with information about various bleeding disorders and resources to manage a bleeding disorder. There will be highly knowledgeable speakers from North Carolina and across the country, sessions for hemophilia, platelet disorders, ultra-rare bleeding disorders, and von Willebrand disease, as well as opportunities to connect with other men, women, and families with bleeding disorders. As always, childcare and a teen track will be provided. Simultaneous Spanish interpretation will also be available.

As in past years, BDFNC will provide a hotel room for anyone who requests one for Saturday night and all meals and snacks are included. The Community Medical Symposium is FREE to attend thanks to the generous support of our sponsors.

More information will be available soon on the BDFNC website.

Coming to a City Block this Spring: Charlotte Festival & Walk

continued from page 1

- Emergency financial assistance
- Medical IDs
- Scholarships
- Travel grants and assistance

The services offered by BDFNC empower those affected by bleeding disorders with the tools and resources they need to advocate for their needs.

YOUR help is needed. Through individual and team fundraising, you can make an impact on the bleeding disorders community. Start thinking about how you can support the Charlotte Family Festival & Walk in April: Some questions to consider are what your team name will be, how you will fundraise in 2024, and begin asking your family and friends to save the date to join you.

Is Charlotte too far for you? You can still make a donation to the event. If you live in the eastern half of North Carolina, you will have another opportunity to fundraise for BDFNC in the fall. Save the date for the Raleigh Family Festival & Walk, which will be on November 2, 2024, at Lake Crabtree Park in Morrisville.

Stay tuned this January for the official kick-off announcement!

BDFNC is seeking people to serve on the Charlotte Festival & Walk Committee. If you have experience with event planning, fundraising, or just a desire to help, please contact Gillian Schultz, Director of Programs, at g.schultz@bleedingdisordersnc.org.

HOPE Family Day

May 18, 2024
Raleigh, NC

Save the date for 2024's HOPE Family Day: Saturday, May 18, 2024, at Marbles Museum in Raleigh. This one-day family event will provide support and connection for parents of children diagnosed with a bleeding disorder as well as for the kids. There will be an educational session about raising a child with a bleeding disorder. Lunch will be provided as well as admission to the Marbles Museum.

Marbles Museum is located in the heart of downtown Raleigh and includes interactive exhibits and discovery through play. In addition to the exhibit, Marbles features an immersive IMAX theater.

More information about HOPE Family Day will be available on the BDFNC website this spring.

Ultra-Rare Bleeding Disorders & von Willebrand Community Day

June 8, 2024
Chapel Hill, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) is pleased to announce the 3rd Annual Ultra-Rare Bleeding Disorders & von Willebrand Disease Community Day. If you have or care for someone with a platelet disorder, ultra-rare factor deficiency (factors I, II, V, VII, X, XI, XII, XIII), or von Willebrand disease, please join BDFNC on June 8, 2024. The hope is that this event continues to grow each year to provide a beacon of hope and support for those impacted by any of these bleeding disorders.

More information will be available on the BDFNC website this spring.

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! More information about this weekend getaway will be available in the spring.

Community Dinners Around the State

North Carolina is a big state. From far western Murphy, NC near the Tennessee border, to Manteo, NC on the Outer Banks, the state is 560 miles wide! And that's just as the crow flies, not taking into account winding roads and indirect routes. While the state is wide, there are people living with bleeding disorders in all corners of NC. The Bleeding Disorders Foundation of North Carolina (BDFNC) is looking to extend its Community Dinners to include areas in more rural parts of North Carolina, in addition to the cities. Be on the lookout throughout the year for a Community Dinner near you. Please reach out to Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org if you would like to make sure that one of these Community Dinners comes to your area.

Raleigh Family Festival & Walk for Bleeding Disorders

October 14, 2023
Morrisville, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) hosted its 15th annual Family Festival & Walk for Bleeding Disorders in Morrisville this past October. While the rain continued the whole day, so did the event! Over $90,000 was raised to support the bleeding disorders community of North Carolina. Despite the rain, attendees got to enjoy an amazing jump rope performance by the Bouncing Bulldogs, music, cotton candy, face painting, inflatable games, crafts, lunch from Sheetz, ice cream from Marble Slab Creamery, coffee from Caribou Coffee, water from Pepsi (and the rain), and a fun photo booth!

Congratulations to the award winners:

Top Fundraising Team: Clot Hoppers

Hospital Cup: UNC Tarhealers

Best Team T-Shirt: Team Liam

Most Enthusiastic First-Time Fundraiser: Edie Marie O'Connell

Fundraiser with the Most Individual Donors: Kathy Register

Team with the Most Active Fundraisers: UNC Tarhealers

Top Fundraiser Under 18: Hayden Otey

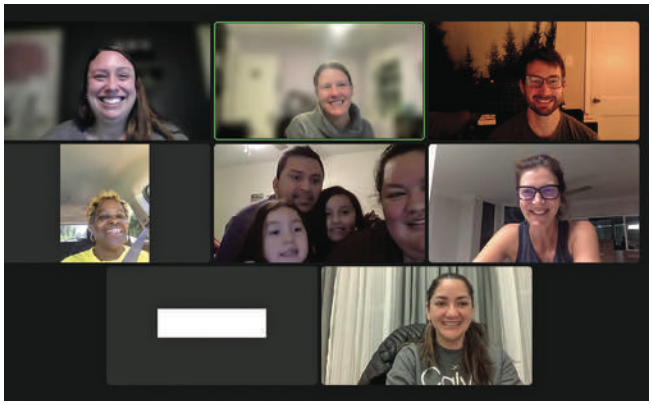
Volunteer Extraordinaire: Karyn Davis

Lifetime Hospital Cups for Retiring Team Captains: Anita Smith (Wake Walkers) and Tracy Griles (UNC Tarhealers)

Save the date for the 2024 Family Festival and Walks: April 27 in Charlotte and November 2 in Morrisville.

Exploring Health Insurance Options and Coverage

November 6, 2023
Virtual



As open enrollment season nears, the complexities of health insurance plans often leave many individuals with numerous questions. To address these concerns and provide clarity, an insightful virtual event titled *Health Insurance Roadmap* was held on November 6, led by Morgan Cook, Takeda Community Education Specialist. Throughout the session, Morgan empowered participants with a comprehensive understanding of various insurance options, factors influencing coverage, and reasons behind potential insurance denials.

The interactive nature of the session fostered an environment where attendees could ask questions, seek clarification, and engage in meaningful discussions. Participants left the event feeling more informed and equipped with the tools necessary to make decisions about their health insurance choices.

This virtual event served as an invaluable resource for attendees. Morgan Cook's expertise provided community members with a navigational guide of insurance options, coverage transitions, and reasons for coverage denials. By explaining the complexities of health insurance, this presentation empowered participants to make more informed and confident decisions about their insurance plans.

HOPE Family Day at Great Wolf Lodge

November 4, 2023
Concord, NC

Families had a blast at the HOPE Family Day at the Great Wolf Lodge, especially at the waterpark! After lunch, families learned more about blood clotting during the hands-on blood clotting science experiment led by Gillian Schultz, Bleeding Disorders Foundation of North Carolina (BDFNC) Director of Programs. After the presentation, families were given waterpark passes to enjoy all the indoor waterpark has to offer, like the interactive play areas! Families with children of all ages attended and connected with other parents of children who have a bleeding disorder. A big thank you to everyone who attended. BDFNC hopes to see everyone at the 2024 HOPE Family Day in May at the Marbles Kids Museum in Raleigh. Stay tuned for more information about this event, which will be announced on the BDFNC website in the spring.

Bleeding Disorders Foundation of North Carolina
260 Town Hall Dr., Suite A, Morrisville, NC 27560 • (919) 319-0014 • info@bleedingdisordersnc.org • www.bleedingdisordersnc.org

Community Connections: BDFNC Gatherings in Asheville and Charlotte

October 26, 2023 - Asheville, NC
November 9, 2023 - Charlotte, NC

This past fall, the Bleeding Disorders Foundation of North Carolina (BDFNC) hosted dinners in Asheville and Charlotte.

On October 26, community members gathered at the Holiday Inn East - Blueridge Parkway in Asheville to learn more about hemophilia and health insurance. The presentation covered topics including types of insurance and what to keep in mind when living with a bleeding disorder and selecting a health insurance policy.

On November 9, people interested in learning more about how gene therapy works got together for dinner at Maggiano's in Charlotte. They learned about different types of gene therapy, particularly gene transfer, which is the type of gene therapy approved for hemophilia A & B.

Teens Hit the Tees

November 18, 2023
Raleigh, NC

Teens from across North Carolina practiced their golf skills at Drive Shack in Raleigh for the last Teen Empowerment Event of the year. While they didn't have much driving range experience, teens had a great time getting to know each other and improving their golf swings. Before heading to the golf bays, teens learned about gaining independence. Thank you to Pfizer for being a sponsor for the Teen Empowerment Program.

Community Conversations

November 16, 2023
Virtual
By: Alisha Curtiss, Community Conversations Leader

Our November Community Conversation was focused on women with bleeding disorders. The group shared some barriers and triumphs to help each other through any difficulties and to celebrate our accomplishments. We look forward to continuing the conversation in 2024!

Holiday Celebration

December 2, 2023
Gastonia, NC

Happy Holidays from the Bleeding Disorders Foundation of North Carolina (BDFNC)! The community had an amazing time celebrating and wrapping up the year at the 2023 Holiday Celebration at the Gastonia Conference Center. There was a face painter, holiday crafts, lunch, and a very informative presentation about the World Federation of Hemophilia's Humanitarian Aid Program, which provides factor to patients in developing countries who do not have the same access to factor as here in the United States. The day ended with Santa who brought all of the children special gifts. He also brought something special for the teens, which he appointed Vic to hand out since Mrs. Claus and the elves were so busy preparing for Christmas that they were unable to join him! It was a great time full of bonding, laughter, and holiday joy. BDFNC hopes to see you at events in 2024 and wishes you a happy and healthy holiday season.

Blood Brothers Program Update

The Bleeding Disorders Foundation of North Carolina (BDFNC) is looking to re-engage men with a bleeding disorder with hopes that you will come out to an event this year. Whether you are a young man just out of college or you are planning for retirement, the Blood Brothers Program is for you!

What kinds of support do you want? In order for Blood Brothers programming to be meaningful, your input is needed. Please let BDFNC know what kinds of activities you'd like to see. Do you want to learn more about treatments for bleeding disorders? Do you want to go axe throwing? This kind of information will be incredibly helpful for BDFNC to plan for you in 2024.

Some events already in the works include the rescheduled Blood Brotherhood & SOAR Weekend in January, sessions at the Community Medical Symposium, the Summer Community Retreat, the fall Blood Brotherhood & SOAR Weekend, and online Blood Brothers Chats.

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

HOPE Program Update

If you have a child with a bleeding disorder, chances are that you don't know other children with a bleeding disorder in your town. But you and your family don't have to be alone. The Bleeding Disorders Foundation of North Carolina (BDFNC) HOPE Program provides support and education to help navigate childhood, from birth to the teen years. Through HOPE activities and events, you can connect with other families and receive valuable resources to help you advocate for your child.

Throughout the year, BDFNC hosts a number of events for families, including HOPE Family Day, the Community Medical Symposium (in the HOPE sessions), the Summer Community Retreat, and family-focused Community Conversations. There are also dinner topics throughout the year directed towards families.

What are you looking for in a program for families? Let BDFNC know! Contact Gillian Schultz, Director of Programs, at g.schultz@bleedingdisordersnc.org, or by calling the BDFNC office at (919) 319-0014.

Unión Latina Update

The Bleeding Disorders Foundation of North Carolina (BDFNC) Unión Latina Program was created to support the needs of Spanish-speaking families in North Carolina. It was great to see the program growing in 2023, and BDFNC hopes this trend continues in 2024.

In addition to learning about living with a bleeding disorder, the Unión Latina Program provides support and community, which has been found to be important in improving one's quality of life. Having a support system to lean on can be so helpful when navigating the healthcare system, schools, work and employment, health insurance, and more.

In 2024, the Unión Latina will be hosting five programs across North Carolina: in Greenville in February, Charlotte in March, Asheville in July, and Raleigh in December. BDFNC is also planning to bring back the Unión Latina Weekend in September at a location still to be decided. These events include presentations by native Spanish speakers and activities to bring the community together. BDFNC is also planning to offer simultaneous Spanish interpreting at more events throughout the year to make them accessible to both English and Spanish community members.

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.

This past fall, BDFNC and women from the SOAR Program exhibited at a number of medical exhibits, including the North Carolina Nurses Association Conference and North Carolina Dental Hygienists' Association Conference (you could read about those experiences in the Fall Edition of *The Concentrate*), and at the School Nurse Association of North Carolina Conference just this month. These conferences are vital in providing resources to medical providers who may not be aware of the signs and symptoms of bleeding disorders in women and girls.

If you are a woman with a bleeding disorder looking for support, please join BDFNC at an event this year. Some events that you may be interested in are the Community Medical Symposium, Ultra-Rare Bleeding Disorders & von Willebrand Disease Community Day, Summer Community Retreat, Blood Brotherhood & SOAR Weekend, *Community Conversations* meetings, and community dinners.

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 *Continued page 16*

Actualización de Unión Latina

El Programa Unión Latina de la Bleeding Disorders Foundation of North Carolina (BDFNC) fue creado para apoyar las necesidades de las familias de habla español en Carolina del Norte. Fue fantástico ver el crecimiento del programa en 2023, y BDFNC espera que esta tendencia se mantenga en 2024.

Además de enseñar a vivir con un trastorno hemorrágico, el Programa Unión Latina ofrece apoyo y comunidad, lo que se ha demostrado que es importante para mejorar la calidad de vida. Tener un apoyo en el que confiar puede ser de gran ayuda a la hora de navegar por el sistema de salud, las escuelas, el trabajo y el empleo, el seguro de salud y mucho más.

En 2024, la Unión Latina organizará cinco programas en Carolina del Norte: en Greenville en febrero, en Charlotte en marzo, en Asheville en julio y en Raleigh en diciembre. BDFNC también está planeando recuperar el Retiro de la Unión Latina en septiembre en un lugar todavía por determinar. Estos eventos incluyen presentaciones a cargo de personas que hablan español como lengua nativa y actividades para unir a la comunidad. BDFNC también tiene la intención de ofrecer interpretación simultánea al español en más eventos durante el año.

Celebración de las Fiestas

2 de diciembre de 2023
Gastonia, NC

¡Felices Festividades de BDFNC! Tuvimos un tiempo increíble celebrando con miembros de la comunidad y terminando el año en nuestra celebración de días festivos 2023 en el Centro de Conferencias de Gastonia. Hubo un pintor de caras, artesanías de días festivos, almuerzo, y una presentación muy informativa por parte del HFA. Terminamos el día con una visita especial del Polo Norte que trajo regalos especiales a todos los niños. Fue un momento increíble lleno de unión, risas y alegría de las fiestas. Esperamos veros en nuestros eventos en 2024 y que paséis unas felices y saludables fiestas.

Unión Latina Event in Greenville

10 de Febrero de 2024
Greenville, NC

Reserve la fecha para un evento de Unión Latina el 10 de febrero de 2024. Este evento es una gran oportunidad para conocer a otros miembros de la comunidad de trastornos hemorrágicos que hablan español. Este es un gran momento para aprender más sobre los trastornos hemorrágicos, ¡especialmente porque la presentación y los recursos estarán en español! Más información estará disponible en el sitio web de BDFNC en enero.Si desea obtener más información o participar, comuníquese con Victoria (Vic) Gioia al correo electrónico v.gioia@bleedingdisordersnc.org o en teléfono (919) 462-6220.

La expansión de Medicaid comeinza en Carolina del Norte

A partir del 1 de diciembre de 2023, más de 600.000 personas ahora podrán obtener cobertura médica a través de Medicaid. Es posible que personas de Carolina del Norte puedan obtener cobertura médica a través de Medicaid incluso si no han calificado antes. Para obtener más información, visita el sitio MasMedicaid.nc.gov.

Completa una solicitud para Medicaid en línea en epass.nc.gov. También pueden enviar una solicitud impresa o completar una solicitud en persona en la oficina local del Departamento de Servicios Sociales (DSS). Si usa ePass, mantener actualizada su información de contacto en ePASS para recibir toda la información importante sobre los beneficios de Medicaid.

Simposio Médico de la Comunidad

15-17 de marzo de 2024
Charlotte, NC

Reserve la fecha para participar con la Bleeding Disorders Foundation of North Carolina (BDFNC) en el Simposio Médico de la Comunidad 2024.

Ya sea que se llame Reunión Anual, Conferencia de Invierno o Simposio Médico de Consumidores/Comunidad, éste es el evento educativo más grande y concurrido del año. El tema de este año, "Creación de recursos de la Comunidad", le proporcionará información sobre diversos trastornos hemorrágicos y recursos para controlar un trastorno hemorrágico. Habrá expertos de Carolina del Norte y de todo el país, sesiones sobre hemofilia, trastornos plaquetarios, trastornos hemorrágicos ultra raros y la enfermedad de von Willebrand, y también oportunidades para conectarse con otros hombres, mujeres y familias con trastornos hemorrágicos. Como siempre, habrá servicio de guardería y una sesión para adolescentes. También se ofrecerá interpretación simultánea al español.

Como en años anteriores, BDFNC proporcionará una habitación de hotel para cualquier persona que pida una el sábado por la noche y todas las comidas y aperitivos están incluidos. La entrada al Simposio Médico de la Comunidad es GRATIS gracias al generoso apoyo de nuestros patrocinadores.

Más información estará disponible en breve en el sitio web de BDFNC.

Esta primavera, en una cuadra de la ciudad: Charlotte Festival & Walk

27 de abril de 2024
Charlotte, NC

¡Guarde la fecha para el 2024 Charlotte Family Festival & Walk for Bleeding Disorders! El 27 de abril, la Bleeding Disorders Foundation of North Carolina (BDFNC) celebrará el 10th Festival y Caminata Anual de Charlotte en las calles de Uptown Charlotte.

El Festival y Caminata culmina meses de campaña de obtención de fondos con una gran fiesta. Este año habrá un nuevo camino y muchas actividades para toda la familia.

El Festival y Caminata Familiar es la mayor campaña de recaudación de fondos de BDFNC, que incluye un evento en primavera en Charlotte y otro en otoño en Raleigh. Los fondos recaudados constituyen la base de todos los programas y servicios disponibles de BDFNC, entre los que se incluyen:

- Defender la causa para garantizar el acceso a tratamientos de trastornos hemorrágicos que salvan vidas
- Educación
- Oportunidades de crear comunidad
- Apoyo emocional
- Programas para hombres, mujeres, adolescentes, familias y en español
- Ayuda económica de emergencia
- Identificación médica
- Becas
- Asistencia y ayudas para gastos de transporte

Los servicios ofrecidos por BDFNC facultan a los afectados por trastornos hemorrágicos con las herramientas y los recursos que necesitan para defender sus necesidades. Necesitamos SU ayuda. A través de la recaudación de fondos individuales y en equipo, puede tener un impacto en la comunidad de trastornos hemorrágicos. Así que empiece a pensar en cómo puede participar en el Charlotte Family Festival & Walk en abril. Empiece a pensar ya en su equipo de la caminata, en cómo recaudará fondos en 2024 y pida a sus familiares y amigos que reserven la fecha para unirse a usted.

¿Charlotte está muy lejos para usted? Todavía puede hacer una donación para el evento. Si vives en la mitad parte de Carolina del Norte, tendrás otra oportunidad de recaudar fondos para BDFNC en otoño de 2024. Reserve la fecha para el Raleigh Family Festival & Walk, que será el 2 de noviembre de 2024, en el Lake Crabtree Park de Morrisville.

¡Permanezca atento este enero para el anuncio oficial del evento!

Soar news

A supplement to
The Concentrate

Winter 2023-24

support • outreach • advocacy • resources
for girls & women with bleeding disorders

NC School Nurse's Conference

December 7-8, 2023
Greensboro, NC
By: April Lindsey-Evans, BDFNC Community Member

The 38th Annual North Carolina School Nurse Conference was held at the Koury Convention Center in Greensboro, North Carolina. The conference had over 600 participants and offered extensive opportunities for professional development to advance the practice of school nurses. Participants could learn from national, state and local experts, discover cutting-edge resources, and network with professionals from a variety of backgrounds. Being an exhibitor at the conference was a great honor. I had a great experience and was able to connect with many attendees and provide a wealth of knowledge about our bleeding community. I would like to thank the Bleeding Disorder Foundation for sharing this experience with me!

BDFNC appreciates April Lindsey-Evans and Linda Nelson, who volunteered their time to raise awareness at this important nursing conference!

Dr. Margaret Ragni Sheds Light on the Necessity of Testing Hemophilia Carriers

By: Giuliana Grossi
September 6, 2023
Reprinted from The American Journal of Managed Care

Women with mild hemophilia who carry the gene are often overlooked when it comes to symptoms and treatment options, noted Margaret Ragni, MD, MPH, professor of medicine and clinical and translational research, Division of Hematology/Oncology, director of the Hemophilia Center of Western PA, and American Society of Hematology expert. In this interview with our Center on Health Equity & Access, she explains why genetic testing is crucial for this population.

Continued next page

Dr. Margaret Ragni Sheds Light on the Necessity of Testing Hemophilia Carriers *continued from previous page*

Is it common practice to test potential carriers or women who are related to those with hemophilia?

We will know that you are a carrier if you're the daughter of a patient with hemophilia, a man with hemophilia. If you are a female relative of someone who has hemophilia, like your nephew, your uncle, a daughter of a woman who's a carrier, we only know that you have a 50% chance of being a carrier. So that's where testing is critical.

But I would argue testing is critical even if we know you have hemophilia because what the testing will establish is what your factor level is. And in people in whom there's equivocation and we're not sure, we usually use this 50% cutoff, because that's the low range of normal, but you can still be a carrier with a normal level—so we do genotyping.

Now, it's become much more common to do genetic testing. If we already know you're an obligate carrier—that is, that you are a carrier—what we really need is your [factor] level. We don't need to do genotyping because we already know it in your son or your father. But many times that's not known. So, in general, if it's not known in the family, we'll do the whole thing.

But the reason that 50% cutoff is important: [It's] not just for diagnosing a carrier, but also for decisions about how to manage your bleeding, and it's not a clear-cut science. Generally, if you're less than 0.5, you can't have an epidural. They won't let you unless you have treatment that brings your level higher and then you need longer treatment, you may be at greater risk for bleeding, all those sorts of things.

And here's another problem: Some women who are carriers don't even know that they're at risk of being carriers, because, don't forget, back 30 years ago, we had the AIDS epidemic. People didn't even want to talk about it or someone died in the family. So again, it was a hush-hush, we didn't talk about it. And so women were the last to know, and certainly their doctors who were not hemostasis doctors, they're pediatricians, they're good upstanding internists or gynecologists, don't think of those things. Why would they?

It's sort of one of those issues when a carrier's first symptom, and most common symptom, is heavy menstrual bleeding, you would think that in the realm of things, you would ask the question, "Do you have any other kind of bleeding? What else is going on, is anybody a bleeder in your family?" Those 2 questions could really pave the way for a lot more things.

But let's just suppose now we have established you are a carrier. One of the problems that can happen is we know during pregnancy, for example, your [factor] level may go up, and that's true for hemophilia A, but not for hemophilia B.

By the way, the other thing I forgot to tell you is, there is now a major movement afoot not to classify them as carriers but as hemophilia A and B. I mean, clearly they're carriers by genetic testing, but by talking about what they are, they're mild hemophilia A if they're above 5%, they're mild hemophilia B if they're above 5% of factor VIIII.

By giving them that name, they're taken more seriously, because physicians believe that bleeding disorders only occur in men [and] cannot occur in women who have to bleed at delivery—and that's part of being a normal woman. But the truth is, they have much more severe bleeding than the normal average woman who has menstrual bleeding, who has bleeding at delivery.

To listen to the interview, visit:
ajmc.com/view/dr-margaret-ragni-necessity-testing-hemophilia-carriers

SOAR Program Update *continued from page 11*

disorders (both symptomatic and non-symptomatic). The mission is to improve the quality of life for girls and women with bleeding disorders, so they may SOAR to their full potential.

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

Teen Empowerment Program

Being a teen with a bleeding disorder can be isolating at times. The Bleeding Disorders Foundation of North Carolina (BDFNC) Teen Empowerment Program provides teens with opportunities to connect with other teens who are in similar situations. This program is for all teens impacted by a bleeding disorder, including those diagnosed, siblings, and children of someone with a bleeding disorder.

Come on out to a Teen Event in 2024! While the calendar is still being finalized, there will be Teen Tracks at the Community Medical Symposium and Summer Community Retreat. Details are being finalized for this year's Teen Retreat, including a new venue! But save the date now for July 18-21.

BDFNC would also like teens to participate in advocacy initiatives. Join the Raleigh Advocacy Days or other advocacy events to learn about how YOUR VOICE makes a difference!

For more information, please contact Gillian Schultz, Director of Programs, at g.schultz@bleedingdisordersnc.org or by calling (919) 319-0014.

Mental Health Initiative

The Bleeding Disorders Foundation of North Carolina (BDFNC) continues to infuse programming and information about mental health into events throughout the year. It is known that managing a bleeding disorder can lead to emotional distress and challenges. 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.

In addition to providing resources and support, BDFNC participates in the Bleeding Disorders Substance Use & Mental Health Access Coalition (BD SUMHAC). The mission of BD SUMHAC is to advocate for equitable access to inpatient mental health and substance use disorder treatment programs for individuals with a bleeding disorder. This coalition came together after a young man with hemophilia was denied access to multiple substance use treatment programs, overdosed, and died.

Across the country, including here in North Carolina, mental health and substance use disorder treatment facilities are denying admission to their facilities because a patient has a bleeding disorder. According to research done by BD SUMHAC, approximately 80% of hemophilia treatment center providers who have tried to refer a patient to an inpatient mental health or substance use treatment facility have reported denials. While North Carolina does face a shortage of inpatient mental health beds, a bleeding disorder should not be a reason that a patient is denied access. Reasons for these denials have included concerns about needles for infusions and a lack of education and understanding of bleeding disorders. BD SUMHAC is working to find out if North Carolina has any regulations specific to inpatient behavioral health treatment and bleeding disorders, and will be providing education about bleeding disorders to facilities and overseeing bodies so a bleeding disorder is not a reason for a denial. When a patient is in a mental health or substance use disorder crisis, the last thing they need to deal with is battling with a facility for admission. *Continued next page*

Mental Health Initiative *continued from previous page*

In addition to the work being done in North Carolina and other states, BD SUMHAC has developed helpful toolkits for medical providers and for patients who are experiencing denials to treatment; has provided feedback to the American Society for Addiction Medicine who have updated their treatment guidelines to include language inclusive of bleeding disorders; is working with the Office of Civil Rights; has provided comments about section 504; has presented about this issue at conference across the country; and more.

You can learn more about BD SUMHAC at bdsumhac.org. If you or someone that you care for has been denied access to mental health or substance use disorder treatment because of a bleeding disorder, please reach out to Gillian Schultz, Director of Programs. Gillian is a core member of the BD SUMHAC team and has been working with the coalition since 2022 to remove these barriers.

The North Carolina Advisory Board for Bleeding Disorders

By: Steven Humes, BDFNC Board President

The North Carolina Advisory Board for Bleeding Disorders (NCABBD) was initially started in 2010 by the Bleeding Disorders Foundation of North Carolina (BDFNC) and the leadership of the Region IV-North Hemophilia Treatment Center (HTC) Network. The NCABBD, which meets quarterly, is composed of staff members of BDFNC and HTCs in North Carolina, as well as community members. It offers an opportunity for those involved to share information and provide feedback on HTC services and BDFNC programming. NCABBD is helpful in identifying unmet needs of the patient population from healthcare, educational, and emotional support perspectives. Steven Humes, who chaired the group before his retirement as the Region IV-North Regional Coordinator and who is now the Board President of BDFNC, leads the meetings.

NCABBD has been able to recruit a few consumer members, but more would be welcome. If you are a consumer who would be interested in joining the NCABBD and can commit to attending a quarterly Zoom meeting, please contact Charlene Cowell at c.cowell@bleedingdisordersnc.org. BDFNC is particularly interested in having a diverse group of members (race, ethnicity, age, gender, type of bleeding disorder, and geographic location). The next meeting will take place on Friday, January 26, 2024, from 1:00 to 3:00 via Zoom.

The North Carolina Bleeding Disorders Community Has Lots to Celebrate!

December 10 - Happy Birthday Colton! Colton's 17th birthday

January 27 - Happy Birthday Jessica!

Welcome Home to NC, Ahmed and Shaymaa!

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

General Donations

Anonymous Donors
Sue and Charles Cowell
Philip Gattone
Sue and Allen Heafner
Linda & Allen Kurtz
Jack and Margaret Prim
Jessica Prim and Oscar Gonzalez
Andy and Shirley Serrill
David and Mary Valentino

In Honor of Collin Schmidt

Odessa Hughes & Brenda Blanton

In Memory of Kenneth McDonald

Noma

In Honor of Dr. Warren R. Jewett

Brenda Plassman

Facebook Fundraiser

Gail Hamilton Woolbright
Steven Humes
Ellen Kearney
Cody Norman

BDFNC Facebook Fundraiser for Giving Tuesday

Various Donors

A special thank you to all of the Pfizer employees who donated as part of the Sanford Pfizer location's 5K fundraiser for the NC bleeding disorders community!

Giving Tuesday fundraiser for George D. McCoy Education Scholarship

Daniah Amir
Natalie Branton
Lori Conger
Sue and Charles Cowell
Charlene Cowell and John Prim
Sandra Daughtry
Karyn and Kyle Davis
Patricia DeSantis
Boyd Furr
William Heafner
Alisa Huffman
Sam Hull
Tamison Jewett
Ellen Kearney
Linda and Allen Kurtz
Marvin Pipkin
Cassandra and Thomas Rector
Katherine Register
Gillian and Karl Schultz
Christy Spain
Joyce Walworth
Emily J Wilson

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA

ANNUAL REPORT

JULY 1, 2022 - JUNE 30, 2023

Bleeding Disorders Foundation of North Carolina is 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.

For all persons affected by bleeding disorders to achieve their full potential without barriers or limitations.

PROGRAMS and EVENTS

35 Events

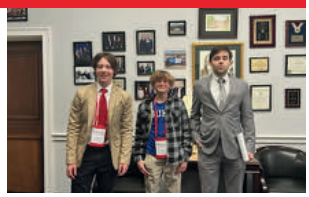
- In-Person & Online
- Ultra-Rare Bleeding Disorders
- Von Willebrand Disease
- Blood Brotherhood (adult men)
- SOAR Program (women & girls)
- HOPE Program (families)
- Teen Empowerment Program
- Unión Latina (en Español)
- Advocacy

646 Participants

ADVOCACY

Your Voice Matters!

- Monthly Advocacy Committee
- NBDF Washington Days
- BDFNC Advocacy Days in Raleigh



- Ensures access to health insurance, doctors, and medications
- Advocated for Medicaid Expansion

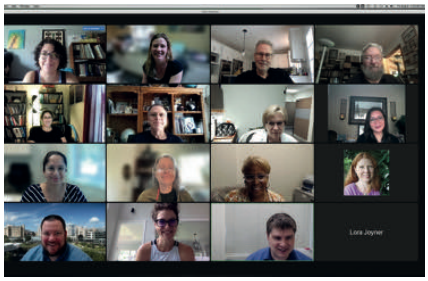
- Advocate against Step Therapy & Copay Accumulator Adjuster Programs

MENTAL HEALTH INITIATIVE

- Presented results of BDFNC Mental Health Survey
- Published Mental Health Resource Guide
- Monthly Community Conversations provides emotional support
- More than **30%** of patients with bleeding disorders report symptoms of a mental health condition
- Core Member and financial supporter of the Bleeding Disorders Substance Use & Mental Health Access Coalition (BD SUMHAC), to advocate for access to inpatient/residential mental health & substance use disorder treatment.

BLEEDING DISORDERS FOUNDATION
OF NORTH CAROLINA

BDFNC COLLABORATES WITH OTHER ORGANIZATIONS TO ENSURE THE BEST SUPPORT FOR THE BLEEDING DISORDERS COMMUNITY.

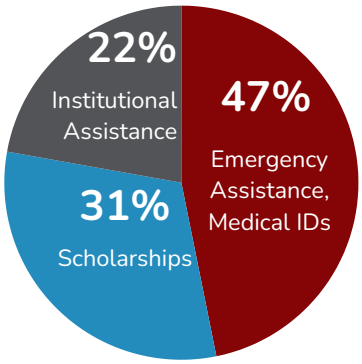


- Partners with all five NC Hemophilia Treatment Centers during quarterly North Carolina Advisory Board for Bleeding Disorders (NCABBD)
- Chapter of the National Bleeding Disorders Foundation
- Member Organization of the Hemophilia Federation of America

- Chairs the Fair Health Coalition
- Member of Care4Carolina
- Member of AllCopaysCounty Coalition

- Exhibits at non-bleeding disorder conferences to raise awareness about bleeding disorders

COMMUNITY ASSISTANCE and SERVICES



$91,821 DISTRIBUTED IN FINANCIAL ASSISTANCE

$42,998: Emergency Financial Assistance and Medical IDs

478 Medical IDs

850+ gas cards

37 Scholarships

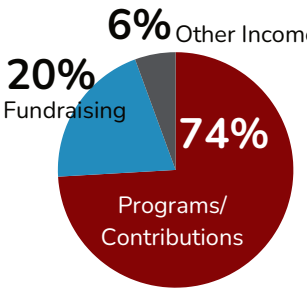
$28,450: Scholarships

$20,373: Institutional Assistance including gas cards to help patients attend medical appointments

FINANCIALS AT A GLANCE

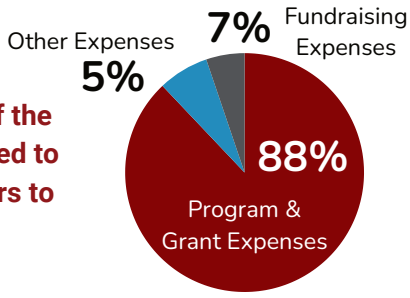
Income ($644,892)

- Contributions & Program Income ($477,798)
- Fundraising Income ($131,021)
- Other Income ($36,073)



Expenses ($580,969)

- Program & Grant Expenses ($510,839)
- Fundraising Expense ($39,904)
- Other Expenses ($30,226)



Net funds at the end of the fiscal year are reinvested to sustain BDFNC for years to come.

Bleeding Disorders Foundation of NC | 260 Town Hall Drive, Ste A, Morrisville, NC 27560
(919) 319-0014 | info@bleedingdisordersnc.org

bleedingdisordersnc.org

Lora Joyner: Championing a Legacy of Care and Empowerment in Physical Therapy

Lora Joyner, a dedicated figure at ECU Health and the ECU Brody School of Medicine, recently achieved an exceptional milestone in her career. Recognized as the National Bleeding Disorders Foundation (NBDF) Physical Therapist of the Year, Lora's relentless commitment to the bleeding disorders community earned her this prestigious honor at the annual Awards of Excellence program.

Lora is also celebrating another milestone: a well-deserved retirement!

With 32 years of unwavering service as a physical therapist and seven years as the clinic manager at ECU Health's Hemophilia Treatment Center (HTC), Lora Joyner embodies the essence of compassion, expertise, and advocacy. Her remarkable journey extends far beyond the clinical setting, touching the lives of the patients she has cared for through various activities.

Beyond her clinical duties, Joyner actively engages in leadership roles within numerous regional and national organizations, presently serving as the national chair of the physical therapy working group of the NBDF. Lora has been a valuable committee member on the North Carolina Advisory Board for Bleeding Disorders, which includes HTCs across the state, the Bleeding Disorders Foundation of North Carolina (BDFNC), and patients. Lora goes above and beyond, volunteering to attend and present at BDFNC events countless times throughout the years. Her multifaceted contributions and leadership have amplified the quality of care and support available to individuals with rare inherited bleeding disorders and their families.

Dr. Beng Fuh, the director of pediatric hematology and oncology, commended Joyner's dedication, leadership, and unwavering commitment to the patients at the HTC. "Lora's invaluable contributions and tireless efforts ensure that patients facing life-changing diagnoses can live their lives to the fullest extent possible," Dr. Fuh remarked.

"When I witness the joy on a child's face, realizing they can still engage in activities post-diagnosis, it reaffirms why I do what I do," Joyner shared warmly. "Helping children and families embrace normalcy and possibilities amid challenging circumstances is incredibly rewarding."

Lora Joyner's legacy of compassion, dedication, and unwavering support continues to inspire and pave the way for future healthcare professionals. Her contributions within the bleeding disorders community serve as a testament to the profound impact that passionate and devoted individuals can have on the lives of those they serve.

While BDFNC, the HTCs, and the patients Lora works with are all sad to see her leave her role, there is no doubt that Lora will remain involved in the community that she has been committed to for 32 years. Please join BDFNC in thanking Lora for her decades of love and service to patients with bleeding disorders!

Opt In for Future Newsletter Mailings

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 future newsletters if you want to continue to receive your copy of The Concentrate delivered by mail to your home address. Starting in Spring 2024, only individuals who opt in will receive a hardcopy newsletter.

If you don't OPT IN, you can still view a downloadable version of *The Concentrate* on the BDFNC website at www.bleedingdisordersnc.org/resources/newsletters.

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. If you have already contacted BDFNC about opting in and received a confirmation, you are all set!

Scan this QR code to access the membership application.

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

HTCs Meet with the Region

November 1-3, 2023
Charlotte, NC

North Carolina was well represented at the Southeast Region Hemophilia Network Training meeting for Hemophilia Treatment Centers (HTC). North Carolina is fortunate to have fantastic hematology treatment centers across the state, and this conference is always an excellent opportunity to bring them together with other HTCs in the Southeast Region.

The Southeast Region Bleeding Disorders Program is a network of twenty-six federally funded HTCs that serve patients in Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee. In addition to the HTCs, nonprofits serving the bleeding disorders community, like the Bleeding Disorders Foundation of North Carolina (BDFNC), were also in attendance. There was great information presented at the conference, from different types of bleeding disorders to current and future therapies. Multiple presentations were from North Carolinians, including a panel session with Gillian Schultz, BDFNC Director of Programs. Gillian's session focused on the challenges people with bleeding disorders are facing when trying to access substance use and mental health facilities, and how a national coalition she is a part of is working to remove these barriers.

NOW Conference for VWD

November 17-19
Phoenix, AZ
By: Cheri Clark, BDFNC Community Member

I had the pleasure of attending the NOW Conference this year in beautiful Phoenix, Arizona from November 17-19. NOW stands for National Outreach for von Willebrand and is held twice yearly, in the spring and fall. It is specifically for those living with or caring for someone with von Willebrand disease (VWD).

Conference topics of conversation vary from von Willebrand 101, which is a basic lesson about VWD, to the mental health aspects of living with a chronic illness. The physicians, who are experts in their fields, and other speakers are very generous with their time. There is plenty of opportunity to have your personal questions answered. In fact, there is an entire session devoted to questions from attendees. One of my favorite talks this year was mental health related and included information on synthetic happiness. Who knew there was such a thing! Even if you have been living with VWD for many years as I have, there are many subjects that will pique your interest, and you will learn something new!

Much time is allowed for networking with others living with VWD. If you know me, you know I have been passionate about getting young girls diagnosed with VWD at a young age, not at 40, which was my age at diagnosis. I was thrilled to be able to meet two young college females, both of whom had recently been diagnosed. I introduced them to each other after finding out they both attended college in the same state. They left Arizona conversing about how they were going to keep in touch and start attending events through their local chapter. My hope is that through these connections, we continue to spread awareness of VWD and improve quality of life for those living with VWD.

The Arizona Hemophilia Association holds NOW twice a year, and the next conference is in April. Sign-ups are currently underway. I would strongly encourage others to attend, as this one-of-a-kind event will improve your knowledge about VWD, help you connect with others, and teach you to advocate for yourself. As an added benefit, you will certainly increase your vitamin D level in sunny Arizona! Conference information can be found here: arizonahemophilia.org/now/

Mild Matters Summit

November 16-19, 2023
Tulsa, OK
By: Amanda Gradzewicz, BDFNC Community Member

Last month I had the pleasure of attending Hemophilia Federation of America's (HFA) Mild Matters Summit in Tulsa, Oklahoma, and it was… life changing. I gained so much knowledge, so many tools, great new friendships, and the wonderful feeling of validation. The Summit took place at a lodge on a large, serene piece of land with walking trails, a big pond, an outdoor pool and hot tub, indoor games, and four bedroom cabins with shared living rooms for lodging. The whole lodge was reserved for HFA's event so it was only "us" and staff on the property; it felt secluded and peaceful. I honestly feel that it helped make this event more intimate, and helped people relax and be open with each other. I mean, there is nothing easy about going up to someone and saying "Hi, my name is _____, I have bleeding disorder _____, and this is seriously impacting my life." HFA was very intentional in creating an environment intended to sprout and grow connections, empower community members with information, and provide and teach us tools to help us improve our diagnostic and treatment journeys.

I gained so much knowledge about mild bleeding disorders and about tools we can use to help our medical team help us. The educational sessions opened with "What are Mild Bleeding Disorders and How Are They Diagnosed?" presented by Jill Johnsen, M.D., from the Washington Center for Bleeding Disorders (live) and Michelle Sholzberg, MDCM (via Zoom). They covered tips on getting a proper diagnosis, such as what labs will show your disorder best, and stressing the importance of using symptom tracking to help your medical providers see the whole picture. The next session, "Bleed Tracking Systems: Why, When, and How!" was presented by Jeanette Jones, MED with HFA. She shared her personal diagnosis/treatment journey with us, education on normal vs. not normal menstrual bleeding, how to access and use the HFA weekly and monthly Pain and Bleed Logs, and the new HFA Menstrual Tracker Guide (PBAC). Then Jill Johnsen, M.D. led a panel along with several other Providers on "Treatment Options for Mild Bleeding Disorders" that educated us on what HTC Physical Therapists can do for us, blood bank information, treatment options for heavy menstrual bleeding, and short factor half-lives and inhibitor risks for mild bleeders.

Nancy Durben, PT at the Portland HTC (live) stressed the importance of physical activity - "Motion is lotion!" She drew attention to "hurt vs. harm" when dealing with pain. "Is this just a 'hurt' or can this 'harm' me?" Nancy also shared what ultrasound can do to educate us about what's going on inside painful joints and what we can do to preserve our quality of life. The last big presentation was "Partnering with Providers for Care - Sharing Your Patient Stories" by Shellye Horowitz, M.A., PPS with HFA. She shared her medical journey with us and tips on how to effectively work with your HTC/medical team. Shellye's key points are keeping defensiveness down, understanding we are all human, doing your part and tracking all of your symptoms, showing appreciation, and recognizing when it's time to find a different provider who could better help you. My favorite part was when Shellye shared the phrase she has heard and often felt: If it is "not severe, not serious," then she said "I bleed like a mild…slowly dripping… You deserve a faucet that does not leak!" And just like that I felt validated and many others did too.

Along with all of the educational tools being provided at the Summit, they had infusion lessons there! Many people were able to learn, for the first time, how to infuse themselves, how to infuse for their children, or both. Those who learned got a "Big Stick" awarded to them and many congratulations from blood brothers and sisters watching or learning beside them.

And that brings me to the most important tool we were provided with at the Summit: the amazing people! I met people with hemophilia A and B, VWD, platelet disorders, factor V deficiency, factor XIII deficiency, double dippers, ultra-rares, and more. I even met someone from the chapter in my home state! Along with Jeanette and Shellye opening up and sharing their journeys, other people opened up about treatment/diagnosis journeys and stories about raising our children with bleeding disorders too. Throughout the summit, we broke off into "Basecamp" small groups: one for Blood Sisterhood, one for Blood Brotherhood, and one for Families. We did many activities with our small groups, and one was role-playing conversations with providers, all types of providers. We role-played our real-life experiences while struggling for treatment and also role-played how these scenarios could have gone better to provide better outcomes and proper treatment for us. It was almost hilariously sad hearing people's stories because we all get it; nearly all of us had been in that position. I was not alone in being told things like "Women can't have hemophilia, you are just a carrier" or "Well, your level as a woman means you don't need factor like a man would with that level" or "A lot of girls get heavy periods, if you start birth control you will stop passing out." I was not alone in receiving a late diagnosis. I was not alone in still not receiving factor until years after my diagnosis. I was not alone in not having factor on hand until I had my severe hemophiliac son. I am not alone and this was life changing for me and many others I met.

I learned that having HFA's education, support, tools, and the Blood Sisterhood/Brotherhood groups, along with the support of our local chapters, is the golden ticket to navigating this journey for ourselves and our families. It feels so good not to feel "so rare."

Transitioning from Pediatric to Adult Care for Bleeding Disorders

By: James Langford
August 25, 2023
Reprinted from the National Bleeding Disorders Foundation

For people with bleeding disorders, the transition from pediatric to adult health care is somewhat like the broader transition from child to grown-up.

The more time and attention that's devoted to preparing for the second stage while still in the first, the easier the shift is likely to be. But regardless of how well prepared you are, the change — when it comes — will probably be unsettling at times.

You're dealing with unfamiliar people, you're asked for information that you may not have even realized you needed, and you discover that the safety net protecting you from the consequences of your own mistakes seems woven quite a bit less tightly than it used to be.

"The majority of youth are unprepared for the change in care," warns the American Society of Hematology, the world's largest professional organization for health care providers specializing in diseases that affect blood, bone marrow, and lymphatic systems. "They may not know their medical history, prescriptions, insurance information, or even how to make a doctor's appointment."

Further complicating things is a transition process that varies by region and health care system. Some hemophilia treatment centers allow patients to remain in pediatric care until age 21; others move them to adult care at age 18.

And in either case, challenges outside anyone's control can disrupt the process.

'I Don't Know What to Do'

For Kelly Wornall and her son, who was diagnosed with von Willebrand disease at age 12 and moved into adult care at age 18 — which happened to be in 2020, during the COVID-19 pandemic — the shift was particularly daunting.

Their longtime pediatric specialist had retired the year before, and her son had just one appointment with a new pediatric provider in the Kansas City area before pandemic restrictions took effect and he turned 18.

"It was utter chaos," Wornall recalls. "During the whole diagnosis process, we saw social workers and there were so many people helping us, and then it wasn't there after the transition into adulthood. Especially since everything had shut down, it would have been nice to transition very slowly."

Instead, her son found himself responsible for navigating his own treatment needs, partly because of federal health privacy laws that limited Wornall's ability to act on his behalf after he reached adulthood.

"He was saying, 'Mom, I don't know what to do. Help,'" she recalls.

Bleeding disorders treatment providers and advocates are familiar with the complications that such confusion can cause and have been working for at least a decade to make the move into adult care easier, in part by developing detailed written guidelines.

"In pediatric care, we really wrap our arms around patients and families and invest in helping them navigate barriers, from family dynamics to understanding and being able to navigate the health care system," says Betsy Boegeman, hematology and oncology clinical social worker at the Children's Minnesota Center for Bleeding and Clotting Disorders in Minneapolis. "While adult care centers provide great care, too, the expectations around independence, autonomy, and responsibility are different."

Preparing for Independence — from the Beginning

Children's Minnesota worked hand in hand with the area's adult hematology center to develop a joint transition policy and procedures to shepherd patients through the transition, she says.

"We have guidelines about how to talk about transitioning to independence basically from birth," Boegeman explains. "Those conversations can start with teaching kids about their bleeding disorders and how to talk about them with friends, and maybe someday their employers."

When children with bleeding disorders reach age 14, the team at Children's Minnesota completes a transition readiness assessment to gauge where patients are and what they still need to learn, she says. *Continued next page*

Transitioning from Pediatric to Adult Care for Bleeding Disorders

continued from previous page

Health care providers and families use the results to fill in any gaps before adolescents move to adult care, which occurs between ages 18 and 21.

"I always recommend that young adults listen to their parents or guardians as they schedule appointments or order medication, then try doing it together, and then try it on their own," Boegeman adds. "It's a good approach for all sorts of things, from doing your own infusions to coming to a visit on your own."

She often refers to Steps for Living, an education program developed by the National Bleeding Disorders Foundation that offers skills development guidelines based on age groups from birth through adulthood.

The section for 16- to 25-year-olds includes a component on transitioning to independence that covers topics such as emergency preparedness and taking charge of personal health care.

"For young adults and adolescents who grow up with chronic medical conditions, not just bleeding disorders, there comes a point when the care has to become more of their responsibility," says Lucy Ramirez, a clinical social worker for the Rush Hemophilia and Thrombophilia Center in Chicago.

While many parents realize the process should be gradual, they often lose valuable time to the demands of everyday responsibilities such as holding jobs and managing children's school and extracurricular activities.

Show and Tell vs. Do-It-Yourself

"You can forget to look at the big picture and think, 'I have to start teaching them how to do some of these things that I've been doing for them,'" Ramirez says. "It's much easier for the parents to just pick up the phone and call the treatment center themselves or keep inventory of a child's medications than to take the time to show the child how to do it."

She says awareness of the challenges of transitioning to adult care for chronic medical conditions has been growing for years.

"The issue was that patients were dropping out of treatment once they became adults, and they were often lost to follow-up for years and years until they actually had a problem," she explains. "By then, they could face serious consequences from not managing their diabetes or cardiac issues or taking the medications that they needed in order to keep themselves in good health."

Because Rush provides lifetime hemophilia treatment, patients don't have to switch to a new center at a certain age unless they go away to college or move from the area, Ramirez says. While they still move to adult care, the comparative consistency allows practitioners to focus largely on teaching the practical skills patients need to take care of themselves.

To assess progress, Rush uses a transition checklist that rates the following capabilities:

- Naming your bleeding disorder and identifying the severity or level
- Describing your bleeding disorder in your own words
- Naming the type of product used to treat your bleeding disorder
- Memorizing your factor dose
- Mixing factor and infusing yourself
- Recognizing a bleeding episode and knowing how to respond
- Knowing whom to call and the number to call for questions about bleeding
- Recognizing the symptoms of an active joint bleed and how to treat it
- Ordering your own factor or other medications
- Keeping a bleeding log
- Scheduling your next clinic appointment
- Naming your health insurance provider and knowing the customer service number

"We start the education process at a fairly young age," Ramirez says, "encouraging them to become comfortable interacting with our staff, asking our staff questions, and then eventually learning how to do what they have to do in order to infuse themselves and make good decisions about their health care."

The online article has many helpful links. To access, go to: hemaware.org/life/transitioning-from-pediatric-to-adult-care

North Carolina Medicaid Expansion Started December 1

On December 1, 2023, 600,000 more people were eligible for health coverage through Medicaid. Even if they didn't qualify before, with Medicaid Expansion, many more North Carolinians may now qualify for insurance through Medicaid. To learn more, go to medicaid.nc.gov.

Apply for Medicaid online at epass.nc.gov. You can also submit a paper application or apply in person at your local Department of Social Services (DSS). If you use ePASS, be sure to keep your contact information up to date to receive all the important information about Medicaid benefits.

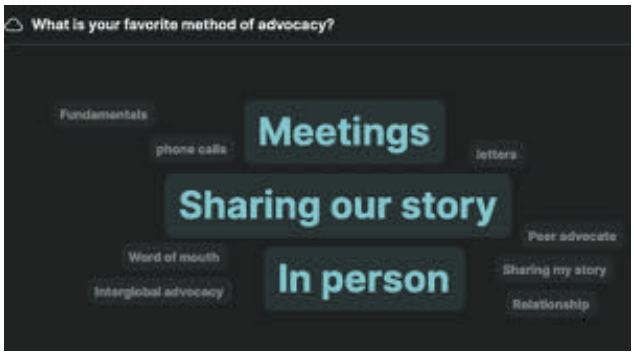
NC Advocate Gathering

December 5, 2023
Virtual

The Bleeding Disorders Foundation of North Carolina (BDFNC) continues to look for ways to increase its advocacy efforts on behalf of the community. One of the most critical pieces: advocates! BDFNC staff cannot do it alone; advocacy depends on hearing from the many voices within the bleeding disorders community.

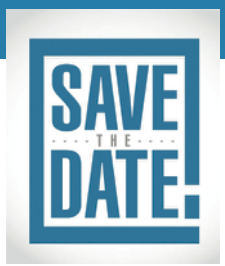
Therefore, BDFNC was excited to hold its second annual Advocate Gathering, which included community members, national organizations, and other stakeholders. Genevieve Skinner, BDFNC Advocacy Director, did a wonderful job leading the meeting. The group celebrated recent successes within the bleeding disorders community at the state and federal levels. BDFNC and the national organizations provided updates on current issues and potential challenges that may affect North Carolina based on trends in other states. Finally, the group talked about how to grow the advocacy program to be sure that their voices are as amplified as possible.

Interested in hearing more about how to stay up to date on BDFNC advocacy issues? No advocacy experience or background needed – BDFNC breaks everything down so it's easy to understand! Contact Genevieve for more information at advocacy@bleedingdisordersnc.org or by calling the office at (919) 319-0014.



Bleeding Disorders Foundation of North Carolina

2024 Calendar of Events Highlights



January 16, 2024
Community Conversations - Virtual

January 18, 2024
Pottery Painting - Fayetteville, NC

January 28, 2024
Blood Brotherhood & SOAR Weekend (*rescheduled*) - Raleigh, NC

February 2, 2024
Community Dinner - Raleigh, NC

February 10, 2024
Unión Latina - Greenville, NC

February 15, 2024
Community Dinner (*tentative*) - Winston-Salem, NC

February 20, 2024
Community Conversations - Virtual

March 15-17, 2024
Community Medical Symposium - Charlotte, NC

March 19, 2024
Blood Brothers Chat - Virtual

April 16, 2024
Community Conversations - Virtual

April 17, 2024
World Hemophilia Day

April 27, 2024
Charlotte Family Festival & Walk for Bleeding Disorders - Charlotte, NC

May 18, 2024
HOPE Family Day - Raleigh, NC

May 21, 2024
Community Conversations - Virtual

June 4-5, 2024
Advocacy Days - Raleigh, NC

June 8, 2024
Ultra-Rare Bleeding Disorders & VWD Community Day - Chapel Hill, NC

June 18, 2024
Community Conversations - Virtual

July 27, 2024
Unión Latina - Asheville, NC

August 2-4, 2024
Summer Community Retreat - Lake Junaluska, NC

November 2, 2024
Raleigh Family Festival & Walk for Bleeding Disorders - Morrisville, 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.

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

IF YOU WANT TO CONTINUE RECEIVING THE NEWSLETTER IN THE MAIL, SEE PAGE 21.