

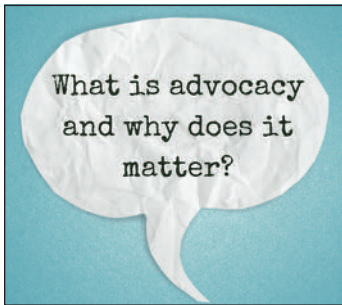
THE CONCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Fall 2024

Advocacy – It's Everywhere!

By: Genevieve Skinner, BDFNC Advocacy Director



The Bleeding Disorders Foundation of North Carolina's (BDFNC) mission states that it seeks to use advocacy to improve the quality of life for persons with bleeding disorders. While the word "advocacy" can sound big and scary, it is actually something that you probably do often. When you advocate, you are teaching about an issue. For BDFNC, advocacy can have many different meanings. This ranges from self-advocacy at the emergency room to legislative advocacy that changes insurance policy.

Self-Advocacy

As many people in the bleeding disorders community know, advocating for yourself and your needs as a patient with a rare disorder is extremely essential. If your treatment is not the best for *Continued page 5*

A Summer of Calls: Checking in with the Membership

By: Charlene Cowell, BDFNC Executive Director

I had the pleasure of working with two amazing interns from the Enloe High School Medical Bioscience Academy this summer, Kate Phan and Sahana Suresh. Together, Kate and Sahana turned a longtime goal into reality: they called the Bleeding Disorders Foundation of North Carolina (BDFNC) membership with a quick but important survey to learn about their interests and current communication preferences. With the help of Donna and Riley, BDFNC community members, this project turned into a well-oiled machine! For example, they quickly learned that they could record Donna's voicemail message to save themselves from repeating it every time they were leaving a message for someone. For individuals who didn't have time to talk on the phone, a SurveyMonkey questionnaire was created to send via text or email so someone could fill it out later. This was available in English and Spanish. We are so grateful to Kate, Sahana, Donna, and Riley for the many hours of commitment to this project! We also appreciate all the community members who took the time to provide feedback to BDFNC so we can continue to meet the needs of our membership.



Summer Outreach Calls Overview

By: Sahana Suresh, BDFNC Intern

At the Bleeding Disorders Foundation of North Carolina (BDFNC), we recently undertook an extensive outreach effort to better understand the needs and preferences of our community. Over several continuous days, our team reached out to 1,365 community member households and gathered

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Save The Date

Community Education Dinner

October 17, 2024
Charlotte, NC

Virtual Unión Latina Program

October 23, 2024
Zoom

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

Charlotte Family Festival & Walk for Bleeding Disorders

April 26, 2025
Pineville, NC

Many more events coming up.

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA

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

(919) 319-0014

info@bleedingdisordersnc.org
www.bleedingdisordersnc.org

MISSION STATEMENT

Bleeding Disorders Foundation of North Carolina is a non-profit organization dedicated to improving the quality of life of persons affected by bleeding disorders through advocacy, education, promotion of research, and delivery of supportive programs and services.

Contact Numbers

Bleeding Disorders Foundation of NC

(919) 319-0014
(919) 319-0016 (fax)

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

National 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.



Summer Outreach Calls Overview continued from page 1



input from over 250 individuals. This valuable feedback is guiding our planning for upcoming events and initiatives.

Over 80% of participants expressed excitement about upcoming events and a strong desire to stay connected through email, text, or phone calls. We also learned that around 56% of our members are interested in both in-person and virtual events, with many expressing flexibility regarding the timing of these events.

In addition to preferences, members shared a range of topics and event suggestions that are important to them. These included education for medical professionals, navigating insurance, transitioning to adulthood, women’s health, rare bleeding disorders, and opportunities for social support and networking.

This outreach took over 150 hours of work across 20 continuous days, and we are incredibly grateful for the dedication of BDFNC community members and volunteers, Donna Blair-Paynter and Riley Blair, who assisted Kate and me. The insights gathered will be invaluable as we continue to shape events and services that truly reflect the needs of our community.

Welcoming April Lindsey to the Board

It’s an exciting time for the Bleeding Disorders Foundation of North Carolina (BDFNC) as April Lindsey, a longtime BDFNC member and volunteer, joins the board of directors! Learn more about April below and please congratulate her on her new role at the next event:

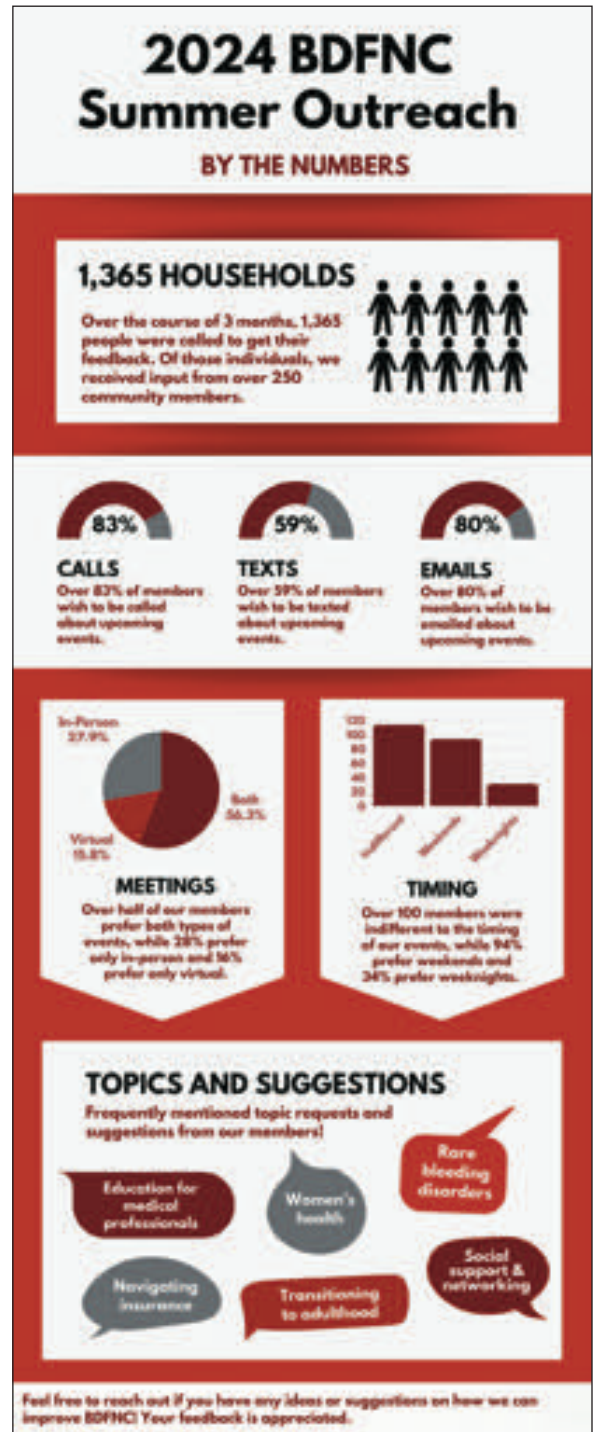


April was born and raised in Reidsville, N.C., and currently resides in Greensboro, N.C. She has three wonderful children: Sergio (23), Raine (19), and Preston (11). April loves dogs and has three: Zeus, Mary Jane, and Storm. She has worked in the healthcare insurance industry for over 17 years, specializing in Operations, Regulatory, and Compliance. She has experience in Commercial, Exchange, Medicaid, Medicare, and Pharmaceutical business. April has a Master of Science in Organizational Leadership. She enjoys traveling to the Caribbean as often as possible in her free time. April is also a member of the community, having been diagnosed with von Willebrand Disease in 2005.

Heartfelt Thanks to Ellen Kearney



After four years of serving on the BDFNC Board of Directors, Dr. Ellen Kearney is stepping down from the board. Although Ellen is no longer on the board, she will continue volunteering with BDFNC in other ways. While Ellen does not have anyone with a bleeding disorder in her family, she has found a passion for this community through the many members she’s met at BDFNC events. Ellen and her family have been donating their time at events for years, making sure they ran smoothly. At our first large conference trying out a hybrid method after being fully virtual because of COVID, Ellen worked tirelessly behind the scenes to make sure the virtual portion went off with minimal hitches. BDFNC is very grateful to Ellen and her family for everything they’ve done for the bleeding disorders community!



Rescheduled for January: Summer Wellness & Physical Therapy Event

January 2025 (date TBD)

Hendersonville, NC

Originally scheduled for August, the *Summer Wellness & Physical Therapy* event is being rescheduled for January 2025. The exact date is still being determined. Once confirmed, the Bleeding Disorders Foundation of North Carolina staff will send a special save the date to anyone in the western region of North Carolina, as well as an email to the full membership.

Let BDFNC Bring You Programming to Meet Your Needs

The Bleeding Disorders Foundation of North Carolina (BDFNC) wants to bring events closer to you. Whether you live in an area that is sparsely populated, a big urban area, or somewhere in between, BDFNC wants to make sure you are getting the support you need. Please contact Gillian Schultz, BDFNC's Director of Programs, to make sure that your needs are being met. Gillian can be reached by email at g.schultz@bleedingdisordersnc.org or by calling her directly, at (919) 272-6000.

This fall, BDFNC will be in Charlotte, Morrisville, Wilmington, and Chapel Hill. Stay tuned for information about events in those areas and beyond.



Join the Latino Community in an Upcoming Virtual Event

October 23, 2024

Zoom

Make important community connections during the next Unión Latina Event, which will be on Zoom on October 23, 2024. Learn about shared decision-making. This is how patients can partner with their doctors and other medical providers to better manage their condition. Registration is open on the Bleeding Disorders Foundation of North Carolina website.

2024 Raleigh Festival & Walk: Don't Miss it!

November 2, 2024

Morrisville, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) Family Festival & Walk isn't just a fundraiser. It's a day of family-oriented fun that builds and strengthens the community of people affected by bleeding disorders in North Carolina while also raising critical funds for BDFNC programs and services. It's also a way for the community to give back. We hope you'll participate and make 2024 the biggest event yet!

Please mark your calendar and come out to Morrisville to meet BDFNC members from throughout the state at the largest NC bleeding disorders community gathering of the year!



2024 Raleigh Festival & Walk: Don't Miss it! *continued from previous page*

Wondering how to get involved in this fun event?

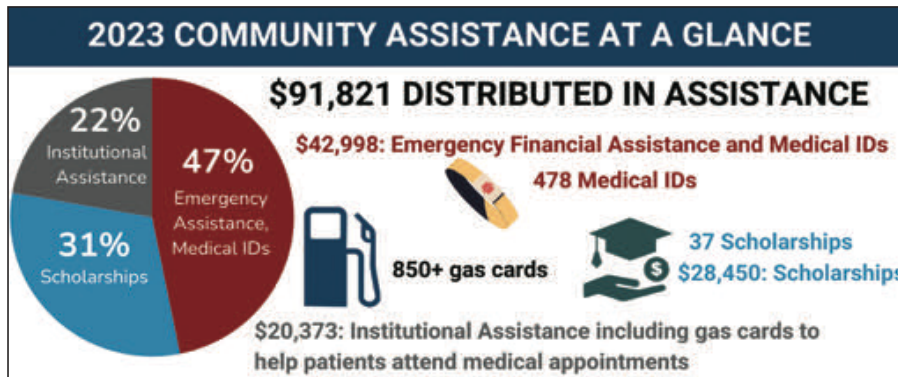
- Create a walk team or register as a walker
- Make a donation, 100% of which goes directly back into NC programs and services
- Sign up to volunteer
- Ask a local business to support through donations of goods or services
- Tell others about the event

Curious about where donations go?

- Emergency financial assistance
- Medical ID jewelry
- Seatbelt straps
- Education and support events
- Programs for men, women, families, teens, in English, and in Spanish
- Year-round advocacy
- Scholarships and grants
- And much more



There is no shortage of reasons to get involved in this event, so now it's time to visit bleedingdisordersnc.org/festival and sign up!



Advocacy – It's Everywhere! *continued from page 1*

your lifestyle, it is critical to advocate with your care team to be able to prioritize what is important to you. For many women, self-advocacy is necessary to get a diagnosis. For parents with children in school, you probably need to advocate to ensure your child has a health plan that takes into account their bleeding disorder. Many of BDFNC's events, especially those dedicated to specific bleeding disorders, discuss self-advocacy. BDFNC's medical ID program is another way that you are supported in your self-advocacy.

Educational Advocacy

When you are telling others about bleeding disorders who may not know much about them, you are participating in educational advocacy. Sharing your personal experience can sometimes be a huge step in this type of advocacy. BDFNC participates in educational advocacy by helping teach doctors, nurses, and all types of clinicians about bleeding disorders. BDFNC attends nurses' and dental conferences. Clinicians are also educated about laws that have passed that may not have come to their attention.

Legislative Advocacy

This type of advocacy is often thought of as the most intimidating, but anybody can do it. You don't need to have advocacy experience to be able to participate in legislative advocacy. The good news is that the content is very similar to self-advocacy and educational advocacy. You live as a person with or a person who cares about someone with a bleeding disorder. Nobody, not even your elected officials, know what that is like better than you. Did you know that if your insurance company tries to make you complete a step therapy process to get the treatment you need, by law it must respond if you submit an exception request? During legislative advocacy, all you need to be able to do is tell your story. During BDFNC's annual Advocacy Day, people with bleeding disorders tell their stories, and with those stories, you can show legislators how they can best support the bleeding disorders community.

Inviting Adults with Bleeding Disorders

November 15-17, 2024
Wilmington, NC

This year's Blood Brotherhood and SOAR Weekend is going to be better than ever! The Bleeding Disorders Foundation of North Carolina (BDFNC) invites adults with bleeding disorders for a fun, educational, and refreshing weekend to build stronger bonds and community among men and women with bleeding disorders. There will be a Blood Brotherhood (men's) and SOAR (women's) track, as well as programming for spouses/partners. Plus there will be networking and social opportunities throughout the weekend.

This year, BDFNC will be partnering with CHES' LadyBugs for an enhanced SOAR track. This allows BDFNC to bring in national speakers who are experts on women with bleeding disorders and who can help women overcome some of their unique barriers.

Information and registration is available on the BDFNC website: bleedingdisordersnc.org/events



Ring in the Holiday Season with BDFNC

December 7, 2024
Chapel Hill, NC



It's hard to believe it, but it will be the holiday season before you know it! Save the date for the Bleeding Disorders Foundation of North Carolina (BDFNC) Holiday Celebration on December 7 in Chapel Hill, North Carolina. Bring some holiday cheer as BDFNC celebrates 2024, the holiday season, and you. More information will be coming this fall.



Events for Teens

Be on the lookout for information about events for teens affected by bleeding disorders this fall and winter! Teen events don't have to be limited to the Teen Retreat and Teen Tracks at larger Bleeding Disorders Foundation of North Carolina (BDFNC) events. You can also connect with other teens, have fun, and make friends with others in the bleeding disorders community through fun and interactive online activities. Think of escape rooms, fun games, and so much more! Stay tuned for more information on BDFNC's socials, website, e-blasts, and texts!

Would you like to help plan events for teens? Contact Gillian Schultz, BDFNC Director of Programs, at g.schultz@bleedingdisordersnc.org or (919) 272-6000.



Save the Date! 2025 Charlotte Festival & Walk

April 26, 2025

Pineville, NC



Save the date for the 2025 Charlotte Family Festival & Walk for Bleeding Disorders: April 26, 2025! In 2025, the Charlotte Family Festival & Walk will be moving to a new location, Pineville Lake Park in Pineville, North Carolina! This new location will provide a scenic setting to celebrate the bleeding disorders community and walk to raise funds that support critical programs and services. More information will be available in early 2025.



Four Days Building Connections for Teens in Bleeding Disorders Community

July 18-21, 2024

Parkton, NC



This summer, teens from North Carolina and South Carolina hopped on buses and rode to Camp Rockfish in Parkton, North Carolina for the annual Teen Retreat. Four days later, they got back on the buses with new memories, friendships, and skills that they can take with them for years to come. Thirty teens spent the weekend learning more about themselves, what they have the potential to accomplish, and that they don't have to let their bleeding disorder get in the way of their goals.



The teens enjoyed activities including kayaking, paddle boarding, a high ropes course with zipline, field games, and swimming. They learned about advocacy in a fun role-playing scenario, where they had to get an idea for a policy through a mock government. They learned about Ryan White and the tragic bad blood epidemic where ten thousand people with hemophilia died because of a blood supply that was contaminated with the HIV and hepatitis C viruses. They learned important things that they should know about managing their bleeding disorder as they grow up into young adults during a lively game of "build the body."



You can check out pictures of the Teen Retreat on BDFNC's Facebook page. The dates for next year's Teen Retreat will be announced soon.



It Was a Beautiful Weekend in the Mountains for the Summer Community Retreat

August 2-4, 2024
Lake Junaluska, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) Summer Community Retreat brought together close to 90 people affected by a bleeding disorder at the Lambuth Inn at the Lake Junaluska Conference and Retreat Center in the beautiful mountains west of Asheville, North Carolina. It was a meaningful weekend of connection, education, and relaxation.

While intense summer storms threatened to dampen the spirit of the weekend, they didn't stand in the way of a great time! On Friday evening, there was a break in the storms allowing everyone to enjoy a campfire and s'mores. There's nothing quite like roasting marshmallows and enjoying the gooey, gooey goodness of s'mores for all ages!



On Saturday, BDFNC held an Infusion and Injection Workshop, with the assistance and guidance of Melanie Clark, RN, and Jennifer Greene, RN, BSN, nurses from the Mission Hematology Program. Most attendees practiced infusion skills using practice devices, called VainSims. These devices allow a patient to safely learn the skills needed for an infusion on practice sleeves, learning techniques without having to poke their arms. Some patients also brought their products to receive guidance and tips for their self-infusions.

Following the Infusion and Injection Workshop, attendees learned about the commonalities they share in the Web of Connections. Parents spent the rest of Saturday participating in the GutMonkey Caregivers Compass workshop facilitated by Margaret Bridges. They learned how to support children through various stages of development, especially when it comes to managing their bleeding disorder. Adults with bleeding disorders participated in a session about Aging with a Bleeding Disorder and a conversation about how to address unmet needs and challenges.

On Saturday night, BDFNC had a movie night and game night! Whether watching the new Ghostbusters movie or enjoying games, including a rousing match of UNO, everyone who attended had a great time!



Sunday's sessions were more intimate, bringing together men with bleeding disorders in the Blood Brothers chat; women with bleeding disorders in SOAR Connections; and parents and spouses in the Resilience session. The weekend sessions wrapped up with Industry Roundtable BINGO.

Throughout the weekend, children and teens participated in activities including arts and crafts, games, teen bleeding disorders trivia, and tie-dyeing,

Continued next page



“The Bleeding Disorder Foundation of North Carolina hosted an amazing event at Lake Junaluska. It was our first retreat ever and we gained so much knowledge and left feeling wonderful from the support of everyone. It was such a heartwarming experience to witness all of the families coming together from all over NC to gain knowledge but also have a great time as well. I am very excited that we came, and we are looking forward to the upcoming events the foundation has planned. Thanks again to Gillian and the staff at the Bleeding Disorders Foundation of North Carolina.”

Ivonne Johnson, parent of a child with a bleeding disorder



It Was a Beautiful Weekend in the Mountains continued from previous page



along with some sessions with their parents including the Web of Connections and Infusion and Injection Workshop.

Of course, it wouldn't be a retreat without free time to enjoy the beautiful setting. Whether at the pool, hiking, or chatting and people-watching while relaxing in the rocking chairs surrounding the Lambuth Inn, the free time gave attendees a chance to relax.

Community member Donna Ott said, "The Summer Retreat for me was a chance for community, emotional healing, learning, and support. I was totally amazed at the support that is

out there for people with bleeding disorders!"

BDFNC is already in the planning stages for next year's Summer Retreat. Save the date for July 25-27, 2025. Next year, BDFNC will be returning to the Crystal Coast Civic Center in Morehead City.

"I feel like it meant a lot to me and helped me out to know what I have and what I can do to help me and I will definitely come and join another event. It was fun and I got to meet some new friends."

Quinton, 11 years old, hemophilia B

Unión Latina in Asheville

Asheville, NC
July 27, 2024

By: Guillermo Sanchez, BDFNC Board Member

For those looking for an event surrounded by nature, the Unión Latina Program in Asheville was the best way to spend a Saturday afternoon. Attendees spent the day at the NC Arboretum where they could enjoy the mountains and learn about the management of a bleeding disorder. Participants learned about online resources to read more about all bleeding disorders and how to talk with your hematologist and other medical specialists to achieve and maintain a better quality of life. At the end of the session, the participants shared experiences about how to take part in sports, under the guidance and supervision of your hemophilia treatment center.

Latino Families, remember to mark your calendar and register for the next meeting of the Unión Latina Program. We love that families participate and have fun.



Infusion and Injection Workshop

August 10, 2024
Cornelius, NC



On a Saturday morning late in the summer, the Bleeding Disorders Foundation of North Carolina, along with Octapharma, InfuCare RX, and some of the staff from the Novant Health Center for Bleeding Disorders and St. Jude Affiliate Clinic, met in Cornelius for an informal and intimate meeting about self-infusion and injection. Following a short conversation about the benefits of self-infusion, participants were individually guided through the techniques of administering their own treatment, whether it was a factor infusion or a SubQ injection. Being able to self-infuse gives patients with bleeding disorders the freedom to live their lives, and not be tied to an HTC, hospital, or home infusion nurse at all times. It also allows patients to administer their medication for bleeds or after injuries without having to wait, sometimes multiple hours, at an emergency room.

Continued next page

Infusion and Injection Workshop continued from previous page



In addition to providing the training, the workshop connected community members with each other to help build a support system. Jackie J. said, “The Infusion Workshop was a very impactful experience for me and my family. We left feeling less alone and even more appreciative of the hemophilia community. We are so grateful for the words of support from all the amazing leaders and will continue to educate ourselves through these amazing workshops!”

Stay tuned to the upcoming events calendar for additional Infusion and Injection Workshops. Please speak to your HTC or medical provider about when they feel self-infusion is right for you, and always follow their guidance. These workshops are for educational purposes only.

Back-to-School Programs

July 24, 2024 and August 20, 2024
Wilmington, NC and Online

Before the start of each school year, parents should provide information about bleeding disorders to their child’s school. But what information does the school need? Who should be informed? When should parents contact the school? Should children have a role? And what about health plans, 504 plans, and IEPs? There is so much to figure out to make sure that your child stays in school and can fully participate in the curriculum.

The Bleeding Disorders Foundation of North Carolina (BDFNC) held two events to provide parents with needed tools and resources. Morgan Cook, Takeda Community Education Specialist, presented *Navigating School with a Bleeding Disorder*. In this presentation, she shared information on laws that help to ensure that children receive an appropriate education, including the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA). Morgan shared information about health plans, 504 plans, and IEPs, and the roles and responsibilities of the school and the parent and student. Importantly, the presentation highlighted helpful tools that can be used when talking with a child’s teacher.

On July 24, BDFNC was at JohnnyLukes KitchenBar in Wilmington, NC for the first of the two presentations on this topic. Attendees enjoyed a delicious dinner, learned about navigating school, and got to know other community members in their area. Then, on August



20, BDFNC offered the presentation virtually on Zoom. This presentation included lots of valuable discussion.

Thank you to Takeda for sponsoring both programs. If you need resources to share with your child’s school, contact BDFNC’s Director of Programs, Gillian Schultz, at g.schultz@bleedingdisordersnc.org or (919) 272-6000.

BDFNC Family Dinner

August 22, 2024
Raleigh, NC

Adults, young children, teens, and parents of all generations came together for an evening of great food and great conversations at BRIO Italian Grille in Raleigh. The evening started with an inspiring presentation by Eric George. Eric shared how his bleeding disorder has had a positive influence on his life. By keeping a positive attitude, remaining resilient, and creating opportunities for yourself, having a bleeding disorder can be something that pushes you forward, not holds you back. Eric talked about how understanding that a physically demanding job he enjoyed wouldn't suit him long-term wasn't a setback. It led him to a career in banking that he's good at and enjoys. He shared stories of the changing challenges of having a bleeding disorder through the generations. Eric, his brother, who is ten years older, another brother who is ten years younger, and his nephew have all met and overcome obstacles and helped each other with the support of their parents and other siblings by turning those obstacles into opportunities.

The discussion that followed the presentation included topics related to self-advocacy and advocating for your children with schools and teachers, sports and physical fitness, as well as legislative advocacy. Resources provided by the Bleeding Disorders Foundation of North Carolina to support community members in all levels of advocacy were also discussed.

A special thanks to Octapharma and BioMatrix for the opportunity to bring people together, many of whom had never previously met but were connected by bleeding disorders, for a special family dinner.

A Reunion of the North Carolina Hispanic Community: Unión Latina Retreat

September 7-8, 2024
Winston-Salem, NC

It was a reunion of the Hispanic bleeding disorders community from September 7-8 in Winston-Salem. While the group may have been small in numbers, the impact was huge. Connecting with a community of others who understand, not just what it's like to be affected by a bleeding disorder, but also to be with other people who are united by their Hispanic heritage, was very meaningful.

Over the weekend, participants got to know each other, learned more about their bleeding disorder, and shared their ideas about how to strengthen the Unión Latina Program. Sessions included "Being Prepared for a Bleeding Disorders Emergency" which helped families be better prepared in the event of a health emergency and visit to the emergency room. In "Becoming Your Own Best Advocate," everyone learned about the importance of being able to advocate for their rights, including access to healthcare and education. "Resources Available to the Latino Community in North Carolina" was an interactive session that will support a hemophilia treatment center initiative to develop a document for individuals and families impacted by a bleeding disorder who have recently moved to this country. This document will help people have an easier transition to American culture and provide information about access to different services, including public education, health care, housing, etc. Other sessions included "Bleeding



Disorders in Women: What Has Changed in Recent Years," "Web of Connection," and a Bleeding Disorders Panel with hemophilia treatment center providers from across the country with the latest information about bleeding disorders and resources and tips for better treatment options.

The Bleeding Disorders Foundation of North Carolina (BDFNC) appreciates the support of the sponsors of this program and Yasmina Abajas, MD, hematologist from the UNC Chapel Hill hemophilia treatment center.

You are invited to a virtual Unión Latina Event on October 23 on Zoom. Registration is open on the BDFNC website.



Unión Latina Noticias

Comunidad. Esta palabra significa mucho cuando se trata del Programa Unión Latina. Al asistir a los eventos que la Bleeding Disorders Foundation of North Carolina (BDFNC) planes, usted se convierte en uno en una comunidad especial y son bienvenidos por otras familias latinas afectadas por trastornos de la coagulación. El Programa Unión Latina es para las personas afectadas por trastornos hemorrágicos y sus seres queridos, y para conectarse con otros que entienden. Los eventos proporcionan apoyo y educación en español

BDFNC está trabajando en la construcción del Programa Unión Latina, y su ayuda es necesaria. Participe en un próximo evento para compartir sus necesidades y lo que necesita para mejorar su calidad de vida como latino afectado por un trastorno hemorrágico.

Unión Latina Asheville

Asheville, NC

27 de julio de 2024

By Guillermo Sanchez

Para quienes buscan de lugares boscosos y rodeados de naturaleza este taller fue la mejor opción para pasar un sábado en contacto con la naturaleza y aprendiendo acerca del manejo adecuado de algún trastorno hemorrágico, los consejos que van desde recursos en línea para aprender mas sobre cada trastorno hemorrágico hasta como hacer equipo con tu hematóloga o hematólogo y otros especialistas médicos para alcanzar y mantener una mejor calidad de vida. Al término de la sesión los participantes compartieron experiencias acerca del como iniciar una actividad deportiva, siempre con el conejo de tu Centro de Hemofilia (HTC).

Familias Latinas, recuerden apuntar en tu calendario e inscribirte a las próximas reuniones de la Unión Latina. Nos encanta que las familias participen y se diviertan.



Súmese a la comunidad latina en un próximo evento virtual

23 de octubre de 2024

Zoom

Establezca importantes conexiones comunitarias durante el próximo evento de la Unión Latina que tendrá lugar por Zoom el 23 de octubre de 2024. Acceda a información sobre la toma de decisiones compartida. Es la manera en que los pacientes pueden trabajar en sociedad con sus médicos y otros proveedores médicos para gestionar mejor su problema de salud. La inscripción está abierta en el sitio web de la Bleeding Disorders Foundation of North Carolina.

2024 Raleigh Family Festival and Walk: ¡No se lo pierda!

2 de noviembre de 2024

Morrisville, NC

El Festival y Caminata Familiar de la Bleeding Disorders Foundation of North Carolina (BDFNC, por sus siglas en inglés) es mucho más que un evento de recaudación de fondos. Se trata de un día de diversión familiar en el que se construye y fortalece la comunidad de personas afectadas por trastornos hemorrágicos de Carolina del Norte y, al mismo tiempo, se recaudan fondos esenciales para los programas y servicios de la BDFNC. **También es una oportunidad para que retribuya la comunidad.** ¡Esperamos que participe y contribuya a que 2024 sea el mayor evento hasta la fecha!

Continúa en la página siguiente

2024 Raleigh Family Festival and Walk *continuación de la página anterior*

Marque su calendario y venga a Morrisville para conocer a los miembros de la BDFNC de todo el estado en la mayor reunión del año de la comunidad de trastornos hemorrágicos de Carolina del Norte.

¿Se pregunta cómo puede participar en este evento divertido?

- Cree un equipo de caminata o inscribese como caminante
- Haga una donación, el 100% de la cual se destina directamente a los programas y servicios de Carolina del Norte
- Inscribese como voluntario
- Pida a un negocio local que lo apoye mediante donaciones de bienes o servicios
- Informe a otras personas sobre el evento

¿Tiene curiosidad por saber dónde van las donaciones?

- Asistencia financiera de emergencia
- Joyería de identificación médica
- Correas de cinturón de seguridad
- Eventos educativos y de apoyo
- Programas para hombres, mujeres, familias, adolescentes y en español
- Activismo todo el año
- Becas y subvenciones
- Y mucho más

Sobran los motivos para participar en este evento, ¡de manera que ahora es el momento de visitar bleedingdisordersnc.org/festival e inscribirse!

Un reencuentro de la comunidad hispana de Carolina del Norte Retiro de la Unión Latina

7 y 8 de septiembre de 2024

Winston-Salem, Carolina del Norte

Fue un reencuentro de la comunidad hispana de trastornos hemorrágicos que se celebró el 7 y 8 de septiembre en Winston-Salem. A pesar de que el grupo era pequeño en número, su impacto fue enorme. Fue muy significativo establecer conexiones con una comunidad de personas que entienden lo que es estar afectado por un trastorno hemorrágico y a las que las une su herencia hispana.



Durante el fin de semana, los participantes se conocieron, accedieron a información adicional sobre su trastorno hemorrágico, y compartieron sus ideas sobre cómo reforzar el Programa de la Unión Latina. Las sesiones incluyeron “Cómo estar preparado para una emergencia de trastornos hemorrágicos”, “Cómo convertirse en su mejor defensor”, “Recursos disponibles para la comunidad latina de Carolina del Norte”, “Trastornos hemorrágicos en las mujeres: Qué cambió en los últimos años”, Web of Connection, y un panel sobre trastornos hemorrágicos con proveedores de centros de tratamiento de la hemofilia de todo el país.

Bleeding Disorders Foundation of North Carolina (BDFNC, por sus siglas en inglés) aprecia el apoyo de los patrocinadores de este programa.

Lo invitamos al evento virtual de la Unión Latina que tendrá lugar por Zoom el 23 de octubre. La inscripción se encuentra abierta en el sitio web de la BDFNC.



Raising Awareness for Women with Bleeding Disorders

This fall, the Bleeding Disorders Foundation of North Carolina (BDFNC) will participate in four statewide conferences to raise awareness about bleeding disorders with medical professionals:

- North Carolina Dental Hygienists Association Annual Session
- North Carolina Nurses Association Annual Convention
- North Carolina Emergency Nurses Association Symposium
- North Carolina School Nurses Association Conference

While you may seek out your medical care based on the doctor who leads the medical team, it is often other medical providers who you spend a greater amount of time with. For routine dental appointments, you probably spend the majority of your time with the dental hygienist. When visiting the doctor, you probably spend a significant amount of time with nurses. These are the people who you see first, before seeing the doctor. That is why BDFNC believes it is extra important to raise awareness with these essential medical providers. It also provides the chance to educate providers about misleading generic information they are taught about bleeding disorders, specifically providing information and resources to let them know **women can have bleeding disorders**.

Nearly every time BDFNC exhibits at a conference, at least one person comes up to the booth to let BDFNC know that because of the resources and education provided at a past conference, they have referred a patient for a diagnosis or have even received a diagnosis themselves! These conferences provide BDFNC the opportunity to reach hundreds, if not thousands, of front-line medical providers to improve awareness of and access to bleeding disorders care.



Resources to Help Someone Get Appropriate Treatment: Better You Know

Do you think you might have a bleeding disorder but have not received a diagnosis? Are you at risk for a bleeding disorder? The National Bleeding Disorders Foundation (previously called National Hemophilia Foundation) developed a program called *Better You Know* to help you identify if you are at risk, help you talk to your healthcare provider, and improve your quality of life. They also have resources that you can provide to your healthcare providers.

From quizzes to better understand your symptoms, tips and tricks, printouts of questions to ask your doctor or to track your symptoms, Better You Know can help you to improve your quality of life. Please pass it along!

For information, visit www.betteryouknow.org.



What's a LadyBug?

The Bleeding Disorders Foundation of North Carolina (BDFNC) is very excited to be partnering with the CHES Foundation for the LadyBugs Program at BDFNC's upcoming SOAR and Blood Brotherhood Retreat in Wilmington NC from November 15-17, 2024. For those who are not familiar with the program, below is a little information about this wonderful program.

The LadyBugs program empowers women ages 16+ with SHeMophilia who are diagnosed with a clotting factor/platelet deficiency, care for someone, or carry any other bleeding disorder. The program's goal is to assist women to find their voice when it comes to decision making about the health of themselves and their loved ones. The LadyBugs program provides education about medical developments, advocacy skill building, stress management techniques and more to encourage women to recognize that their health is equally important.



Why a Ladybug?

Ladybugs actually bleed from their knees when threatened. As a defense mechanism, the ladybug secretes a foul-tasting, yellow fluid from their knee joints to deter predators.

History of the LadyBugs Foundation

Barb Forss founded the LadyBugs Foundation in 1998 after she was diagnosed with Factor VII (7) deficiency. A diagnosis that led her on a medical journey of nearly forty years to achieve after being told mostly by male doctors, that women do not bleed.

She recognized the need for women to network with other women with bleeding disorders to provide them the education needed to advocate for themselves. Barb has continued her work through empowering presentations at the chapter, national and international level.

Learn more about the LadyBugs program here: <https://ches.education/ladybugs>

Head to the BDFNC website for more information about the upcoming event: www.bleedingdisordersnc.org/events



Advocacy Program Updates

By: Genevieve Skinner, BDFNC Advocacy Director



The Bleeding Disorders Foundation of North Carolina's (BDFNC) Advocacy Program has been working for bleeding disorders patients in a variety of ways. In August, I had the opportunity to sit down with a member of Senator Tillis's staff and several other healthcare advocacy groups. Senator Tillis's office was there to hear the priorities for the patients in North Carolina and ask what he should focus on for the rest of the year.

BDFNC also recently collaborated with the Fair Health North Carolina Coalition and the North Carolina Medical Society to put on a successful webinar for clinicians across North Carolina about Step Therapy. Over 50 clinicians attended and learned about how to help their patients avoid unnecessary step therapy protocols.

Next issue be on the lookout to hear how our combined Advocacy/SOAR event with Senator Mary Wills Bode as a guest speaker. If you don't want to miss information on our next advocacy event, email advocacy@bleedingdisordersnc.org to join our advocacy team!



Build Up With the Community Blood Brothers Program Update

By: Guillermo Sanchez, BDFNC Board Member and Blood Brother

What does an adult man with a bleeding disorder find when they join the Blood Brothers Program? The Blood Brothers Program provides a shared identity that allows men with a bleeding disorder to openly talk about their daily life living with an uncommon condition. As a group, we understand what other members are feeling and can share experiences and insights into managing our bleeding disorder. The Blood Brothers Program helps to provide support and resources to increase access to adequate health care, mental health care, financial wellness, educational opportunities, and community participation.

The Bleeding Disorders Foundation of North Carolina (BDFNC) wants YOU to be part of the Blood Brothers Program! This summer, Blood Brothers chatted about what they would like to see from the program during the Blood Brothers chat at the Summer Community Retreat. This fall, connect with the bleeding disorders community during the Blood Brotherhood & SOAR Weekend on November 15-17 in Wilmington, or during the Blood Brothers Chat, which will be held on Zoom sometime this fall. Whether you're a young man just out of college or planning for retirement, the Blood Brothers Program is for you!

As we look to the future, we are building a list of resources that can be used to help educate and fulfill our social interaction needs. If you have ideas and are willing to support the Blood Brothers Program, please contact us. We will be happy to connect with you to discuss how we can grow the Blood Brothers Program. If you have ideas, please contact Gillian, BDFNC's Director of Programs, at g.schultz@bleedingdisordersnc.org.





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

Supporting Parents of Children with Bleeding Disorders

HOPE Program Update

By: Gillian Schultz, BDFNC Director of Programs

Once you're in the groove of something and following a predictable pattern for some time, it is easy to forget how things used to be. As the mom of a teenager with hemophilia who infuses prophylactically, plays soccer, and acts as you would expect a typical teenager to, it can be easy to forget when hemophilia was something that was a much greater part of our everyday life. But then, when I talk with parents who have children who are newly diagnosed with a bleeding disorder, those feelings come rushing back, and I remember how important the HOPE Program was to me, and I hope it will be for them.

Making connections with other families can provide a glimmer of hope for making things feel like they will be okay. In addition to the opportunities I have to speak with new community members on the phone, this summer offered several opportunities to meet parents with babies, toddlers, and school-aged children, and families in more rural parts of the state, who were looking for the same kind of connection and support that I sought out when my son was a baby. Knowing that there is a community that understands can be so reassuring in helping to ease feelings of fear and the unknown.

The name "HOPE" Program is not an accident. HOPE stands for help, opportunity, partnership, empowerment. I see these words as a vision of what the future can hold. If you have a child with a bleeding disorder, and you feel that you need support, please don't be afraid to call us. Join the Bleeding Disorders Foundation of North Carolina (BDFNC) at an event. Join our HOPE Facebook group, and help to build an online support system for families with children who have a bleeding disorder in North Carolina. You and your child are not alone. We have an entire community here to support you.

This summer, BDFNC held several events for families, including the Summer Retreat and back-to-school programs. This fall, we will continue to provide opportunities to learn and connect.

The HOPE Program is for parents and caregivers of children diagnosed with a bleeding disorder. Through education, resources, and facilitating social connections, BDFNC provides you with the tools to be empowered and take control of your child's bleeding disorder. 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? Let me know! We want to ensure that we're providing you with the support that you need. Please email, call, or text me. I can be reached at g.schultz@bleedingdisordersnc.org or directly at (919) 272-6000.

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Unión Latina de Hemofilia

Unión Latina Update

Community. This one word means so much when it's about the Unión Latina Program. By attending events that the Bleeding Disorders Foundation of North Carolina (BDFNC) plans, you become one in a special community and are welcomed by other Latino families affected by bleeding disorders. The Unión Latina Program is for people affected by bleeding disorders and their loved ones, and to connect with others who understand. Events provide support and education in Spanish

BDFNC is working on building up the Unión Latina Program, and your help is needed. Join an upcoming event to share your needs and what you need to improve your quality of life as a Latino affected by a bleeding disorder.

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.

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. 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 or reach out to Gillian at g.schultz@bleedingdisordersnc.org.

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 is busy this fall raising awareness of bleeding disorders in women and girls. In September, BDFNC exhibited at the North Carolina Dental Hygienists' Association and the North Carolina Nurses Association conferences. Later in the fall, BDFNC will also exhibit at the North Carolina Emergency Nurses Conference and the North Carolina School Nurses Conference. These opportunities allow BDFNC to raise awareness about the signs and symptoms of bleeding disorders. Specifically at the nurses conference and the school nurse conference, there is an additional emphasis on women and girls with bleeding disorders.

Continued page 20



ALTUVIIIIO[®]
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Fc-VWF-XTEN Fusion Protein-ehtl

Connect with an **ALTUVIIIIO**[®] Peer Mentor

ALTUVIIIIO Peer Mentors are real patients or caregivers who have had similar experiences to yours.

You'll have the opportunity to:

- Ask questions
- Hear firsthand experiences
- Learn helpful tips
- Get to know others in the community

Maybe it's because I've always had such great support, but **engaging with others** is the best way for me to stay happy.

—AJ

AJ | ALTUVIIIIO patient

AJ is a promotional speaker compensated by Sanofi.



Sign up today to meet a Peer!



SOAR Program Update continued from page 18

The SOAR Program met at the Summer Community Retreat for a breakout session to allow women to connect about important topics for them and get support from other women who can share similar experiences. This fall, BDFNC is excited about a partnership with the CHES Foundation Ladybugs Program to bring an enhanced women's track to the Blood Brotherhood and SOAR Weekend. This partnership will allow BDFNC to bring in expert speakers from across the country. Registration is open on the BDFNC website. Plans are also in the works for a virtual adolescent gynecology and bleeding disorders program in the spring. More details to come.

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 or by calling the BDFNC Office at (919) 319-0014.

Teen Empowerment Program



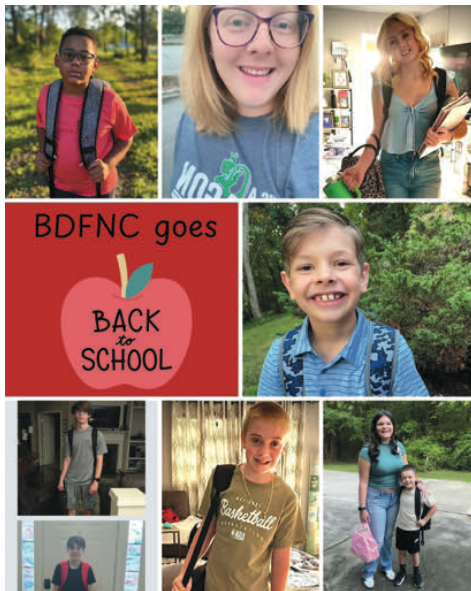
The Bleeding Disorders Foundation of North Carolina (BDFNC) knows that teens with bleeding disorders have unique needs. Between navigating school, getting a job, beginning to date, applying for college, and managing a bleeding disorder, there's a lot to figure out. Teen Empowerment Program activities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

Over the next several months, BDFNC will be hosting two virtual events for teens. More info to come! If you'd like to help plan them, please contact Gillian.

BDFNC also needs teens to complete this short survey to keep the Teen Empowerment Program meaningful: forms.gle/PD6SYCZt8qK6KPbR6

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

Teens: One-minute survey to shape future programming



**Do you need resources for your child's school or daycare?
For tips on working with your child's teachers and helpful tools for developing 504 plans and IEPs, contact Gillian Schultz, BDFNC's Director of Programs, at g.schultz@bleedingdisordersnc.org or (919) 272-6000. Or visit the following websites.**

**National Bleeding Disorders Foundation Steps for Living Website:
stepsforliving.bleeding.org/through-years/school**

**Hemophilia Federation of America Back to School Toolkit:
hemophiliafed.org/resource/back-to-school**

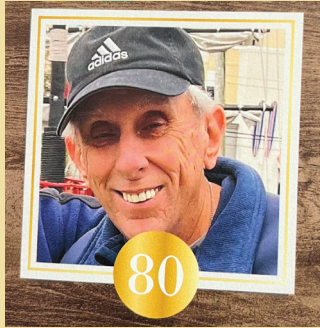


The North Carolina Bleeding Disorders Community Has Lots to Celebrate!



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!



80 Never Looked So Good!

Allen Heafner celebrated a very special milestone this year, turning 80 years young! His wonderful family surprised Allen with a birthday party. In lieu of gifts for anyone who felt inclined, they asked for donations to be made to the Bleeding Disorders Foundation of North Carolina (BDFNC). How sweet is that?!

BDFNC and the Heafner family would like to thank the following donors:

Charlene Cowell • Laura Dunn • Gloria Miller • Nancy Miller Campbell • Mr. and Mrs. Gerald Turner



Celebrating Phil: It's Easy To Do

It was a wonderful way to end the month of August, celebrating Phil Poovey's birthday. As part of his birthday each year, some of Phil's friends show their love by contributing to a scholarship fund in honor of his late husband, the George D. McCoy Scholarship.

A heartfelt thank you to all those who donated:

Charlene Cowell • Karyn and Kyle Davis • Betty Hansen • Sylvia Herbert

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

Facebook Fundraisers

Shelley Willis

General Donations

Karyn and Kyle Davis

Olivia Droney

Paul and Margaret Ising

Linda and Allen Kurtz

Jessica Prim and Oscar Gonzalez

George D. McCoy Education Scholarship

Charlene Cowell

Karyn and Kyle Davis

Betty Hansen

Sylvia Herbert

In honor of Allen Heafner

Charlene Cowell

Laura Dunn

Gloria Miller

Nancy Miller Campbell

Mr. and Mrs. Gerald Turner

In honor of Charles and Kathy Register

William Katz

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



Behind the Giving: Cathy and Randy Lambe



Cathy and Randy Lambe knew about hemophilia but didn't know anyone who had the disease until meeting Charles and Kathy Register in the 1980s through the Durham Savoyards, a local light opera company. They all had a shared love of music and theater and found they had many other things in common. The Registers are how they found out about the Bleeding Disorders Foundation of North Carolina (BDFNC).

Cathy's first production with the Savoyards was in 1981, her first theater experience since high school, and certainly her first time appearing in a grass skirt and body stocking. She has done many things with the Savoyards ever since, both onstage for 30+ years and backstage, including being on the board for years and finally serving as President. Randy also joined the board as Business Manager for many years.

Randy and Cathy both love nature and being outdoors. Randy joked that he originally wanted to be a zoologist, but wound up marrying one instead. He has a PhD in Physics and taught college physics for a while before becoming a manager at Data General. He participated in the design and development of the first laptop computer around 1983.

His other interests include radio-controlled model airplanes, ham radio, and history including aviation and World War II history.

Cathy's undergraduate and Master's degrees were in Zoology, but she went on to work in basic research at Duke Physiology and then at Burroughs Wellcome in drug research and development. She was fortunate enough to help develop the first antiviral drug – the anti-herpes drug Zovirax. She also helped develop a drug targeting a particular type of leukemia.

Her love of gardening led to her becoming trained as a Master Gardener and sharing gardening information with others. She has volunteered for many years with the Durham Habitat for Humanity ReStore and also enjoys classes in Improv Theatre.

The staff and board of BDFNC extend their heartfelt gratitude to Cathy and Randy for their unwavering support and generous financial contributions to our organization. The Lambes' commitment helps BDFNC continue making a meaningful impact in the bleeding disorders community.

Congratulations to Hayden on his win!!



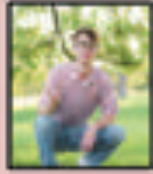
We are very excited to share that Hayden won third place in swimming at the annual CSL Behring Gettin' in the Game Junior National Championships (JNC). This special event took place September 20-22, in Henderson, Nevada.

Nominees for the program got to participate in a clinic where they learned the fundamentals of baseball, basketball, swimming, or golf, learned about the importance of physical activity, and had a chance to show off their abilities in a national competition with fellow participants from around the country.

Hayden had a great time and appreciated the opportunity to participate!



2024 George D. McCoy Education Scholarship Winners



Luke Braun
Georgetown, TX



Alex Riggs
Orlando, FL



John Waters
Pensacola, FL

2024 Optum® Infusion Pharmacy/BDFNC Education Scholarship Winners



Tabitha Allred
Salt Lake City, UT



Melanie Anderson
Osseo, WI



Felipe Bonini
Fort Myers, FL



Fatima Celis Galindo
Oldsmar, FL



Luc Chapall
Matua Township, NJ



Gracie Cosman
Fallon, NV



Grace Chung
Montgomery, AL



Jack Davis
San Antonio, TX



Emily De La Fuente
Riverside, CA



Jocelyn Doerr
Blandon, PA



Karissa Doerr
Blandon PA,



Brian DuVal
Golden Valley, MN



James Hensley
Frederick, MD



Xavier Johnson
Tallahassee, FL



Benjamin Landers
Richland, WA



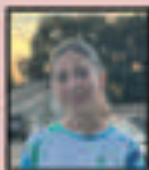
Julietta Medina Rojas
Charlotte, NC



Justin Najimian
East Brunswick, NJ



Elizabeth Norman
Hartford WI,



Yissel Drozco
Modesto, CA



Ashley Otterstien
Buffalo, NY



Brooke Thomas
Fenton, MI



Taylor Young
Mt. Washington, KY



Travel Tips for Young Adults with Bleeding Disorders

A globe-trotting college traveler shares advice for traveling safely.

By: Shelley Flannery

Reprinted from Hemaware

Having a bleeding disorder shouldn't keep you from seeing the world. Just ask Devin Smith, a recent college graduate in Iowa with von Willebrand disease who completed a study abroad program.

"During my four months overseas, I was able to travel all around Ireland, as well as to Scotland, Germany, Czechia, Austria, Slovakia, and Italy," Smith says. "I've also traveled with my family to Bulgaria and Switzerland."

His No. 1 piece of advice is to be well prepared. Here are his top travel tips.

Work with Your HTC Nurses

Smith recommends meeting with your hemophilia treatment center (HTC) nurses before you travel. They can help you confirm the appropriate medications and supplies to pack, review your current treatment plan to carry with you, and talk through where the nearest HTC might be at your travel destination, says Tami Bullock, RN-BC, BSN, a nurse coordinator at the Iowa Hemophilia and Thrombosis Center in Iowa City.

"An HTC nurse can also review your plan for receiving infusions if you need assistance and help you to know if you have emergency care insurance coverage while traveling," Bullock says.

Request a Travel Letter

This document, signed by your health care provider, outlines your diagnosis and everything a medical team would need to know to treat you when you're away from home. It should include 24-hour contact information for your regular HTC should questions arise.

"The travel letter has been extremely helpful for when I go through airport security, too," Smith says. "I just ask them to read the letter, and it explains everything."

Bullock says the travel letter serves as authorization for security agents to allow medications and supplies, including liquids and needle products, to be in your carry-on luggage. "Have your prescription label on each box, vial, or bottle of medication," she says.

Safely Transport Your Supplies

Check the storage requirements for your factor products and other medications. Many must be refrigerated, which means you'll need to transport them in a cooler with ice. "Use caution with hotel refrigerators, which sometimes have areas where items can freeze," Bullock says.

"Don't leave factor exposed to extreme temperatures, hot or cold," she adds. "Don't leave it in a hot car or on the beach."

If traveling by air, carry your cooler on the plane with you instead of checking it in your luggage to avoid the risk of it being lost in transit. If you'll be gone for more than a week or two, consider shipping your supplies to your destination.

Have a Trusted Travel Buddy

Wear an up-to-date medical ID tag throughout your travels. Also, when Smith goes with others, he makes sure that at least one person in his group is aware of his bleeding disorder.

"That way," he says, "they can help advocate for me if I'm unable to advocate for myself."

For more tips on traveling with a bleeding disorder, visit [Steps for Living \(stepsforliving.bleeding.org\)](https://stepsforliving.bleeding.org) or our tips for traveling around the holidays (hemaware.org/life/5-holiday-travel-tips-bleeding-disorders-families).

For more tips on traveling with a bleeding disorder, visit [Steps for Living \(stepsforliving.bleeding.org\)](https://stepsforliving.bleeding.org) or our tips for traveling around the holidays (hemaware.org/life/5-holiday-travel-tips-bleeding-disorders-families).



How PTSD Can Affect People with Hemophilia and Other Bleeding Disorders

While post-traumatic stress disorder is commonly connected with soldiers, people battling chronic illnesses can have it, too. Here's how to identify the symptoms and get the help you need.

By: Andrea Atkins

Reprinted from Hemaware

Justin Levesque had no physical symptoms of hemophilia, but he still felt unwell. "I was just getting nauseous all the time and feeling sick and tired whenever I went out in public, and I wasn't functioning socially," says Levesque, 37, an artist based in Portland, Maine. "I basically felt terrible."

He describes it as a "mental storm," but it goes by another name in medical literature: post-traumatic stress disorder, or PTSD, a condition that affects about 12% of adults with hemophilia, most of whom are men — and that is only now being fully understood.

In a study of 178 people with hemophilia, 101 reported having experienced a traumatic event related to their disease, according to study author Amanda Stahl, LICSW, a social worker at the Boston Hemophilia Center at Brigham and Women's Hospital. Of those who experienced trauma, 82% described it as chronic, meaning it was not a single incident.

"When you go through a medical trauma," Stahl says, whether it's a bleed, developing an inhibitor, or an unpleasant childhood memory of needles, "it can really challenge your ability to cope. It can impact your identity and inform how you view the world. Once you experience repeated traumatic stressors, your body can become programmed to react to ordinary stress the same way it would as if you were experiencing something more traumatic."

That's what happened to Levesque, who had an inhibitor that was resolved once he started taking a new medication for his hemophilia. The good news was that the drug ended his bleeding episodes and he spent less time on daily and weekly disease treatments. But it also gave him more time to think.

Putting Out New Fires

Without the daily fears of hemophilia, Levesque says, he was beset by memories and thoughts that he hadn't had time to contemplate before. "All of a sudden, I wasn't putting out fires every day or thinking about the problem right in front of me," he says. "And the rest of the train sort of catches up to the front here, and it's a crash, basically."

Stahl says that a diagnosis of PTSD includes exposure to a traumatic event, followed by the following symptoms:

- Intrusive memories (recurring, invasive thoughts of frightening medical scenarios, nightmares about a certain event)
- Avoidance (staying away from social settings, a health care provider's office, or even injections)
- Negative thinking or mood (feeling sad or in pain)
- Alterations in arousal or reactivity symptoms (hypervigilance, irritable or aggressive behavior, problems with concentration)

Stahl's study revealed that one-third of the participants could identify a traumatic event and went on to experience at least one of these symptoms.

Christi Humphrey, LCSW, a trauma-informed social worker at Hemophilia of Georgia, says people with hemophilia often have traumatic memories of childhood medical experiences that are "alive and well when the person has contact with the medical field. A strategy can develop where they escape the feelings by avoiding infusions or doctor's appointments, or avoid talking about what happened."

Levesque says he realized how traumatized he was by memories of being held down for painful injections as a child. Today, with the help of a trauma-informed therapist and medication, he feels better. "The difference is like night and day," he says.

Help Is Available

It's important for people who are having PTSD symptoms to understand that it's not unusual and that they're not alone, Humphrey says. "Your brain is designed to protect you, and it will go to great lengths to ensure your survival, including causing feelings designed to avoid fearful experiences," she says.

"Finding solutions starts with acknowledging the distressing thoughts, memories, and feelings. Seeking help from trained providers can start the process of change and open doors to new emotional experiences."

EMDR Therapy May Be Beneficial

Many people with PTSD are finding relief with eye movement desensitization and reprocessing (EMDR), says Humphrey, who is trained in the therapy.

EMDR is a technique in which a therapist guides a person through a series of standardized eye movements designed to stimulate brain activity. The goal is to help people identify ways to feel safe before exploring difficult memories, then learn to reprocess those memories so they don't cause symptoms.

"Every night in rapid eye movement (REM) sleep, the brain naturally processes situations and ideas from the day," Humphrey says. "EMDR mimics REM sleep to help with more traumatic memories and situations that are not as easily processed by the brain." The therapy "takes the traumatic memory and helps the brain process it in new ways so the memory can become more emotionally tolerable."

To be effective, the first step in the process requires developing a bond with a therapist, Humphrey says. While EMDR therapy does not work overnight, she says, it can be very effective at treating PTSD pain and trauma.

If you're experiencing symptoms of PTSD, contact your hemophilia treatment center for a referral to a mental health professional.



Save the Date for Washington Days 2025

March 5-7, 2025

Washington, DC



We hope you will join the Bleeding Disorders Foundation of North Carolina in Washington D.C. next March for the National Bleeding Disorders Foundation's (NBDF) annual Washington Days. It is an exciting few days during which you learn how to be an advocate and then get to put what you learned into action (alongside an experienced advocate). Past attendees have said they feel even more connected to their community after attending and



advocating on behalf of their fellow people with bleeding disorders. It is also a great opportunity for kids and teens to learn to speak confidently about their disorder. Email advocacy@bleedingdisordersnc.org if you would like more information!



Medical Debt Relief Program



The federal government has approved Governor Roy Cooper and the Department of Health and Human Services (NCDHHS) plan to relieve medical debt for North Carolinians. Starting October 1, 2024, eligible hospitals will begin to work with patients to relieve their medical debt dating back to 2014. All 99 eligible hospitals in North Carolina have elected to participate in the program. These hospitals will receive additional Medicaid reimbursement to relieve the debt owed by current Medicaid enrollees. Additional patients may be eligible for the debt relief program depending on their income level. If you have questions about this program, go to ncdhhs.gov/medicaldebt or email advocacy@bleedingdisordersnc.org.



Bleeding Disorders Foundation of North Carolina

2024 Calendar of Events Highlights



October 17, 2024

Community Education Dinner - Charlotte, NC

October 23, 2024

Unión Latina Virtual Program - Zoom

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

April 26, 2025

Charlotte Family Festival & Walk for Bleeding Disorders - Pineville, 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.

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OF NORTH CAROLINA



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