

THE C NCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Fall 2022

Raleigh Festival & Walk: Join in the Fun for a Great Cause!

October 22, 2022

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 2022 the biggest event yet!

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

Continued page 4

Mental Health Survey Results are Here

Managing and taking care of your mental health is important. While the Bleeding Disorders Foundation of North Carolina (BDFNC) is not a mental health organization, being able to successfully manage yours or your loved one's bleeding disorder requires that your mental health is also managed. In 2021, BDFNC began a *Mental Health Initiative* to better determine the mental health needs of the bleeding disorders community through a task force of interested community members and hemophilia treatment center (HTC) staff, a social media campaign, the start of the monthly *Community Conversations* support group meetings, a dedicated webpage to mental health on

284 Survey Responses



our website, programming that addresses mental health, and the administration of a mental health survey to assess the needs of those with a bleeding disorder in North Carolina.

The mental health survey was developed in partnership with the University of North Carolina Wilmington's

Continued page 6

In this Edition:

UPCOMING EVENTS	Page 4
RECENT EVENTS	Page 8
SUPLEMENTO DE LA UNIÓN LATINA	Page 11
SOAR SUPPLEMENT	Page 12
OUR YOUNG VOICES	Page 13

Save The Date

Raleigh Festival & Walk
October 22, 2022
Morrisville, NC

Unión Latina Event
October 29, 2022
Raleigh, NC

Blood Brotherhood Event
November 5, 2022
Charlotte, NC

Community Conversations
November 15, 2022
Virtual

Teen Empowerment Event
November 19, 2022
Location TBD

Holiday Celebration
December 3, 2022
Greenville, NC

Community Conversations
December 13, 2022
Virtual

Latin Union Event
January 14, 2023
Location TBD

Winter Conference & Medical Symposium
March 2-3, 2023
Location TBD

Many more events coming up.
See page (23) for the complete list.

**BLEEDING
DISORDERS
FOUNDATION**
OF NORTH CAROLINA



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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)

National Hemophilia Foundation

(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

Community Health Charities

(919) 554-3272
www.healthcharities.org

About This Publication

THE CONCENTRATE is the official newsletter for the Bleeding Disorders Foundation of North Carolina (BDFNC). It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

An electronic version may be found on the BDFNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the BDFNC office.

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

BDFNC does not endorse any specific products or services and always recommends that you consult your physician or local treatment center before pursuing any course of treatment.

Hemophilia Treatment Centers

East Carolina University 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

St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital Hematology & Oncology Clinic

301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

UNC Hemophilia and Thrombosis Center

170 Manning Drive
3rd Floor Physicians Office Building
Campus Box 7016
Chapel Hill, NC 27599-7016
Phone: (919) 966-4736

Wake Forest University School of Medicine

The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone (Adult Clinic): 336-713-5440
Phone (Pediatric Clinic): 336-716-4324

Additional Medical Resources

Duke University Medical Center Hemostasis and Thrombosis Center

DUMC Box 3422
Durham, NC 27710
Phone: (919) 684-5350

Mission Hospital Pediatric Hematology/ Oncology Program

21 Hospital Drive
Asheville, NC 28801
Phone: (828) 213-9770

Resource Information

National Hemophilia Foundation

www.hemophilia.org

Hemophilia Foundation of America

www.hemophiliafed.org

American Society of Pediatric Hematology/Oncology

847-275-4716
www.aspho.org

Accessia Health, formerly Patient Services Inc. (PSI)

Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-800-366-7741
www.accessiahealth.org

Centers for Disease Control & Prevention

1-800-311-3435
www.cdc.gov

Coalition for Hemophilia B

1-212-520-8272
www.coalitionforhemophiliab.org

ClinicalTrials.gov

A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

Committee of Ten Thousand (COTT)

1-800-488-2688
www.cott1.org

LA Kelley Communications

1-978-352-7657
www.kelleycom.com

PAN Foundation

Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-866-316-7263
panfoundation.org

Patient Notification System

The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.
1-888-UPDATE-U
www.patientnotificationsystem.org

World Federation of Hemophilia

1-800-520-6154
www.wfh.org

VISION STATEMENT

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

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



Is your health insurance changing in 2023?

Is your insurance changing in 2023?

It's important that people with bleeding disorders make sure that their medications and providers will be covered by new insurance. You can contact the providers at your hematology center to be sure that they accept the insurance. Also, it's important that your hematology center knows about any changes in insurance BEFORE your next appointment. The best practice is to update your insurance information in the center's online portal or call their office as soon as your insurance has changed. This way, it's one less thing to worry about later.

Want resources on insurance and bleeding disorders? Check out the Health Insurance Toolkit, created by the National Hemophilia Foundation:

www.hemophilia.org/bleeding-disorders-a-z/healthcare-coverage/personal-health-insurance-toolkit

Strengthening the HNC Board of Directors

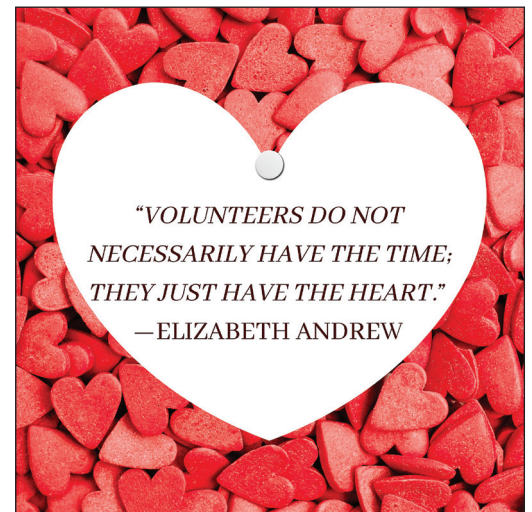
The ongoing challenge for any nonprofit organization is building and sustaining a high-functioning board of directors. To help ensure the long-term sustainability of the Bleeding Disorders Foundation of North Carolina (BDFNC), the Board of Directors has made the decision and commitment to be more deliberate and focused in the ongoing process of building our board.

At this time BDFNC is looking for board members with these talents and/or individualities:

- Individuals who represent the diverse demographics of our community
- Fundraising
- Accounting/Finance
- Public Relations/Communications
- Legal
- Mental Health professionals

The board and volunteer positions are open to BDFNC members and qualified individuals outside of the affected community. Persons who could be potential candidates include: professionals in your local sphere of influence, friends, alumni from local colleges and universities, retired individuals who worked in related industries, and North Carolina small business owners in related industries.

CALL TO ACTION: If you know of anyone who might be a good candidate for BDFNC's board of directors or other volunteer roles, please contact Charlene Cowell by phone (919) 319-0014 or email board@bleedingdisordersnc.org.



Raleigh Festival & Walk: Join in the Fun for a Great Cause!

continued from page 1

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 what to expect when you get to the event?

- Inflatable slide
- Photo booth
- Face painting
- Caricature artist
- Ice cream
- Inflatable tic-tac-toe basketball game
- Delicious lunch
- Vendors who can share the latest information about bleeding disorders
- Guest starring: Jeff Hogan from WRAL
- DJ with fun music to get everyone hyped
- Performance by Bouncing Bulldogs
- And 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!



Unión Latina Event

October 29, 2022

Raleigh, NC

Save the date for the next Unión Latina event on October 29 at Pullen Park in Raleigh. More details are expected to be announced very soon. Join the Bleeding Disorders Foundation of North Carolina (BDFNC) for programming to support the Spanish-speaking community.



SOAR Event – Women and Girls with Bleeding Disorders, You Are Not Alone

October 16, 2022

Charlotte, NC

Join the Bleeding Disorders Foundation of North Carolina (BDFNC) for a SOAR event. Chelsea Rivenbark from the East Carolina University Hemophilia Treatment Center (HTC) will be presenting a program about periods: what is normal, how to deal with heavy menstrual bleeding, and how to prepare girls for their first periods. This event is open to women with a bleeding

Continued next page

SOAR Event – Women and Girls with Bleeding Disorders, You Are Not Alone *continued from previous page*



disorder, moms of daughters with a bleeding disorder, and teen girls with a bleeding disorder. More information is available on the BDFNC website.

SOAR is a program of BDFNC for women and girls with a bleeding disorder in order to provide support, outreach, advocacy, and resources. The SOAR Program is for all females with a bleeding disorder, including those diagnosed with hemophilia, platelet disorders, ultra-rare factor deficiencies, and von Willebrand disease, and carriers of any of these disorders (both symptomatic and non-symptomatic).

Men's Event: Help Plan for the Future

November 5, 2022

Join the Bleeding Disorders Foundation of North Carolina (BDFNC) for an event for men with a bleeding disorder. Help to brainstorm new ideas and activities for next year and connect with your fellow Blood Brothers from across North Carolina. More information will be announced on the BDFNC website and through email.



Teens! This Event is for YOU

November 19, 2022

Charlotte, NC

Save the date for the last Teen Empowerment event of 2022 on November 19. This event will be for all teens in the North Carolina bleeding disorders community. The Bleeding Disorders Foundation of North Carolina (BDFNC) hopes to build on this year's events and ideas. Stay tuned to your email and the BDFNC website for more information.



Holiday Celebration

December 3, 2022

Greenville, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) hopes to see you and your family at the Annual Holiday Celebration, this year being held at the Hilton Greenville in Greenville, NC. Celebrate the holiday season with Santa, lunch, crafts, and activities with your bleeding disorders community. More information will be announced soon on the BDFNC website.



Charlotte Family Festival & Walk for Bleeding Disorders

April 22, 2023

Charlotte, NC



Save the date for the 2023 Charlotte Family Festival & Walk for Bleeding Disorders – on April 22, 2023 in uptown Charlotte. While the Bleeding Disorders Foundation of North Carolina (BDFNC) is currently focused on the Raleigh Festival & Walk taking place on October 22 in Morrisville, plans are already in the works for next year's Charlotte event. Registration for the Charlotte Festival & Walk will open in January, but in the meantime, it's never too early to start thinking about your fundraising efforts and team T-shirt design!

Mental Health Survey Results are Here

continued from page 1

(UNC-W) Department of Social Impact. With input from BDFNC, a survey was developed that would assess connections to mental health conditions, the prevalence of those conditions, if there is a correlation

"[I have] anxiety about the future of myself and potentially children that I could pass it to. PTSD from emergency room visits with no advocacy."

between pain/hospital stays and mental health, and barriers to care. The criteria also looked at the demographics of who responded including bleeding disorder type, gender, age, non-white or white, and urban vs. rural. Additionally, open-ended questions were included that could be used to make some additional conclusions and help to direct further research.

"Basically when I'm having trouble with my bleeding disorder it makes the symptoms of my mental health more intensified."

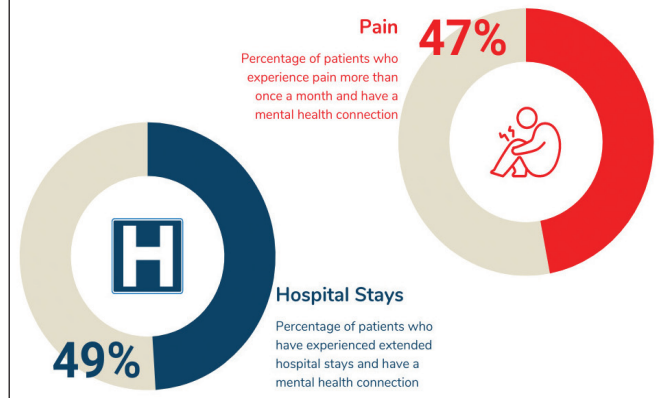
across North Carolina through print and/or electronic means (email/social media) over four months, between November 1, 2021 and March 1, 2022. A total of **284 surveys** were completed, with

the number completed electronically and mailed back split equally. The patients who completed the survey were diagnosed

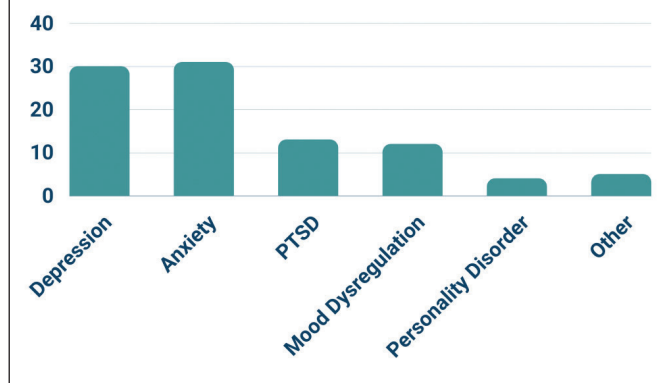
"As a parent, we have always a kind of fear in us for something to happen to our child that causes a bleeding problem. We are always worried about our child until he returns home from preschool."

With the help of the HTC's, surveys were distributed to over 2,200 individuals with bleeding disorders

Impact of Pain and Hospital Stays on a Person's Mental Health



Percent of patients with a Connection to a Mental Health Condition



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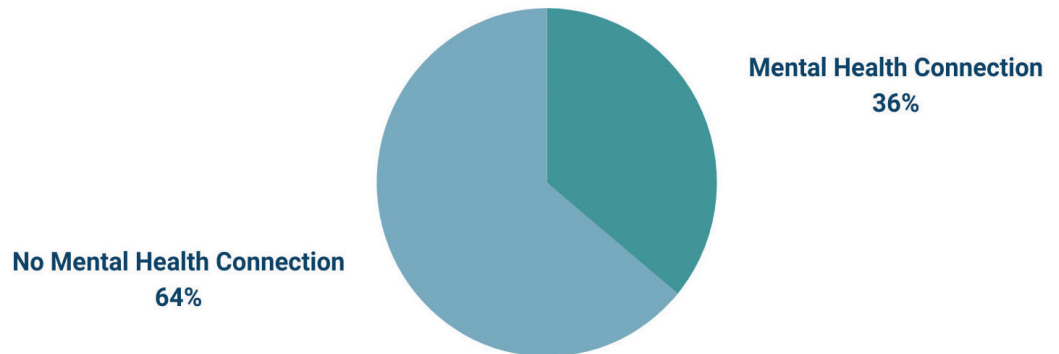
Mental Health Survey Results are Here

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with hemophilia, von Willebrand disease, or a platelet disorder.

More than **1/3 of patients** with a bleeding disorder reported a connection to a mental health condition, meaning they were diagnosed with, had sought treatment for, or experienced symptoms of a mental health disorder. The mental health conditions that the survey looked at were **depression, anxiety, PTSD, mood dysregulation, personality disorder, or other.**

Percentage of Patients with a Bleeding Disorder Who Report a Connection to a Mental Health Condition



Depression and anxiety were the most common mental health conditions reported, with 18% of patients indicating that they have had a diagnosis of each disorder. However, even more people indicated that they had symptoms of depression and anxiety. Thirty percent of patients indicated they had symptoms of depression and 31% of patients indicated symptoms of anxiety. When looking at all of the diagnoses that

"It can sometimes feel isolating, and causes a lot of anxiety for me as a mom."

were asked about, **29% of patients reported symptoms of a mental health condition but had not tried to receive any treatment.**

The survey found that the severity of a person's bleeding disorder does not have an impact on

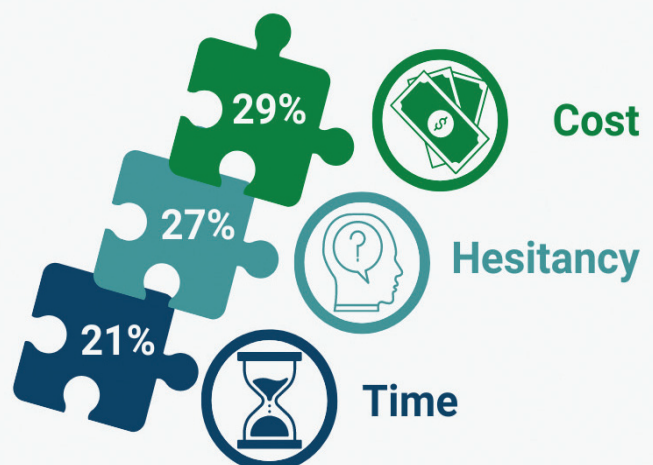
whether a person reports a mental health condition. However, **pain and hospital stays were significant influences on mental health. Forty-seven percent of patients who experienced pain** more than once a month had a personal connection to mental health. While patients who have had hospital visits were not more likely to report a mental health condition than those who have not had hospital visits, **49% of those who have had extended hospital stays** due to their bleeding disorder reported a mental health condition.

The responses were closely split between men and women. However **49% of women** reported a personal mental health condition while only **27% of men** reported a personal mental health condition. Patients in urban counties are more likely to report mental health conditions than patients in suburban or rural counties. Due to the sample size, race was split into white and non-white. **White patients reported a mental health condition at the rate of 42% while 31% of non-white patients reported a mental health condition.**

It is known that there are barriers in North Carolina to accessing mental health services. An alarming **70% of patients** with a

"It has been hard to find a therapist that knows how to help me with pain management."

Barriers to Mental Health Treatment



Mental Health Survey Results are Here

continued from previous page

mental health connection **reported a barrier** to mental health treatment. When asking survey participants about their barriers, **the most common barriers were cost (29%), hesitancy to seek treatment (27%), and time (21%).**

“[I] worry a lot about my own health to the point of extreme anxiety.”

So what does this all mean? It is clear that BDFNC needs to continue its research into mental health in the bleeding disorders community and its commitment to providing resources and programming about mental health for those affected by bleeding disorders. BDFNC plans to continue collaborating with the HTC's to support the community. There will be continued emphasis on mental health at BDFNC events. BDFNC plans to continue to post on social media throughout the year to help normalize the conversation about mental health and contribute to ending the stigma. In addition, BDFNC hopes to translate the survey into Spanish in order to hear from the Spanish-speaking population, and the organization would like to continue its research into how mental health affects parents and caregivers of someone diagnosed with a bleeding disorder.

“[I] spent three years in therapy/ group therapy following HIV diagnosis in 1984.”

This survey was just the first step. Mental health conditions are nothing to be ashamed of and are a reality for many living with a bleeding disorder. BDFNC continues to be here as a support for you and your family.

“I was completely healthy before my child was born. Being a dad, I always worried about my child growing up with factor 8 deficiency. Due to overthinking and continuous worrying, I got diagnosed with a moderate to severe anxiety and depression problem. I took medication and receive counseling from a mental health specialist. Now, I am doing fine.”



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

ADVATE
[Antihemophilic Factor (Recombinant)]

For more information, please visit AdvateRealLife.com

Not an actual patient.

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Just the Start: Ultra-Rare & von Willebrand Disease Education Day

June 26, 2022
Chapel Hill, NC

The first of what is expected to be an annual event for the Bleeding Disorders Foundation of North Carolina (BDFNC) was a huge success! The Ultra-Rare Bleeding Disorders and von Willebrand Disease Education Day was held on June 26 at the UNC Friday Center in Chapel Hill and brought together community members affected by a mix of conditions, ranging from factor 1 deficiency, factor 7 deficiency, platelet disorders, and von Willebrand disease (VWD), along with experts who could share their expertise about these bleeding disorders.



While VWD is the most common bleeding disorder, BDFNC knows that there is a limited amount of education to support those with VWD. And for ultra-rare factor deficiencies and platelet disorders, there is even less. This event was just the start of what is expected to bring ongoing education, resources, and support for the ultra-rare bleeding disorder and VWD community here in North Carolina. One attendee shared, "I feel supported by people who understand rare bleeding disorders. BDF[NC] provides a forum for education, connection, support, understanding, and advocacy."

If you are affected by a platelet disorder, ultra-rare factor deficiency, or VWD, please let Gillian Schultz, Director of Programs, know what kind of education and programming you would like to see in the future. You can reach her by emailing g.schultz@bleedingdisordersnc.org or calling her directly at (919) 272-6000.

A Beautiful Weekend Away: Summer Community Retreat

July 8-10, 2022
Lake Junaluska, NC



After being postponed for two years because of COVID-19, the Bleeding Disorders Foundation of North Carolina (BDFNC) finally held the Summer Community Retreat at the Lake Junaluska Conference and Retreat Center in Lake Junaluska, NC. Located west of Asheville, near the entrance to the Great Smoky Mountains National Park, the Conference and Retreat Center overlooks the lake, surrounded by the mountains. The Summer Community Retreat combines the Adult Retreat and Family Retreat, two popular events held in the past, into one event for everyone.

Community members from across North Carolina gathered together for two-nights and three-days of connection, education, community building, and fun. There were sessions for parents, including a panel of parents who shared helpful information about raising a child with a bleeding disorder. Adults with bleeding disorders attended a session about aging and what to think about as you not only have to consider your bleeding disorder, but also comorbid conditions that occur when getting older. Kids' sessions included mini-golf, games, and activities. Teen activities included a session about transitioning into young adulthood. There was also an interesting music session; a session about mental health; a presentation about gene therapy, which included a fun and interactive jeopardy game; and a program about musculoskeletal ultrasound, where attendees had the opportunity to have an ultrasound done on their joints. Attendees also gathered for a campfire and s'mores on Friday evening (although the fire was put out by a quick but heavy downpour) and game night on Saturday night.

BDFNC looks forward to this event again next year!



New Members Meet

July 30, 2022

Virtual Program on Zoom

On July 30, the Bleeding Disorders Foundation of North Carolina (BDFNC) held an event for new community members to meet and connect. Living with a bleeding disorder can feel isolating, and BDFNC doesn't want our members to feel like they are alone. New Member Gatherings are designed to bring people who are newly diagnosed, or parents/guardians of newly diagnosed children, together with those who are new to North Carolina to network and start building a support system. Attendees played a fun game of Kahoot! where they learned more about BDFNC, met Charlene and Gillian, and had the opportunity to share stories and ask questions.

The next New Member Gathering will be held as part of the Family Day event on October 9 at the North Carolina Zoo.



Teens: Our Future

August 11-14, 2022

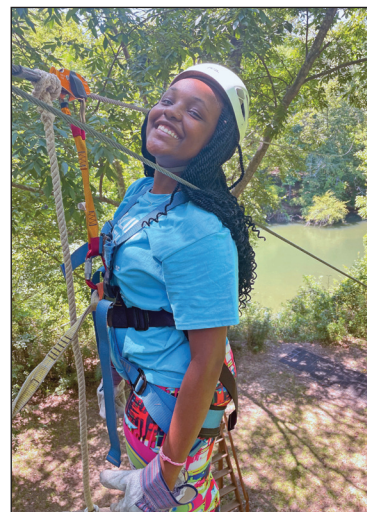
Rock Hill, SC



Have you ever wondered what it's like to take nearly three dozen teenagers to a camp for four days? Well, that's what happened and it was fantastic! Teens from NC and SC gathered together for the annual Bleeding Disorders Foundation of North Carolina (BDFNC) and Bleeding Disorders Association of

South Carolina (BDASC) Teen Retreat. Teens were driven or bused from all over both states to be able to experience this special event.

It can be isolating as a teenager, and especially if you or someone you love lives with a rare condition like a bleeding disorder. That's why BDFNC



invites all teens from the community (not just the teen with a bleeding disorder) to bring a friend for a one-of-a-kind retreat. Not only does bringing an additional person make the teen more comfortable, but it helps educate others about bleeding disorders.

While education and advocacy skills are a big part of the agenda, teens wouldn't know it, thanks to fun programs like the *Leading Edge Program* that GutMonkey brings to the event. While teens are laughing and enjoying the time together, they're also building critical skills that they can use in life.

It is truly a magical event to see teens from the bleeding disorders community come together and create lasting friendships. These young advocates are the future of this community, and it is BDFNC and BDASC's goal to make sure they are prepared to lead.

Save the date for next year's Teen Retreat: August 10-13, 2023 in Rock Hill, SC. Busing will be offered for NC teens.



Evento de la Unión Latina

29 de octubre, 2022
Raleigh, NC

No olvides agendar la próxima reunión de la Unión Latina, el día 29 de octubre en el "Pullen Park" de Raleigh. Forma parte de la Fundación de Desórdenes Sanguíneos de Carolina de Norte y apoya a la comunidad que habla español.



Actualización Unión Latina

Por: Guillermo Sanchez, Unión Latina Coordinado voluntario



Cuando salimos de situaciones difíciles, generalmente las personas y sus comunidades tienden a modificar algunas de sus habilidades. Hoy en día, que podemos decir que se ha controlado pandemia causada por COVID-19, tenemos que enfocarnos en fortalecer las habilidades que se debilitaron, utilizar las que se fortalecieron

y aprovechar cualquier habilidad desarrollada o adquirida durante ese periodo.

La Comunidad Latina tiene que reorganizarse y continuar sus esfuerzos para acceder a servicios en distintos ámbitos. Para las personas que han migrado desde algún país Latino Americano a Carolina del Norte y que tienen algún desorden sanguíneo, es de mucha importancia involucrarse y participar en las distintas actividades del Programa de la Unión Latina que ofrece la Fundación, para que juntos podamos informar y educar sobre los distintos desordenes sanguíneo, exigir acceso a atención medica de calidad y recibir el tratamiento adecuado para cada uno.

Te invitamos a que ingreses a nuestras distintas redes sociales para que te mantengas informado sobre las distintas actividades de la Fundación y que participes. Puede ser en las reuniones de la Unión Latina o en cualquier otra actividad que elijas, ¡Nos aseguraremos que tu participación sea escuchada!

Recuerda ponerte en contacto con la Fundación si tienes alguna idea o sugerencia.

BLEEDING DISORDERS FOUNDATION
OF NORTH CAROLINA

**FAMILY
FESTIVAL**
AND WALK

Octubre 22, 2022
9:00am-11:30am
Lake Crabtree
County Park
Morrisville, NC

¿YA TE REGISTRASTE?

VEN AL FESTIVAL Y CAMINATA DE LA FUNDACIÓN DE TRASTORNOS HEMORRÁGICOS DE CAROLINA DEL NORTE (BDFNC) Y APOYANOS A RECAUDAR FONDOS PARA BENEFICIO DE LOS DISTINTOS SERVICIOS Y PROGRAMAS DE AYUDA A LA PERSONAS QUE VIVEN CON ALGUN TRASTORNO HEMORRÁGICO EN CAROLINA DEL NORTE.

Regístrate, participa y diviértete en las distintas actividades que tenemos planeadas: pinta de caras, inflables, básquetbol, manualidades, música ... además de un sabroso lunch, café, helado y algodón de azúcar.

Registro:

Adulto: \$25 Menor de edad: Gratis

Por cada registro recibe una pulsera y playera del Festival y la Caminata.



Contactanos para más información:
festival@bleedingdisordersnc.org
919-319-0014
o visita: bleedingdisordersnc.org

Ven al Festival y Caminata de la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) y apóyanos a recaudar fondos para beneficio de los distintos servicios y programas de ayuda a la personas que viven con algún trastorno hemorrágico en Carolina del Norte.

¡Contáctanos para más información!



Project ECHO: Recognition and care for women with bleeding disorders

September 12, 2022

Reprint from Hemophilia Federation of America

Hemophilia Federation of America (HFA) is pleased to announce that we will be hosting a 4-part Project ECHO® provider education series targeting obstetricians and gynecologists (OB/GYNs) with a focus on women and bleeding disorders. Project ECHO® uses a virtual telementor approach and believes in the “All Teach, All Learn” method. The series will occur on the 2nd Wednesday of each month at 11 AM EST, starting on August 10, 2022 and ending on November 9, 2022.

Women with bleeding and heavy menstrual bleeding are likely to consult their OB/GYN for help therefore, our target audience is OB/GYNs. HFA believes that it is crucial that OB/GYNs are knowledgeable about bleeding disorders and identifying at-risk women and girls. Our hope is that each session will foster discussion on key topics that speak to the unique current challenges that many OB/GYNs face daily.

Each session will have a didactic presentation followed by a case presentation where we hope to have active participation among the attendees. Each session will build on the previous lecture so we encourage you to attend all 4 sessions. The series was developed with subject matter experts and HFA looks forward to sharing this knowledge with you.

Physicians and nurses will receive 1 credit hour for their attendance at each session.

Educating Medical Professionals One Conference at a Time



Almost 450 nurses from across North Carolina are more familiar with bleeding disorders thanks to the Bleeding Disorders Foundation of North Carolina's (BDFNC's) ongoing commitment to exhibiting at the North Carolina Nurses Association Conference (NCNA) every year. The NCNA conference was held in Raleigh from September 15-16. BDFNC's booth was popular – and not just because there was candy! Nurses were really interested in hearing more about bleeding disorders and how to detect the signs and symptoms that go undiagnosed all too often. BDFNC even met nurses who were very familiar with bleeding disorders because they either had patients or family members with these conditions. It was eye-opening to some nurses who felt like they had experienced symptoms themselves and plan to get tested thanks to the information at our booth, which

is a common occurrence whenever BDFNC attends these conferences.

A special thank you to Cheri Clark, BDFNC community member and nurse, for being an avid volunteer for these exhibits and sharing her story about being undiagnosed until her 40s. Cheri's story helps medical professionals understand why this information matters, and what a difference it can make in the life of a person who is living undiagnosed.

Our Young Voices

Fall 2022



Support Group Meets Monthly

July 20, 2022 and August 17, 2022
Virtual Program on Zoom

The Bleeding Disorders Foundation of North Carolina (BDFNC) hosted two Community Conversations support groups this summer to provide a safe place for people to come together for fellowship. On July 20, attendees shared a meaningful conversation about how to create a sense of belonging, both in and out of the bleeding disorders community. On August 17, attendees talked about changes that they are going through.

Community Conversations groups meet on the third Tuesday of every month at 7:00 PM on Zoom. Visit the BDFNC website for more information.



In the Next Edition

Read all about the Blood Brotherhood & SOAR Weekend, Family Day, Raleigh Family Festival & Walk, SOAR event, Unión Latina event, Blood Brotherhood event, and Teen Empowerment event in the Winter Edition of *The Concentrate*.



Blood Brotherhood Program Update

The Bleeding Disorders Foundation of North Carolina (BDFNC) would like to connect men with bleeding disorders to the Blood Brotherhood Program. This program provides peer support for adult men, 18+, with a bleeding disorder. Whether you are new to “adulting,” or you have been around the block, BDFNC hopes that you will participate in the Blood Brotherhood Program.

This summer, Blood Brothers from across the state, as well as others with a bleeding disorder, had the opportunity to connect at the Summer Retreat. At the Blood Brotherhood & SOAR Weekend in September, men had another opportunity to connect, learn, and brainstorm about future programming. Later this fall will be another Blood Brotherhood event. Additionally, join the Community Conversations virtual meetings on the third Tuesday of each month to connect with others affected by bleeding disorders across North Carolina.

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

For more information about the Blood Brotherhood Program, or if you have ideas that you would like to share, please contact Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org or by calling the BDFNC office at (919) 319-0014.



HOPE Program Update

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

Raising kids is hard. Raising kids with a bleeding disorder adds an additional layer of complexity. But you don’t have to do it alone! The Bleeding Disorders Foundation of North Carolina (BDFNC) HOPE Program provides peer support and education to help navigate raising a child with a bleeding disorder, from birth through 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.

This summer, families had the opportunity to hear from other parents with tips and tricks to navigate raising a child with a bleeding disorder at the Summer Retreat. In October, connect with other families at Family Day at the

Continued next page

HOPE Program Update *continued from previous page*

North Carolina Zoo. You can also connect online monthly during the Community Conversations virtual meetings on the third Tuesday of every month. Other events will be announced soon. In addition, if you need resources to navigate your child's success in daycare or school, contact BDFNC.

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



Unión Latina Program Update

By: Guillermo Sanchez, Unión Latina Volunteer Coordinator

Usually when we come out of difficult situations, people and their communities tend to modify some of their skills. Today, when we can say that the pandemic caused by COVID-19 has been controlled, we have to focus on strengthening the skills that were weakened, use the ones that were strengthened, and take advantage of any skills developed or acquired during that period.

The Latino Community has to reorganize itself and continue its efforts to have access to services in different areas. For people who have migrated from a Latin American country to North Carolina and who have a bleeding disorder, it is very important to get involved and participate in the different activities of the Latin Union Program offered by the Bleeding Disorder Foundation of North Carolina, so together we can inform and educate about the different bleeding disorders, demand access to quality medical care, and receive the appropriate treatment for everyone.

We invite you to visit our different social networks to stay informed about the variety of activities offered by the Foundation and to participate. It can be in the meetings of the Latin Union Program or in any other activity that you like, we will make sure that your participation is heard!

Remember to contact the Bleeding Disorders Foundation of North Carolina if you have any ideas or suggestions.

SOAR Program Update

Bleeding Disorders don't just affect 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 fall, BDFNC is going to be busy providing support and raising awareness about women and girls with bleeding disorders. There are two educational and support events coming up: the Blood Brotherhood & SOAR Weekend in September, and a SOAR Luncheon on October 16. Don't forget about the monthly Community Conversations virtual support groups that meet on the third Tuesday of each month.

Additionally, BDFNC will be traveling the state this fall to exhibit at several conferences, including the North Carolina Nurses Association, the North Carolina Emergency Nurses Association, the North Carolina Dental Hygienists' Association Conference, and the School Nurse Association of North Carolina. These exhibits are an excellent opportunity for BDFNC to share statistics and stories about women and girls with bleeding disorders and provide resources for medical professionals who come across patients with a bleeding disorder.

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 that 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

The Bleeding Disorders Foundation of North Carolina (BDFNC) Teen Empowerment Program is going strong! This is a new program to help teens connect and to provide valuable opportunities to prepare for independence. While today's teens with a bleeding disorder are suffering fewer complications from their bleeding disorder than past generations, they still have unique needs. This program will provide them with an outlet to share experiences, make friends, and even learn along the way. BDFNC also believes that all family members are affected by a bleeding disorder, whether personally diagnosed themselves or not. So the Teen Empowerment Program is for any teen, including siblings and children of someone with a bleeding disorder.

Did you know that the Teen Empowerment Program doesn't have a logo? **BDFNC is inviting teens to submit logo designs for a logo contest that the community will vote on.** You can submit a design to Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org. More specifics about this competition will be announced soon!

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

Attention: Spouses, Partners, and Caregivers



Are you a spouse, partner, or caregiver to someone with a bleeding disorder? While the Bleeding Disorders Foundation of North Carolina (BDFNC) hopes that you've always found benefit in BDFNC programs, a stronger network of support is being developed just for you! Nick Henry, who is the partner of someone with a bleeding disorder, is helping BDFNC to create a program specifically for spouses, partners, and caregivers in order to provide support and resources. Interested in learning more? Reach out to Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org or (919) 272-6000 and she can connect you with Nick.

Mental Health Initiative

There is nothing to be ashamed or embarrassed by if you are living with a mental health condition. Having a chronic condition like a bleeding disorder can add to your stress and cause other symptoms of a mental health condition, but help and support are out there! Read about the Bleeding Disorders Foundation of North Carolina's (BDFNC) Mental Health Survey results on the cover of this edition of *The Concentrate*. BDFNC continues to plan more programs and provide additional resources to support mental health. One opportunity to support your mental health and wellness is the monthly *Community Conversations* virtual support group. Meeting on the third Tuesday of every month on Zoom, this group provides connection with others who understand what it's like to be affected by a bleeding disorder. BDFNC is also still collecting stories about how you have been affected by a mental health condition. You can anonymously share your story with us: <https://www.surveymonkey.com/r/WRB6GTH>.

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.

Scan the QR Code to
SHARE YOUR STORY



Help END THE STIGMA
about MENTAL HEALTH

If you're interested in sharing your thoughts or have ideas, consider joining the BDFNC Mental Health Task Force which meets quarterly.

Contact Gillian Schultz, Director of Programs at g.schultz@bleedingdisordersnc.org or by calling the BDFNC office at (919) 319-0014 to find out more.



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

Jack came in 5th overall at the subregional of Drive, Chip and Putt. And he placed 2nd in the drive, and tied for 1st in the putt! Congrats Jack!!

Jack Traficanti, community member with VWD



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

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

2022 Friends of BDFNC

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

Employee Giving Programs (various)

April Lindsey Evans

*Facebook Fundraisers –
 Birthday Fundraiser Benefiting George
 D. McCoy Scholarship Fund*
 Charlene Cowell

In Memory of Pearl H. Smith
 Sarah Clodfelter

In Memory of Ella M. Jefferson
 Ellen Kearney

In Honor of Shannon Elderdice

Maria Moon

Mental Health Program
 Karyn & Kyle Davis

General Donations

Irene Cowell

Sue & Allen Heafner

Drs. David Howell & Sara Miller

James Jarratt

In honor of Phil Poovey's birthday – benefiting the George D. McCoy Scholarship Fund

Sue & Charles Cowell

Charlene Cowell & John Prim

Dan Dalton

Karyn & Kyle Davis

Alisa Huffman

Steven Humes & Mark Waters

Ellen Kearney

Allen & Linda Kurtz

Marvin Pipkin

Charles & Kathy Register

Nick & Laurie Register

Amy Shair Miller & Jim Miller

Skip & Emily Wilson

*Thank you to everyone who donated by selecting BDFNC as your
 charity through AmazonSmile!*



Back to School with a Bleeding Disorder

By: Gillian Schultz, Director of Programs

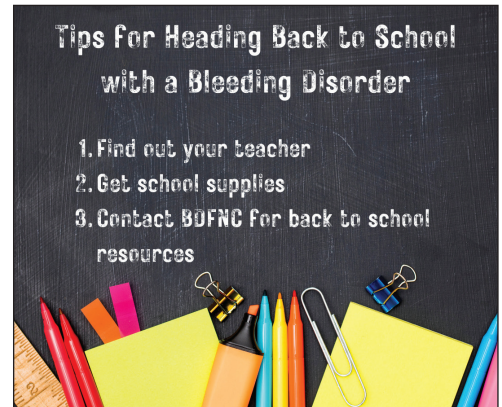
The beginning of the school year is a busy and exciting time of the year! The anticipation of teacher assignments, finding out if friends are in the same class, bus schedules, buying new clothes and back to school supplies – there's so much to do. There also seems to be an endless number of open houses and curriculum nights. And of course, getting our kids back to a regular bedtime pattern, with usually earlier bedtime and earlier wake time once school starts, can be hard. But it's also exciting to anticipate what the school year will be like.

Of course, when we add in preparing a child with a bleeding disorder for school, there can also be nervousness about how to manage everything. If your child gets infusions, are you able to get them done before school in the morning? I know of some families who infuse in the evening, just because it is hard to get up even earlier for an infusion.

I am usually able to fit my son Noah's infusions before school in the morning, but if he sleeps even 10 minutes late, it can be really hard. Plus, what happens if he gets hurt or has a bleed at school? I have been going to Noah's school, and daycare before that, for eight years now, so his teachers can be prepared for having a child with hemophilia in their class. But still, every year, I find myself trying to balance telling them too much or not enough.

When Noah was younger, he liked coming in with me to show his new teachers where he gets factor and to show off his medic alert bracelet. As he went through elementary school, he became much more private about his hemophilia, so I followed his lead

Continued next page



1970
First patients ever receive gene therapy

1997
First rFIX products approved by FDA

1999
First gene therapy trial in hem B

2018
Late-stage trials for gene therapy in hem B underway

EVERY STEP HAS BEEN EVOLVING THE SCIENCE OF GENE THERAPY IN HEMOPHILIA B

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Back to School with a Bleeding Disorder *continued from previous page*

and didn't force him to participate if he didn't want to. But this year, he started middle school. A whole new school with new levels of independence. So it was important to get him involved again. I had him share what hemophilia is, what it's like when he has a bleed, and why he needs to be able to see the nurse. We talked about types of bleeds and what he deals with most often, the kinds of accommodations the school needs to provide him if he has a bleed while at school, and when it's important to call me. We also answered any questions they had.

Noah also has a 504 plan that covers his hemophilia. The school and I meet annually to review and make any necessary modifications to the plan. A 504 plan provides accommodations so that a child with a disability can still access the same curriculum as their peers. A bleeding disorder qualifies as a disability when it comes to 504 plans. You can work with your medical provider and school to determine the best accommodations for your child.

So far, Noah's transition into middle school has been smooth. He has had no issues with his hemophilia at school, and hopefully, it will stay that way. By taking the time to meet with his teachers, I can rest a little easier, knowing that they are looking out for him.

Whom should you meet with at your child's school?

- School nurse
- Classroom teachers
- Elective or specials teachers
- PE teacher
- Principal/Assistant Principal
- School Counselor
- It may also be helpful to have information shared with front office staff and first responders.

If you need resources for meeting with your child's school, please contact me at the Bleeding Disorders Foundation of North Carolina by email at g.schultz@bleedingdisordersnc.org, or by calling me at (919) 272-6000.

Brenda Nielsen Wins Nurse of the Year

Reprint from UNC Health and UNC School of Medicine Newsroom



Each year, the National Hemophilia Foundation (NHF) honors those who have made significant contributions to the inheritable blood and bleeding disorders (IBD) community at its annual Awards of Excellence program. Honorees are nominated by their peers for their outstanding dedication and service to the community. After careful deliberation, the NHF selected this year's winners and announced them at the NHF Bleeding Disorders Conference Houston, Texas.

Brenda Nielsen, MSN, RN-BC, was selected as the NHF Nurse of the Year, for her 30 years of service to the IBD community marked by a wide and inimitable range of accomplishments, in her role as nurse consultant at the University of North Carolina Hemophilia Treatment Center; helping to establish camp for people with bleeding disorders at Camp Carefree in North Carolina, and spearheading child advocacy legislation in North Carolina. This legacy has manifested itself in the quality of life experienced by her patients and the growing awareness of bleeding disorders among her colleagues and future health care professionals.

Nielsen has been a nurse consultant at the UNC Hemophilia Center since 1992. She received both her bachelor's degree and her master's degree in nursing at the University of North Carolina at Chapel Hill. She especially enjoys getting to know and working with children, families, and adults with bleeding disorders and watching them develop into independent hemophilia or von Willebrand experts. As an adjunct assistant instructor at the School of Nursing at UNC-Chapel Hill, she serves as a resource for nursing students and faculty about bleeding disorders. She is a member of the Medical Board of Camp Carefree in Stokesdale, NC, and she is an advocate for providing a camp experience for all kids.

The NHF Nursing Working Group, said, "Brenda is an amazing nurse who is more than deserving of this award. Because of her commitment and care, her patients have been able to thrive throughout their lives."



PPTA Posts Statement on Monkeypox and Plasma Protein Therapies

Aug 22, 2022

Reprint from the National Hemophilia Foundation



The Plasma Protein Therapeutics Association (PPTA) recently posted an online update that addresses safety concerns relevant to the recent monkeypox virus (MPXV) outbreak and plasma protein therapies.

According to the new statement, while the presence of the MPXV in the blood (viremia) of individuals with symptomatic infections of monkeypox has been detected, the risk remains theoretical. To date, there have been no reported cases of transmission of MPXV by blood and blood components, including by plasma and plasma-derived products.

MPXV is spread most often by close/intimate contact, including direct contact with monkeypox rash, scabs, or body fluids from a person with monkeypox. It can also be transmitted by touching

objects, fabrics (clothing, bedding, or towels), and surfaces that have been used by an infected person. There is currently no in vitro screening assay for the monkeypox virus.

The PPTA statement also describes the multiple viral inactivation steps employed in the manufacturing process of plasma protein therapies, including heat and detergent treatments, nanofiltration, plus other techniques. Another area of risk-mitigation includes existing donor screening procedures that would make it “highly unlikely” that a person exhibiting disease symptoms associated with MPXV would be accepted for donation. Donor deferral would be likely as these symptoms include raised temperature/fever, fatigue, headache, enlarged lymph nodes and skin lesions.

“Given this currently available scientific evidence, PPTA considers that MPXV infectivity does not occur in plasma or is low,” read the update. “Due to the characteristics of the virus and multiple, complimentary steps with significant and robust virus removal and virus reduction capacity utilized during manufacturing of plasma protein therapies, PPTA considers that the current MPXV outbreak is not a concern for the safety margins of plasma protein therapies manufactured by PPTA member companies.”

Scientists continue to investigate monkeypox, including modes of transmission. NHF will continue to monitor this situation and will share any relevant updates as they become available.

Read the full PPTA statement here: <https://www.pptaglobal.org/28-news/ppta-news/1140-ppta-statement>

Conditional Approval in Europe for Gene Therapy

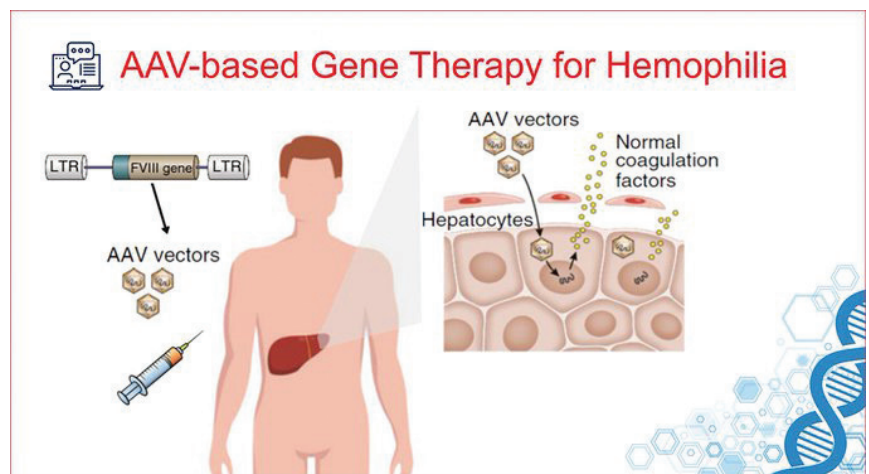
Aug 25, 2022

Reprint from the National Hemophilia Foundation

The European Commission granted conditional approval to BioMarin’s Hemophilia A gene therapy Valoctocogene Roxaparvovec which will be known as Valrox.

With this approval in Europe the regulators will monitor the use of Valrox for 15 years to ensure safety of the therapy.

More information can be found in the BioMarin press release: <https://tinyurl.com/genetherapy2022>



NC goes to Texas: NHF Bleeding Disorders Conference

August 25-27, 2022

Houston, TX



North Carolina was well-represented at the National Hemophilia Foundation (NHF) Bleeding Disorders Conference (BDC) with more than 12 families and individuals. The conference was fantastic, offering a wide array of topics including general information and those specific to individual bleeding disorders. Additionally, some sessions were provided in a virtual format for those who could not travel to TX.

Hear from Dilli Wagley, NC community member whose family attended their first NHF BDC this year: Obviously, attending any kinds of activities related to bleeding disorders conducted by BDFNC, NHF or WFH [World Federation of Hemophilia] will help patients, caregivers and family members to educate them about what is bleeding disorder

and how we can prevent internal bleeding injury. We are updated about the new treatments that are available in the market, learn the social experiences, societal acceptance and safe and unsafe activities.

So, I would like to encourage all the patients, caregivers and family members to participate in as many events as you can related to bleeding disorder. My wife and I were kind of depressed when we heard our son has hemophilia. She used to cry every time we visited HTC and doctors. I did not know anything about bleeding disorder before my son was born. Last spring we attended the BDFNC conference in the Winston-Salem. From there we learned that we are not only parents that have a bleeding disorder. I would like to suggest other parents to involve every single family member in your kids' life. Education and knowledge are key tools to overcome any kind of stereotypical thinking. Together we can make a safe haven for our children. If anyone needs help where and how we can apply for a travel grant please don't not hesitate to reach me. I know life is very busy here in the US but please take some time to visit the BDFNC events.

Save the date: the 2023 NHF BDC will be August 17-19 in Washington, DC!



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Patient Assistance Programs



In addition to the Bleeding Disorders Foundation of North Carolina Emergency Financial Assistance Program and the Medical ID Program, there are many national patient assistance resources that people with bleeding disorders should know about. From assistance with loss of insurance, to access to medication, and medical equipment, there are resources. Both the Hemophilia Federation of America (HFA) and the National Hemophilia Foundation (NHF) have created a list of resources for the community. These can be accessed here:

HFA - <https://tinyurl.com/assistancehfa>

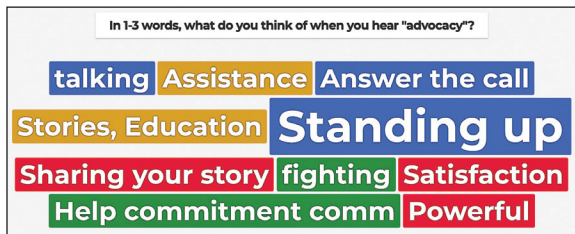
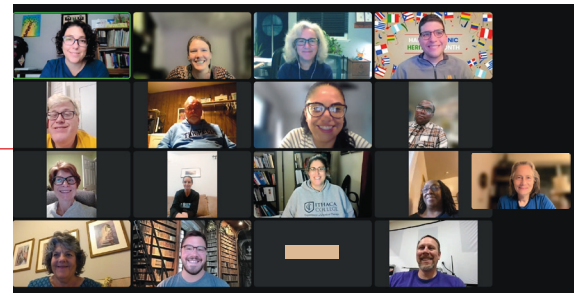
NHF - <https://tinyurl.com/assistentcnhf>

Advocate Gathering

August 25-27, 2022

Houston, TX

As 2023 approaches in the coming months, it was a great time to host the second Advocate Gathering and have 21 advocates join. This is an opportunity to bring together the bleeding disorders community including members, national organizations, and other stakeholders, to reflect on our advocacy efforts and look to 2023. Bleeding Disorders Foundation of North Carolina (BDFNC) has always been fortunate to have a core group of advocates who speak on behalf of the community throughout the year and participate in a monthly Advocacy Committee call to discuss ongoing issues.



But the future of access to medications, therapies, and providers depends on strengthening and growing the advocacy program. This was why BDFNC was thrilled to welcome multiple people to the Advocate Gathering who had not been current participants on the Advocacy Committee.

After brief introductions, advocates shared what came to mind when they heard the word “advocacy.” With the help of Miriam from the Hemophilia Federation of America, participants got a nice overview of key historical advocacy moments in

the bleeding disorders community. Kathy Register, one of BDFNC’s founders and a longtime advocate, shared a powerful firsthand story of what it was like during the HIV/AIDS crisis for people in the hemophilia community. Charlene and the National Hemophilia Foundation crew, Josie, Matt, and Nathan, used a Kahoot game to provide a more recent overview (2008-today) of all the advocacy achievements here in North Carolina. Finally, BDFNC unveiled its newest initiative: the Advocacy Ambassador Program. With this program, BDFNC hopes to continue growing the advocacy efforts to remain a voice for people with bleeding disorders in NC and on the federal level.

If you would like to get involved with the Advocacy Committee, please contact Charlene Cowell at advocacy@bleedingdisordersnc.org.



Bleeding Disorders Foundation of North Carolina

2022 Calendar of Events Highlights



October 22, 2022

Raleigh Festival & Walk - Morrisville, NC

October 29, 2022

Unión Latina Event - Raleigh, NC

November 5, 2022

Blood Brotherhood Event - Charlotte, NC

November 15, 2022

Community Conversations - Virtual

November 19, 2022

Teen Event - Location TBD

December 3, 2022

Holiday Celebration/Unión Latina -
Greenville, NC

December 13, 2022

Community Conversations - Virtual

January 14, 2023

Unión Latina Event - Location TBD

March 2-3, 2023

Medical Symposium & Winter
Conference - Location TBD

April 22, 2023

Charlotte Festival & Walk -
Charlotte, NC

Events will be added throughout the year and the dates/locations may change. All event details will be sent via email and text as soon as they are confirmed. Please make sure you are getting the most up to date information. Email BDFNC at events@bleedingdisordersnc.org or call (919) 319-0014 to be added to the email and/or text groups.

Dan Bull

Empowerment advocate

About Dan

Dan is a Hemophilia Community Liaison who is passionate about helping people take control of their lives. He understands that empowering those with bleeding disorders to take an active role in their treatment makes all the difference in the Mid-Atlantic community.

Hobbies

- Rock climbing
- Camping

"I make a choice every day to be grateful and make the most of right now, which is all I have guaranteed."

Connect with Dan

DLBU@novonordisk.com
(240) 285-3948

Hemophilia Community Liaison



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FAMILY '22 FESTIVAL

— AND WALK —

RALEIGH, NC

