

THE C NCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Summer 2022

Raleigh Festival & Walk for Bleeding Disorders: Coming Soon!

October 22, 2022

Morrisville, NC



Let's walk together in support of the bleeding disorders community! Save the date for the Raleigh Family Festival & Walk for Bleeding Disorders, taking place on October 22 at Lake Crabtree County Park in Morrisville! The Bleeding Disorders Foundation of North Carolina (BDFNC) is planning for a fun and festive day at the lake where the community can get together and celebrate its fundraising accomplishments.

The Family Festival & Walk for Bleeding Disorders is BDFNC's largest fundraiser of the year, with proceeds going toward supporting critical programs and services including emergency financial assistance, medical IDs, scholarships, programs and events that support and

Continued page 6

Has Your Info Changed?

By: Charlene Cowell, BDFNC Executive Director

As the Bleeding Disorders Foundation of North Carolina (BDFNC) continues to grow, we've also been moving to a different database system over the last year. One of the many benefits of the new database is that BDFNC can better serve the community by knowing each person's interests and contact preferences. **But we need your help to do that.**

Please take five minutes to complete our membership application online so that we can make sure your contact information is updated. We also ask for information about your household members and relationship to the bleeding disorders community. This helps us to know whether to send you information about a specific event, or for when we have important information related to your bleeding disorder.



Your information is never shared outside of BDFNC, but the additional information allows us to better serve you.

Make sure your contact information is correct by completing this form : www.bleedingdisordersnc.org/get-involved/become-a-member/

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Save The Date

Summer Community Retreat

July 8-10, 2022

Lake Junaluska, NC

Community Conversations

July 19, 2022

Virtual

New Member Welcome

July 30, 2022

Virtual

NC/SC Teen Retreat

August 11-14, 2022

Rock Hill, SC

Women's Event

August 20, 2022

Location TBD

SOAR/Blood

Brothers Weekend

September 17-18, 2022

Location TBD

Raleigh Festival & Walk

October 22, 2022

Morrisville, NC

Holiday Celebration

December 3, 2022

Greenville, NC

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
Brody School of Medicine**
600 Moyer Boulevard
Pediatric Hematology/Oncology
MA Suite 333
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.



FROM THE DIRECTOR OF PROGRAMS



Since the start of the COVID pandemic, time has seemed to both stand still and rush by! The world has changed so much during these past two years. As both the Director of Programs for the Bleeding Disorders Foundation of North Carolina (BDFNC) and a parent of a child with hemophilia, I have seen such strength in this community.

I have seen this community stay together through virtual programs and events over the past two years. Not long before the pandemic, Charlene, BDFNC's Executive Director, and I talked about how to utilize Zoom. We had no idea what we were doing, but were quickly thrown into it at the beginning of the pandemic like everyone else. We have held coffee chats, game nights, "dinner" programs, meetings, tai-chi sessions, art and music therapy, retreats, and more, all thanks to modern technology! Along with community members from across North Carolina and the country, we have participated in advocacy initiatives and have accomplished amazing things! And I am so proud that we have really begun to address the mental health issues in the bleeding disorders community.

But at the same time, we have lost connection with so many who haven't been interested in or haven't been able to participate in all the Zoom activities (who can blame them?). It's definitely not the same as being together in person. I have missed seeing new connections being made between new members of the community. Living with a bleeding disorder is hard, but one of the special qualities of this community in particular is the connection that we have to one

another. I remember one of my first events, as a parent of a baby with hemophilia, and how I was welcomed in with open arms. It didn't matter that I didn't know anyone with hemophilia. It didn't matter that I was scared. It didn't matter that I didn't know much of anything about hemophilia. I was embraced by this community, and I can't imagine having gone through the past 11 years without the support of BDFNC and the people I have met along the way.

While I don't expect things ever to go back to the way they were before, I am excited to see what this next chapter will bring. I don't think virtual programs will ever go away. They provide an amazing opportunity for people to connect with each other from far distances! But I am also excited for all the in-person programming that we are planning for the remainder of the year. If you look at the BDFNC calendar, we will be offering a mix of in-person, virtual, and hybrid opportunities over the next several months. If you are new to BDFNC since the start of the pandemic, I hope that you will join us at an upcoming event! If you have lost touch during COVID, that's okay! I hope that we will reconnect again!

I am always here if you have ideas or just want to talk! Feel free to call or email me anytime. I can be reached on my cell phone at (919) 272-6000 or by email at g.schultz@bleedingdisordersnc.org.

Warm Regards,

Gillian

Strengthening the HNC Board of Directors

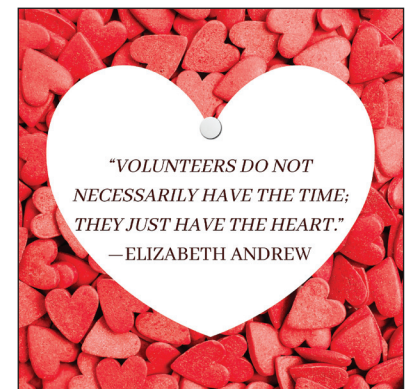
The ongoing challenge for any nonprofit organization is building and sustaining a high-functioning board of directors. To help ensure the long-term sustainability of the Bleeding Disorders Foundation of North Carolina (BDFNC), the Board of Directors has made the decision and commitment to be more deliberate 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 our 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 our board of directors or other volunteer roles, please contact Charlene Cowell by phone (919) 319-0014 or email board@bleedingdisordersnc.org.



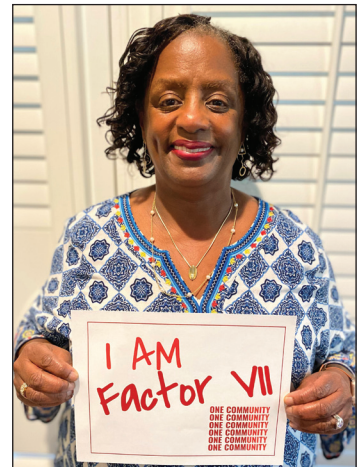
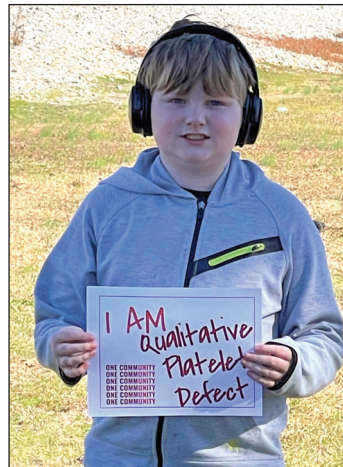
Ultra-Rare Bleeding Disorders & von Willebrand Disease Education Day

June 26, 2022
Chapel Hill, NC

When Bleeding Disorders Foundation of North Carolina (BDFNC) administered its last Needs Assessment in 2020, the results were clear: there needed to be more education to support platelet disorders, ultra-rare factor deficiencies, and von Willebrand disease (VWD). At educational events since then, BDFNC has been trying to infuse more about these bleeding disorders into its programming and is excited to be holding the inaugural Ultra-Rare Bleeding Disorders & von Willebrand Disease Education Day on June 26.

The day will include two tracks about living with and managing your bleeding disorder, one for ultra-rare bleeding disorders, including ultra-rare factor deficiencies and platelet disorders, and the other for VWD.

A recap of the event will be available in the Fall edition of *The Concentrate*.



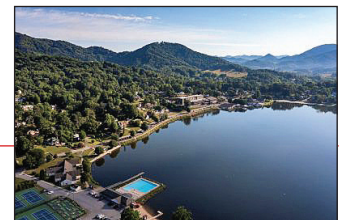
Do you have VWD or an ultra-rare bleeding disorder? Let BDFNC know what types of information you'd like to learn by emailing Gillian at g.schultz@bleedingdisordersnc.org or calling her directly at (919) 272-6000. BDFNC programming and events are planned FOR YOU, so your input is important.

A Weekend Getaway in the NC Mountains: Summer Community Retreat

July 8-10, 2022
Lake Junaluska, NC

Bleeding Disorders Foundation of North Carolina (BDFNC) is excited to finally hold the Summer Community Retreat after pushing the event off for two years because of the COVID pandemic!

This event is taking the place of the past Adult and Family Retreats, and will provide a weekend getaway where members of the bleeding disorders community in North Carolina can get together to connect, learn, and have fun!



There will be sessions for parents of a child with a bleeding disorder and for adults with a bleeding disorder, as well as children's and teen tracks. Additional sessions will bring everyone together to get to know one another better and create a true feeling of community.

More information about the event is available on the BDFNC website.

Welcome New Members!

July 30, 2022

Virtual



New community members are invited to join the Bleeding Disorders Foundation of North Carolina (BDFNC) at the *New Member Welcome & Gathering*, taking place July 30 on Zoom. During the hour-long virtual event, you will get to know the BDFNC staff, learn about programs and services available to you, and participate in fun activities. BDFNC knows that it can be challenging to navigate living with a bleeding disorder, and the organization strives to provide you with the resources you need to help you thrive.

More information and registration can be found on the BDFNC website.



Teen Retreat Returning

August 11-14, 2022

Rock Hill, SC

The NC/SC Teen Retreat is coming back this year! Bleeding Disorders Foundation of North Carolina (BDFNC) and Bleeding Disorders Association of South Carolina (BDASC) are thrilled to be heading back to Camp Canaan in Rock Hill, SC, for four days of teen fun and empowerment! Gut Monkey will also be back, bringing their engaging and experiential Leading



Edge Program that helps teens to grow and become more independent. At Camp Canaan, teens will also have the opportunity to participate in the high ropes course, zip line, kayaking, swimming, and more!

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Raleigh Festival & Walk for Bleeding Disorders: Coming Soon!

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educate the community, and more. Your help is needed to make this event a success! More information will be announced this summer, with details available on the BDFNC website and social media platforms.

Here's what YOU can do to make this event a success:

- Register to participate in this year's Festival & Walk.
- Promote your walk team and ask others to join your team or donate.
- Set up your own fundraising event at your home, office, school, place of worship, or neighborhood.
- Contact local restaurants and businesses about hosting a fundraising event.
- Contact potential supporters like car dealerships, doctor's offices, banks, insurance companies, or any business that you think could be interested. Not sure about asking? We're happy to assist. This is also a great awareness raiser!
- Need some fundraising ideas? Contact the BDFNC office or look on our website for suggestions.



Save the Date for Fall Events

While it's only the start of summer, Bleeding Disorders Foundation of North Carolina (BDFNC) is busy planning for the fall. Save the date for upcoming fall events, including:

- *Community Conversations*, August 16, September 20, October 18, November 15
- *Blood Brotherhood & SOAR Weekend*, September 17-18
- *Family Day*, October 8
- *Holiday Celebration*, December 3

You can also read more about the *Raleigh Family Festival & Walk for Bleeding Disorders*, which will be on October 22, on the front cover.

Watch your email and the BDNFC website for announcements about all of these events and other events as they are scheduled.

Music Brings Healing to BDFNC

March 22, 2022

Virtual



Bleeding Disorders Foundation of North Carolina (BDFNC) partnered with Piedmont Music Therapy out of Charlotte, NC for the second program in its Music Therapy series for Mental Health. Music therapy is a clinical and evidence-based therapy that uses music to accomplish therapeutic goals. Gabby Jones, licensed music therapist, led participants through a variety of different activities that included listening to music, participating in music making, and breathing exercises, to help lower stress levels and raise emotional awareness.

Conversations with the Community

April 19 and May 17, 2022

Virtual



Bleeding Disorders Foundation of North Carolina (BDFNC) is excited to have community member and community leader Alisha Curtiss leading the monthly *Community Conversations* meetups. Alisha is a mom and woman with hemophilia.

In April, Charlene kicked off the evening by talking about BDFNC's recent name change and the launch of the new website. Then Alisha facilitated a great conversation about building awareness about your bleeding disorder. Awareness is important for so many reasons, especially when it comes to advocating for yourself or your loved one at the hospital or in school. BDFNC's name change is one way the organization is

trying to help bring critical awareness to ALL bleeding disorders. Community members can help by sharing information about BDFNC with friends, family, neighbors, medical providers, and others.

May's *Community Conversations* event was very thought-provoking, thanks to Alisha's questions to help guide the conversation about quality of life and how to measure it. It was a great opportunity to step back and think about what's important to each of us and how we take care of ourselves. Attendees left with new ideas and suggestions on how to do this, with help by others in the group.

Please join Alisha and BDFNC members for the upcoming *Community Conversations*, which take place on the third Tuesday of every month via Zoom.



Celebrating World Hemophilia Day

April 25, 2022

Virtual

While World Hemophilia Day is officially celebrated on April 17 every year, Bleeding Disorders Foundation of North Carolina (BDFNC) celebrated on April 25 this year because of the Easter holiday. It was a fantastic evening as 33 community members from around the state gathered virtually to celebrate and honor this important day. Once again, BDFNC partnered with Sanofi to provide an interactive, hands-on program with activities to help reinforce the realities of bleeding disorders worldwide.



This year's event, themed "One Family," focused on joint health.

While joint health is important for everyone with a bleeding disorder regardless of where they live, joint health is much more complicated in places where medication is scarce. Unfortunately, there are still far too many people with bleeding disorders living in countries without adequate access to clotting medicine, which leads to debilitating joint damage. After discussing this reality, the group used household items to experience a few complications and challenges for someone with joint damage, including picking up a coin from a flat surface without having full function of the joints in your hands.

After the hands-on experience and a debrief, attendees discussed ways that the North Carolina community can support people across the world. It was a powerful experience! The final activity of the evening was creating compassion cards with colored pencils so everyone was able to draw or write a message. Once complete, the cards will be mailed to people outside of the U.S. who live with a bleeding disorder. While this took less than 10 minutes of time, it means so much to those who receive these positive messages!

Latin Union Event at Dave & Buster's

April 30, 2022

Concord, NC

By: Kristin Britt, community member

Latin Union events are a great way to meet other welcoming families of people that are also part of the bleeding disorders and the Latin community. In April we got together for an amazing presentation put about dental wellbeing with a bleeding disorder. After we all introduced ourselves, including our names and ages and the bleeding disorder name each of us has, we had a great lunch. There was also time after the presentation to mingle and enjoy the activities at Dave and Busters thanks to the amazing people of the foundation.



Teen Retreat Returning

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All teens in the bleeding disorders community are welcome to attend, including those diagnosed with a bleeding disorder, siblings of someone with a bleeding disorder, and children of someone with a bleeding disorder. Teens may also bring a friend. BDFNC provides transportation from Greenville, NC, and from the BDNFC office in Morrisville, NC.

Space for this event is limited, so make sure to register early. More information can be found on the BDFNC website.



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LET'S GO

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about PK at UnderstandingPK.com

PK; Pharmacokinetics

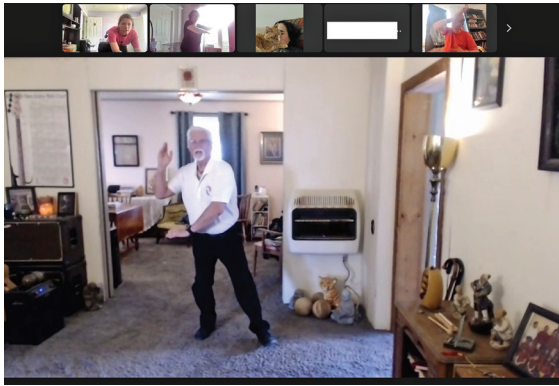
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Finding Calm Through Tai Chi

May 7, 2022

Virtual



Tai Chi is known throughout the world as moving meditation. Through slow, gentle movements, focusing on the breath, one enters a meditative state, where the stress and worries of daily life disappear, if only for a moment. It can also help with pain management and stress management, and can help to increase strength, flexibility, and balance, which makes it perfect for the bleeding disorders community. As part of the Bleeding Disorders Foundation of North Carolina's (BDFNC) Mental Health Initiative, Rick Starks led 12 attendees through an overview of Tai Chi, meditation, and breath work to bring focus, relaxation and stress relief, ending with an interactive Tai Chi tutorial.

Rick is 68 years old and has severe hemophilia B. Having survived all courses of treatments, Rick found his true passion as a martial artist. His passion was a two-edged sword. While he did gain self-confidence, strength, and flexibility, eventually becoming a state heavyweight champion in Taekwondo, he also suffered numerous injuries. Those injuries led to hip replacements and his ankles were so deteriorated that he was unable to walk more than a block or two. This resulted in a heart attack. Looking for a form of exercise, he returned to his passion and discovered Tai Chi, an ancient Chinese martial art. He credits this with providing him with pain management and supporting his mental health. Rick did a fantastic job sharing his experience, advice, and answered questions about how to make the most out of Tai Chi. A big thank you to Rick, and to the Hemophilia Alliance Foundation for making this possible!

Yoga for Mental Health

June 9, 2022

Cary, NC or Virtual



Over the past year, the Bleeding Disorders Foundation of North Carolina (BDFNC) has held a variety of events to help someone manage their mental wellness using alternative modalities, besides just therapy or medication. The final program of the series was Yoga for Mental Health. Through regular practice, yoga has been shown to help with mental clarity, calmness, relaxation, and stress management. BDFNC partnered with Pat Connolly, MSW, at the UNC Wellness Center of Northwest Cary who led four in-person participants and two virtual participants through a gently yoga session. She shared postures that could be done seated as well as ways to modify other movements to take into account each person's individual physical ability level. Pat brought the session

back to mental health by reminding participants to stay in the moment, by practicing alternative nostril breathing, and through the practice of tapping.

While this was the final session being presented through the Hemophilia Alliance Innovations Grant that BDFNC was awarded last summer, BDFNC will continue to offer programs for the bleeding disorders community that address mental health.

Evento de la Unión Latina

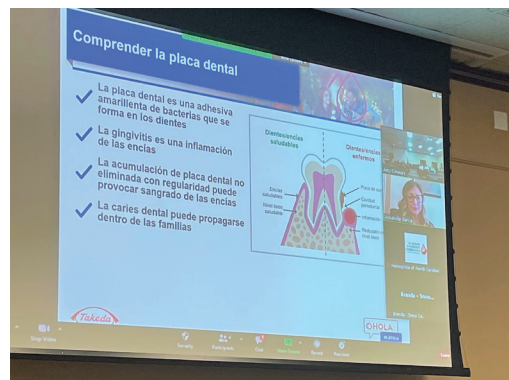
30 de abril, 2022

Concord, NC

Por: Guillermo Sanchez, miembro de la comunidad

Finalmente llegó el día en que nos reunimos nuevamente en persona. Familia que integran la Unión Latina de Hemofilia participaron con alegría y entusiasmo en la plática educativa sobre la salud bucal, en la que aprendieron acerca de la importancia del cuidado de dientes para evitar sangrados y tener una sonrisa saludable. Además de compartir algunas experiencias sobre las visitas al dentista y los cuidados e higiene bucal, las familias tuvieron la oportunidad de conversar sobre otros temas de importancia y disfrutar de una comida deliciosa. Después de la plática las familias se divirtieron y ganaron sorpresas en el área de juegos. ¡Fue una tarde de aprendizaje y diversión!

No pierdas la oportunidad de participar en la próxima reunión de la Unión Latina. Busca en nuestras redes sociales las próximas actividades.



Aprendizaje + diversión = Unión Latina



El Programa de la Unión Latina surge del interés de cubrir las necesidades culturales y de lenguaje que tienen las personas de Latino América con algún desorden sanguíneo y sus familias que viven en Carolina del Norte.

Además de una atención médica especializada, consideramos que para crecer y mantener una buena calidad de vida, una persona diagnosticada con

algún desorden sanguíneo, debe de formar parte de grupos sociales en donde encuentre información y apoyo por parte de personas que viven con la misma condición. La Unión Latina ofrece la oportunidad de aprender habilidades para evitar y lograr superar dificultades a las que se enfrentan las personas que viven con algún desorden sanguíneo, ya sea en la familia, la escuela, en actividades recreativas y deportivas, y en el empleo. Tener un espacio para escuchar y compartir puntos de vista diferentes ayuda a enriquecer y generar confianza tanto en el individuo como en la familia, saber que no estamos solos nos ayuda a crecer de forma personal, familiar y social.

Es muy importante que mamás y papás escuchen y compartan con otras familias consejos prácticos sobre el cuidado en casa y en la escuela de menores de edad con algún desorden sanguíneo. Es sorprendente la comprensión y el apoyo que se obtienen en la convivencia entre grupos de mamás y papás.

El convivir y realizar actividades adecuadas con otros adultos con algún desorden sanguíneo, en un marco cultural y de lenguaje similar, mejora la autoestima de los individuos y ayuda a generar un mayor y mejor conocimiento del desorden sanguíneo. Convivir con personas con la misma condición de salud, en tu idioma, te enseña más allá de lo que se pueda leer sobre tu desorden sanguíneo. La convivencia te enseña esos pequeños trucos y habilidades que se desarrollan día con día al vivir con algún desorden sanguíneo.

El Programa de la Unión Latina es una excelente herramienta de conocimiento y entendimiento de lo que implica vivir con algún desorden sanguíneo. Te invitamos a que participes de forma activa, atendiendo a las reuniones y enviándonos tus recomendaciones y comentarios sobre el programa.

¡Esperamos verte pronto!



What a Symptomatic Hemophilia Carrier Wants Others to Know

By: Jennifer Lynne

Reprinted from Hemophilia News Today

What happens when a **symptomatic hemophilia carrier** needs minor surgery? Will her increased risk of bleeding be recognized?

The story of Kim H. came to my attention on Facebook. She is 39 years old and lives in Pennsylvania. I recently interviewed Kim over Zoom, as her story is important. Kim is no stranger to hemophilia. According to Kim, her father had severe **hemophilia A** (factor VIII deficiency) and passed away after a brain aneurysm caused uncontrollable bleeding.

When Kim's younger sister **became pregnant**, both women were tested and determined to be carriers of the hemophilia gene. Kim's hematologist said she was missing 50% of her factor VIII and may experience bleeding issues with surgery. She was labeled a symptomatic carrier. She had heavy periods and joint issues, but no other bleeding problems.

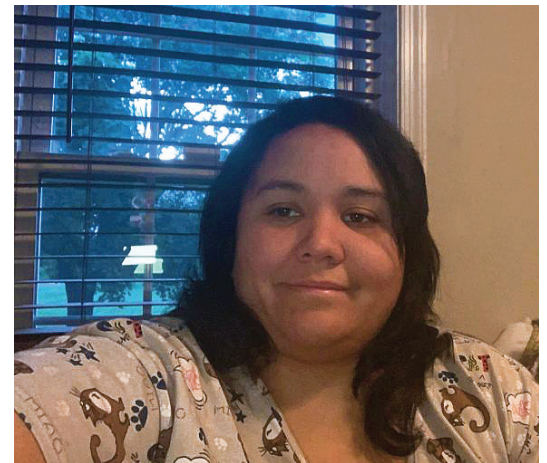
Hemophilia carriers are always women. According to the Hemophilia Federation of America, "Approximately 1/3 of women carrying the hemophilia gene experience bleeding symptoms. Carriers with clotting factors levels of less than 60% of normal may have symptoms similar to a male with mild hemophilia. They are often called symptomatic carriers or are diagnosed with **mild hemophilia**."

As Kim's story illustrates, the label "symptomatic carrier" can be confusing and dangerous. Excerpts of our conversation follow.

JL: Tell me what happened?

KH: In March, I had a tear in the meniscus ligament in my knee. The plan was to perform laparoscopic surgery for a minor repair. I gave the surgical team a warning that I am prone to heavy bleeding and they might want to get a hematologist on board. My warnings were dismissed.

There was severe heavy bleeding during the surgery. In order to stop the bleeding, they put a massive amount of tourniquet pressure around my knee. They got the bleeding under control. They sent me home.



Kim H.

What a Symptomatic Hemophilia Carrier Wants Others to Know

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Three days later, the pain was so severe I was screaming. I was rushed to the hospital, and that is where they discovered a **pseudoaneurysm** in my knee had ruptured. The pseudoaneurysm was probably caused by the tourniquet pressure used to stop the bleeding during the surgery.

I had been bleeding so much that the pressure in my leg was really bad. I had developed **compartment syndrome** [extremely painful muscle pressure] in my leg from all of the bleeding. The surgery was 12 hours. Not only did they have to do a bypass to fix the aneurysm, but they also had to do a **fasciotomy** down my leg to relieve the pressure from compartment syndrome.

How was the next surgery different?

A vascular surgeon was on the team and he listened to me. They had a hematologist guiding them. They saved my leg. They saved my life. They told me I need to start seeing a hematologist regularly because what I experienced wasn't a minor bleeding issue.

I lost 2.5 liters of blood and spent 32 days in the hospital. I had three surgeries in a week and a half. [The] third surgery helped closed the fasciotomy, but I still have an open wound because my calf was so swollen.

I need a walker to walk. I have a wheelchair. I am very reliant on family members and I may need more surgery. All of this is because of a minor knee repair.

What do you want people to know about being a carrier and your experience?

I don't think many parents realize that if their daughters are [symptomatic] carriers, their daughters are going to have **symptoms**. A heavy period or bleeding longer from a cut may not seem like a big deal, but when it comes to medical treatment like surgery, it's a big deal.

The word "carrier" is very dangerous. If I say I am a carrier, people think I just passed down the gene. There is so much more to it with this disorder, and people don't realize it.

When I was a kid, I was told women could not be hemophiliacs, [as] hemophilia only affects males. I am sitting here now, I'm going no, that's not accurate, and it's sad. It is so damaging. This belief that women aren't affected by hemophilia is still there among the **medical community**. Doctors look at you like you don't know what you are talking about, and you are making this up.

Kim says the doctors expect her to make a full recovery, but it will be long, and she will require more surgery. She says it will be at least a year before she can think about going back to work. If she could help just one woman by telling her story, she told me it would be worth it.

I wish Kim well in her recovery and thank her for sharing her story.

“

THE WORD
"CARRIER" IS VERY
DANGEROUS.

”

Kim H. - symptomatic carrier

<https://hemophilianewstoday.com/2022/05/20/what-symptomatic-hemophilia-carrier-wants-others-know/>



In the next Edition

Stay tuned to the Fall Edition of *The Concentrate* to read about the Ultra-Rare and von Willebrand Disease Education Day, Summer Community Retreat, Teen Retreat, and more!



Blood Brotherhood Program Update

Bleeding Disorders Foundation of North Carolina (BDFNC) is looking to re-engage men with a bleeding disorder now that we can be back together in person! For the first in-person event since before the COVID pandemic, BDFNC planned a fun activity – “Axe Throwing for Men with Bleeding Disorders” in Greenville, NC. Other upcoming opportunities to connect with other men with a bleeding disorder are at the Summer Community Retreat in July and Blood Brotherhood Weekend in September, as well as during the *Community Conversations* virtual meetings which take place on the third Tuesday of the month on Zoom.

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

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



HOPE Program Update

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

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

BDFNC hopes to see you at an upcoming HOPE or general event, including the Summer Community Retreat, Family Day, and Community Conversations online meetup groups. Other smaller educational opportunities are also being planned for later this summer and fall. While school might be getting out for summer now, if you need resources to help your child succeed in school or daycare, BDFNC can help.

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.

RECRUITING PARENT MENTORS –
Please contact Gillian Schultz,
Director of Programs, at
g.schultz@bleedingdisordersnc.org
or by calling her at (919) 272-6000
for more information.





Unión Latina Program Update

By: Guillermo Sanchez, Unión Latina Volunteer Coordinator

The Unión Latina Program was created from the interest of meeting the cultural and language needs of people from Latin America with a bleeding disorder and their families who live in North Carolina.

Besides specialized medical care, we believe that, in order to grow and maintain a good quality of life, a person diagnosed with a bleeding disorder must be part of social groups where they can find information and support from people who live with the same condition. The Unión Latina offers the opportunity to learn skills to avoid and overcome difficulties faced by people living with a bleeding disorder, whether in the family, at school, in recreational and sports activities, and at work. Having a space to listen and share different points of view helps to enrich and build trust both in the individual and in the family. Knowing that we are not alone helps us grow personally, with our family, and socially.

For parents it is very important to listen and share practical advices on caring for minors with a bleeding disorder at home and at school. It is surprising all the understanding and support that can be obtained from groups of parents that are or have gone through similar situations.

Spending time with other adults with a bleeding disorder, in a similar cultural and language setting, improves the self-esteem of individuals and helps generate a greater and better understanding of the bleeding disorder. Enjoying time with people with the same health condition, in your language, teaches you beyond what you can read about your blood disorder, and doing safe activities teaches you those little tricks and skills that are developed day by day when living with a bleeding disorder.

The Unión Latina Program is a powerful tool to increase knowledge and understanding of what it means to live with a blood disorder. We invite you to participate actively, attending the meetings, and share with us your recommendations and comments about the program.

We hope to see you soon!

Please contact Gillian Schultz, Director of Program, at g.schultz@bleedingdisordersnc.org for more information about the Unión Latina Program.



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.

Later this year, BDFNC plans to continue its awareness-raising activities by exhibiting at a variety of conferences, including the North Carolina Nurses Association Conference, the North Carolina Emergency Nurses Association Conference, and the North Carolina Dental Hygienists' Association Conference. These conferences are vital in providing resources to medical providers who may not be aware of the signs and symptoms of bleeding disorders in women and girls.

Please also join BDFNC at upcoming events including the Ultra-Rare Bleeding Disorders & von Willebrand Disease Education Day, Summer Community Retreat, SOAR Weekend, and *Community Conversations* online meetup groups to find a community of women who share experiences.

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 kicked off its first year in January! 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 maybe even learn along the way. BDFNC also believes that **all** family members are affected by a bleeding disorder, whether they are personally diagnosed 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.

Mental Health Initiative

Scan the QR Code to
SHARE YOUR STORY



Help END THE STIGMA
about MENTAL HEALTH

The impact of bleeding disorders on one's mental health and wellness is finally being addressed. In an article, *Interrelationship between depression, anxiety, pain, and treatment adherence in hemophilia: results from a US cross-sectional survey*, in the journal, *Patient Preference Adherence*, it was found that a significant number of survey participants suffer from anxiety and depression. Locally, Bleeding Disorders Foundation of North Carolina (BDFNC) has been a leader when it comes to learning about these issues and helping to provide resources in North Carolina. On June 11, the results of the BDFNC survey on mental health and the North Carolina bleeding disorders community were presented at BDFNC's monthly board meeting. Those results will be shared in the Fall Edition of *The Concentrate*.

Throughout Mental Health Awareness Month in May, BDFNC shared statistics and posts through a social media campaign to raise awareness about mental health and bleeding disorders, and to help end the stigma of talking about these issues. BDFNC continues to ask for you to share your experience with mental health conditions by sharing your story with us: <https://www.surveymonkey.com/r/WRB6GTH>. Your submission is anonymous unless you choose to provide your name.

As with many chronic conditions, the stress of managing a bleeding disorder can lead to emotional distress and challenges. BDFNC is committed to moving the conversation about mental health in the bleeding disorders community from talking about it to DOING something about it. The Mental Health Initiative brings that talk to action to support the bleeding disorders community.

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!

Happy Birthday
Adler



Adler and his mom
Meredith. Both have a
qualitative platelet disorder

*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.

Happy Birthday
Michelle



Michelle and Nick

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
Dan & Sarah Jane Cox
Amit Nanda

In Memory of
Margaret Thomas Martin
Connie Roderick

*In Honor of Stan
and Ann Sholar*
Susan Sydes

Mental Health Program
Karyn & Kyle Davis

General Donations

Irene Cowell
Sue & Allen Heafner
Linda & Allen Kurtz
Carrie Regler

Facebook Fundraisers

Elizabeth Parks
Sharon Sebolt

Thank You 

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



Volunteer and Make a Difference

"Alone we can do so little; together we can do so much."

~ Helen Keller

Bleeding Disorders Foundation of North Carolina (BDFNC) is a small organization that makes a big impact. With just two full-time employees and one part-time employee, you may wonder how BDFNC does so much. The answer is because of dedicated volunteers! Volunteers are the backbone of BDFNC.

You too, can make a difference by volunteering. There are many opportunities to help, from event volunteers, office help, help with mailings, making phone calls, volunteer jobs that can be done at home, sitting on a committee, and so much more!

If you would like to volunteer for BDFNC, please fill out a Volunteer Form on the website: www.bleedingdisordersnc.org/get-involved/volunteer.

And thank you to all the individuals and groups that help to make a difference.

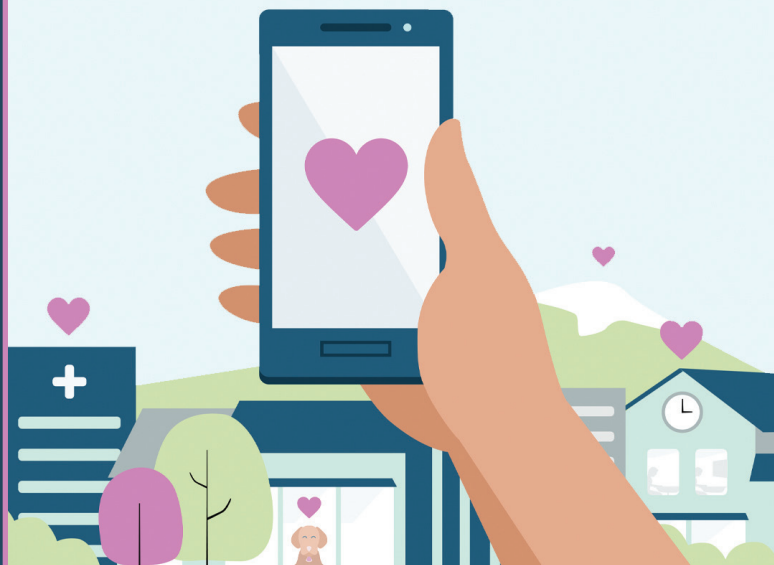


Recruiting Committee Members

BDFNC is looking for individuals who would like to provide their input about the programs offered to the community. If you would like to sit on the ***Programs and Offerings Committee***, please contact Gillian Schultz, Director of Programs, at g.schultz@bleedingdisordersnc.org or (919) 272-6000.

Turn on AmazonSmile in the Amazon app to generate donations.

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- 1. Make sure you're signed up for AmazonSmile: go to www.smile.amazon.com; sign in to your Amazon account; select your charity.**
- 2. Update your Amazon app on your phone.**
- 3. Open the app and find 'Settings' in the main menu (≡). Tap on 'AmazonSmile' and follow the on-screen instructions to turn on AmazonSmile on your phone.**

Bone Health in VWD and Hemophilia Carriers the Focus of Retrospective Study

Reprinted from National Hemophilia Foundation

The issue of poor bone health represents a significant public health concern in the U.S. population, including for individuals with hemophilia who are at increased risk for low bone mineral density (BMD) and bone fractures. While low BMD in hemophilia has been the focus of previous studies – linked to recurrent joint bleeding, decreased weight bearing, and immobility – less is understood about this complication in other groups. Hemophilia carriers (HCs) and persons with von Willebrand disease (PWvVWD) are two such groups.

A team of investigators therefore conducted a population level, retrospective study to learn more about the prevalence of osteoporosis, osteoarthritis, and bone fractures in both HCs and PWvVWD. The study, led by hematologist Divyaswathi Citla-Sridha, MD at the University of Arkansas for Medical Sciences, was published on April 13, 2022, in the journal *Haemophilia*.

Citla-Sridha and colleagues reviewed de-identified electronic health record data culled from 26 major integrated healthcare systems, encompassing 360 hospitals. 940 HCs and another 19,580 PWvVWD were identified. The prevalence of osteoporosis, osteoarthritis, and fractures were reported to be “significantly higher” among both the HC and PWvVWD data groups.

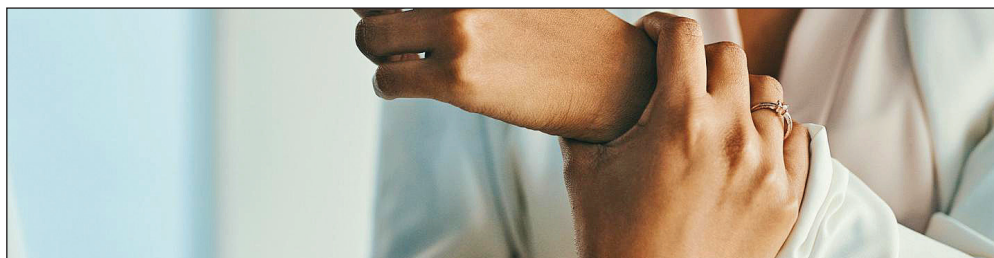
Within the HC group, investigators observed higher rates of risk factors often associated with low BMD, including vitamin D deficiency, obesity, hypothyroidism, smoking, corticosteroid use, malignancy, and the use of nonsteroidal anti-inflammatory drugs (NSAIDs). The prevalence of risk factors was also higher in the PWvVWD group. In light of these findings, the authors signal the need to screen these patients for risk factors for poor bone health, while also providing education to prevent complications.

“This study highlights the need for Haemophilia Treatment Centres to focus on the bone health in these patients and pay closer attention to other risk factors during their routine comprehensive visits,” concluded the authors. “Further prospective, multi centre studies are necessary to validate these findings.”

Source: HCP Live, April 15, 2022

<https://www.hemophilia.org/news/bone-health-in-vwd-and-hemophilia-carriers-the-focus-of-retrospective-study>

Bone Health & Bleeding Disorders



ACA Plans: Ending the Family Glitch

Reprinted from Hemophilia Federation of America
WashingtonWire, April 2022



What is the
Affordable Care Act
"Family Glitch"?

The so-called "family glitch" is one of the persistent deficiencies in the Affordable Care Act. Under the ACA, people with access to employer-sponsored health coverage only qualify for subsidies to help them buy Marketplace health insurance if premiums for their employer plan are unaffordable (i.e., above 9.83% of household income). Affordability, however, is measured against the cost of individual coverage. This means that family members are ineligible for subsidized ACA coverage if one parent has an offer of affordable employer-sponsored single coverage, even when the employee's cost to cover additional family members is not affordable. Because of the family glitch, an estimated 5.1 million Americans – mostly children of low-income workers – can't access subsidized Marketplace health insurance. Affected families face the choice of remaining uninsured, or enrolling in employer plans that may cost 25% or more of family income. Patient groups

(including HFA), state insurance regulators, and health policy experts have long sought a fix for the family glitch.

On April 5, 2022, the Biden Administration issued a proposed rule to eliminate the family glitch. If the rule is finalized, family members of workers who are offered affordable self-only coverage – but unaffordable family coverage – will be able to qualify for ACA subsidies. The Administration forecasts that 200,000 uninsured people would thereby gain coverage, and nearly 1 million Americans would see their coverage become more affordable. If finalized, the proposed rule would take effect before the open enrollment period for 2023 coverage.

States Get Extra Time to Complete Medicaid Eligibility Redeterminations After PHE Expires

Reprinted from Hemophilia Federation of America
State of the States, Winter 2022

New guidance released this month by CMS grants state Medicaid agencies up to 14 months following the expiration of the COVID-19 public health emergency (PHE) to complete all eligibility redeterminations, renewals and/or terminations, even though states must still start the process within the 12-month grace period initially provided by the agency.

The PHE is currently slated to expire on April 15* but because the Biden Administration has pledged to give states at least 60 days advanced notice before it expires, observers expect that the Administration will renew the PHE into mid-summer. (Past PHE declarations have been for 90-day periods, but the Administration could choose to extend the PHE for a shorter period and still comply with its promised 60-day notice).

The federal Coronavirus Aid, Relief, and Economic Security (CARES) Act passed in March 2020 halted all eligibility redetermination for the duration of the PHE and prevented states from removing any Medicaid or Children's Health Insurance

Continued next page



States Get Extra Time to Complete Medicaid Eligibility Redeterminations After PHE Expires *continued from previous page*

Program (CHIP) enrollees who become ineligible during that time. Since then, Medicaid/CHIP enrollment has surged by nearly 20 percent to a record 85 million Americans. As a result, this “maintenance of effort” requirement created a massive number of eligibility determinations for states to make in a short period of time once the PHE expires.

According to the Urban Institute, up to 15 million Americans under age 65 are likely to lose Medicaid coverage during this redetermination process. The Georgetown University Center on Children and Families warns that 6.7million of these will be children who have either aged out of coverage (in non-expansion states), live in households whose income now exceeds Medicaid limits, or have relocated during the pandemic and not updated their information with state agencies.

CMS’ guidance cautions that even with needed technology upgrades and training of new staff, state Medicaid agencies will only be able to process about one-ninth of needed eligibility determinations each month. The 14-month window is intended to give them sufficient time to do so and spread out the impact of mass numbers of coverage terminations. HFA and allied patient groups have called on

both CMS and state Medicaid directors to take proactive steps to minimize disruption to patient access to care and ensure those who lose Medicaid coverage are informed of and transitioned to alternative pathways to coverage (such as the ACA Marketplace).

****Update since the original article:**

On April 12, U.S. Health and Human Services Secretary Xavier Becerra renewed the official determination that COVID-19 constitutes a national public health emergency. The renewal means that waivers allowing for expanded telehealth services, enhanced federal funding for Medicaid, and a pause on Medicaid disenrollments will continue at least through July 2022.

A Texas Sized Family Reunion

HFA Symposium
April 20-23, 2022
San Antonio, TX

On April 20, members of the bleeding disorders community from around the country convened in San Antonio, TX, for a Family Reunion! It has been three years since the last Hemophilia Federation of America (HFA)

Symposium, and attendees were so happy to be back

in person. Several folks from North Carolina attended the event, representing the Bleeding Disorders Foundation of North Carolina.

The three-day event included sessions for everyone, and for all bleeding disorders. Notable was the keynote, *Unburying My Father*, which included both a keynote presentation and exhibit. Zander Masser shared a moving story about the impact his father’s hemophilia and death had on him, through memories, stories of those who knew him best, and photographs.

The final night event this year was one for books! Keeping with the theme of everything in Texas being bigger, there were life-sized games, including a life-sized Hungry, Hungry, Hippos, Jenga, and more; plus great music and food. It was a fun night for everyone before heading home.



Advocacy Days: Our Voices Matter

June 15-16, 2022

Raleigh, NC

Advocacy: It's in our blood. That's the slogan that 23 advocates saw as they entered the training dinner on June 15 in preparation for Bleeding Disorders Foundation of North Carolina's (BDFNC) Advocacy Days event. Coined by the Hemophilia Federation of America,



BDFNC displayed this message as a reminder that our voices matter. From the HIV/AIDS crisis to the recent copay accumulator adjustment programs ban in North Carolina, the bleeding disorders community has been a leading source for legislative advocacy. After all, who will advocate for people with bleeding disorders if we don't do it ourselves?

The main focus for Advocacy Days this year was Medicaid expansion. BDFNC has been advocating for Medicaid expansion in North Carolina for twelve years now; and we are closer than ever to success in getting health coverage for those who need it most! BDFNC members helped explain why health coverage is so important for the bleeding disorders community. Even if they aren't personally



affected by the lack of expansion, legislators want to hear from their constituents about why it's important — and attendees talked about how if they needed Medicaid but weren't eligible, it would impact their ability to care for their bleeding disorder.

In addition to legislative meetings, advocates had a chance to talk with dozens of legislators who stopped by the booth. Not only did the legislators hear about the importance of Medicaid expansion, but advocates took the time to educate them on bleeding disorders. One North Carolina advocate shared his experience of growing up without access to medication which resulted in permanent damage to his joints. Advocates also had a chance to sit in on a House of Representatives session to see the legislative process at work.

Thank you to everyone who came out to the 2022 BDFNC Advocacy Days to share their voices and stories on

behalf of the entire bleeding disorders community.

In the coming weeks, BDFNC will be sending out information on how everyone across North Carolina can share their story from the comfort of their own home. Affordable access to health insurance and medication depends on our action and willingness to share why it is so important.





Bleeding Disorders Foundation of North Carolina

2022 Calendar of Events Highlights

<u>June 26, 2022</u>	VWD/Ultra-rare Bleeding Disorders Day - Chapel Hill, NC	<u>October 8, 2022</u>	Family Day & New Members Event - Location TBD
<u>June 28, 2022</u>	Spouses & Partners Event - Virtual	<u>October 18, 2022</u>	Community Conversations - Virtual
<u>July 8-10, 2022</u>	Summer Community Retreat - Lake Junaluska, NC	<u>October 22, 2022</u>	Raleigh Festival & Walk - Morrisville, NC
<u>July 19, 2022</u>	Community Conversations - Virtual	<u>October 29, 2022</u>	Unión Latina Event - Location TBD
<u>July 30, 2022</u>	New Members Event - Virtual	<u>November 5, 2022</u>	Blood Brotherhood Event - Location TBD
<u>August 11-14, 2022</u>	Teen Retreat Rock Hill, SC	<u>November 15, 2022</u>	Community Conversations - Virtual
<u>August 16, 2022</u>	Community Conversations - Virtual	<u>November 19, 2022</u>	Teen Event - Location TBD
<u>August 20, 2022</u>	Women's Event - Location TBD	<u>December 3, 2022</u>	Holiday Celebration/ Unión Latina - Greenville, NC
<u>September 17-18, 2022</u>	SOAR (women)/ Blood Brotherhood (adult men) Weekend - Location TBD	<u>December 13, 2022</u>	Community Conversations - Virtual
<u>September 20, 2022</u>	Community Conversations - Virtual		

* We are providing the year's tentative calendar of events early this year so members can save the dates. 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 information. Email BDFNC at events@hemophilia-nc.org or call (919) 319-0014 to be added to the email and/or text groups.



**BLEEDING
DISORDERS
FOUNDATION**
OF NORTH CAROLINA



**BLEEDING DISORDERS FOUNDATION
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FAMILY '22 FESTIVAL

— AND WALK —

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in-person if
conditions permit