

THE CONCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Spring 2023

Important Medicaid and CHIP Information

If you or a family member are currently enrolled in Medicaid or NC Health Choice for Children (North Carolina's Children's Health Insurance Program -- CHIP), you may need to take steps to find out if you can continue your coverage. During the COVID-19 health emergency, eligibility reviews were paused. However, they have resumed. This means that you could lose your Medicaid or NC Health Choice coverage.

Make sure that North Carolina has your current mailing address, phone number, email, and other contact information, and check your mail. The Medicaid department will contact you about your coverage.



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Raising Awareness on WRAL



Anyone in the WRAL-TV viewing area may have seen the Bleeding Disorders Foundation of North Carolina (BDFNC) spotlighted on the WRAL Community Cares feature. In recognition of Bleeding Disorders Awareness Month, the Whitley Law Firm chose BDFNC as its featured charity for March. The Community Cares commercials aired every hour on March 6 and periodically throughout the month.

Charlene Cowell, BDFNC's executive director, accepted a giant check – a donation from the Whitley Law Firm, sponsors of the Community Cares series. Charlene was also able to use the time on the commercial to raise awareness about bleeding disorders. With limited time, as is the case with commercials, BDFNC felt the best focus would be to raise awareness about von Willebrand Disease (VWD). VWD affects up to 1 in 100 people but most are either misdiagnosed or undiagnosed.

Through this commercial, BDFNC received multiple new member applications from people affected by bleeding disorders who were unaware of the organization, as well as inquiries as to next steps if someone suspects an undiagnosed bleeding disorder. Without a doubt, this incredible opportunity made possible by Whitley Law Firm and WRAL will save lives!

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Save The Date

Ultra-Rare & VWD Day
June 3, 2023
Chapel Hill, NC

Community Conversations
June 20, 2023
Virtual

Unión Latina Event
June 24, 2023
Greenville, NC

Summer Community Retreat
July 8-9, 2023
Morehead City, NC

NC/SC Teen Retreat
August 10-13, 2023
Rock Hill, SC

NHF Conference
August 17-19, 2023
Baltimore, MD

Welcome to BDFNC
August 26, 2023
Virtual

Blood Brotherhood & SOAR Weekend
September 22-24, 2023
Pine Knoll Shores, NC

Raleigh Festival & Walk
October 14, 2023
Morrisville, NC

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

BLEEDING DISORDERS FOUNDATION
OF NORTH CAROLINA



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

MISSION STATEMENT

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

Contact Numbers

Bleeding Disorders Foundation of NC

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

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

National Hemophilia Foundation

(888) 463-6643
www.hemophilia.org

About This Publication

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

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

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

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

Hemophilia Treatment Centers

East Carolina University Health Hemophilia Treatment Center

435 Clinic Drive
Module F
Greenville, NC 27834
Phone: (252) 744-4676

Hemophilia Treatment Center of Levine Cancer Institute and Levine Children's ADULT:

1021 Morehead Medical Drive, Suite 50100
Charlotte, NC 28204
Phone: (980) 442-4363

PEDIATRIC:

1001 Blythe Blvd., Suite 601
Charlotte, NC 28203
Phone: (704) 381-9900

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.



Welcoming Ann Skinner to the Board



Ann Skinner is returning to the Bleeding Disorders Foundation of North Carolina (BDFNC) board after having served from 2011 to 2013. She is a founding member of SOAR, BDFNC women's group, and is a member of the National Hemophilia Foundation's Rare and Ultra-rare Priority Action Team. Ann has a PhD in Developmental Psychology and is a Research Scientist at Duke University's Center for Child and Family Policy, where she has worked for over 20 years. Her research is focused on parenting and child, adolescent, and young adult development around the world. Since 2020, her research has also been concentrated on studying how COVID-19 has impacted families in multiple countries, and on adolescent and young adult substance use. She has a rare factor disorder (Factor I deficiency). Please join BDFNC in welcoming Ann back to the board!

BDFNC Wins Nonprofit Award



Each year, the Morrisville Chamber of Commerce celebrates the leadership of a nonprofit organization that has demonstrated meaningful progress in the community. Winners advocate for positive change within the Morrisville community and enhance the way of life for community members through their mission and cause – often going above and beyond the call of duty. The Bleeding Disorders Foundation of North Carolina (BDFNC) was honored to win the 2022 Nonprofit of the Year award and appreciates the hard work and dedication of everyone who helps BDFNC meet its mission!

Seeking Candidates for the BDFNC Board of Directors

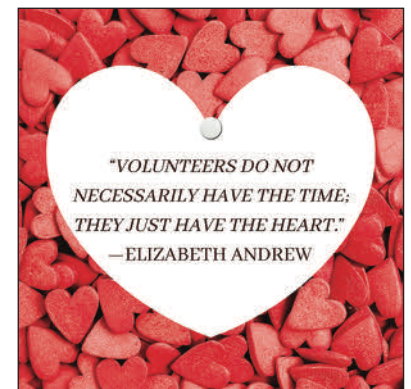
The ongoing challenge for any nonprofit organization is building and sustaining a high-functioning board of directors. To help ensure the long-term sustainability of the Bleeding Disorders Foundation of North Carolina (BDFNC), the Board of Directors has made the decision and commitment to be more deliberate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



Important Medicaid and CHIP Information continued from page 1

You can check and/or update your contact information and learn more information here: <https://tinyurl.com/NCmedicaidunwinding>

If you are no longer eligible for coverage, you may be able to purchase a health insurance plan through the Health Insurance Marketplace (www.healthcare.gov).

For more information:

- Find contact information for your state Medicaid Office on <https://tinyurl.com/NCmedicaidunwinding>
- Visit medicaid.gov
- Call the Marketplace Call Center at 800-318-2596 to learn more about Marketplace coverage

Event Attendance Policy

Now that Bleeding Disorders Foundation of North Carolina (BDFNC) events are back to being in person, please remember to carefully read the *Event Registration and Attendance Policy* every time you register for an event. Before registering, carefully consider whether you are the intended audience of the event and how far you will need to travel to get there.

All events and activities (except fundraisers) are free of charge for you to participate in; however, there are often significant costs associated with events. BDFNC strives to provide accurate attendance counts to venues for food and beverage and hotel costs and cannot recover amounts paid for people who register but do not show up. To help ensure that resources are used in the most efficient way possible, BDFNC established the *Event Registration and Attendance Policy*. This policy outlines what happens when you do not show up for an event, as well as how registrations are handled by BDFNC.

Once you register, BDFNC expects that you will attend. However, BDFNC also understands that sometimes things may come up that prevent you from attending. If this is the case, and you are unable to attend for any reason, please contact BDFNC. As a community affected by unpredictable bleeds, as well as the spread of illnesses, including COVID-19, stomach flu, and other contagious illnesses, BDFNC knows that sometimes you have to cancel at the last minute. Again, please let BDFNC know that you won't be able to attend. "No showing" to an event may put your ability to attend future events in jeopardy. However, not attending an event due to bleeds, unexpected illnesses, or other emergencies are understandable reasons to cancel, and will not be held against you **as long as you let BDFNC know**. People who "no show" to an event will be placed on a waiting list and possibly charged a hotel deposit (if applicable) if they do not show up for an event in the future.

You can read the Event Registration and Attendance Policy in full on the BDFNC website: bleedingdisordersnc.org/event-registration-and-attendance-policy.

See you at an event soon!

BDFNC's Biggest Charlotte Fundraiser Back This Spring!

April 22, 2023
Charlotte, NC

The Bleeding Disorders Foundation of North Carolina's (BDFNC) biggest Charlotte event was back in Uptown Charlotte this spring! The Charlotte Family Festival & Walk for Bleeding Disorders returned to S. Mint Street, in front of Truist Field and Romare Bearden Park. By the time this newsletter is distributed, hundreds of community members and supporters will have flooded the streets of Charlotte for this exciting event! Read the recap about the Festival & Walk in the Summer edition and save the date for the Raleigh Festival & Walk, taking place on October 14 in Morrisville.

Medicaid Unwinding: What Does it Mean?

May 2, 2023
Virtual

Be on the lookout for the recap of this virtual educational dinner in the Summer edition of *The Concentrate*. North Carolina community members and the Bleeding Disorders Foundation of North Carolina (BDFNC) were pleased to have Eva Fulcher, Deputy Director for Member Operations for NC Medicaid, join for a virtual session to give an overview of Medicaid Unwinding and how NC is handling this major undertaking. For more information about Medicaid Unwinding, read the front cover article, “Important Medicaid and CHIP Information.”



NC Advocacy Days

May 17-18, 2023
Raleigh, NC



Have you ever wondered who would be the best person to advocate for people with bleeding disorders? **That person is you!** Join fellow community members in Raleigh on May 17 and 18 to make sure that legislators are aware of issues affecting the bleeding disorders community.

Participants do not need to have any experience or know anything about the issues. The Bleeding Disorders Foundation of North Carolina (BDFNC) staff and speakers will give everyone all the information they need. All participants need to do is share their experience about living with a bleeding disorder or having a loved one who does. Legislators want to hear about the issues that affect the community. Don't worry about having to go in alone!

Participants will be grouped with folks who have varying amounts of experience, and there will always be someone in the group who is well versed about the issues.

Ultra-Rare Bleeding Disorder & Von Willebrand Disease Education Day

June 3, 2023
Chapel Hill, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) is thrilled to be offering an educational opportunity for community members affected by bleeding disorders including platelet disorders, ultra-rare factor deficiencies, and von Willebrand disease. Building upon last year's successful inaugural Ultra-Rare Bleeding Disorder & VWD Education Day, this year's program is looking to be even better! There will be both educational and networking opportunities. More information is available on the BDFNC website.



Unión Latina Event

June 24, 2023
Greenville, NC



Join the next Unión Latina event on June 24 in Greenville, NC. The Bleeding Disorders Foundation of North Carolina (BDFNC) hopes to connect with Spanish-speaking families from eastern North Carolina at this event.

Learn more about resilience. Managing stress is an important aspect of our everyday lives. This presentation will discuss some of the common causes of stress and provide some examples of how to better adapt and manage adversity. Through some interactive and fun activities, you will explore what it means to be resilient and learn some associated skills as well as tips and tools for living a healthy lifestyle.

BDFNC is still confirming the venue for the event. In addition to the presentation, there will also be lunch and an activity. All attendees will receive a gas card to help with transportation costs. Stay tuned to the BDFNC website for more information soon.

Summer Community Retreat

July 8-9, 2023
Morehead City, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) invites you to this year's Summer Community Retreat, on the weekend of July 8-9 in Morehead City, NC. This year's event will be held at the beautiful Crystal Coast Civic Center. Hotel accommodations will be just down the road at the Hampton Inn Morehead City.



BDFNC is busy working on an engaging agenda, including workshops for adults with bleeding disorders and parents of children with bleeding disorder, a fun children & teen track, and a visit to the North Carolina Aquarium.

Past attendees have said the event provides an excellent opportunity to connect with other people affected by bleeding disorders. One person who attended last year said, "Over the years, I have met so many people with whom I feel a deep connection, whether they have VWD or hemophilia (A or B) or a platelet disorder. I have learned from them, and like to believe that some of them have learned from me. These past two years of the pandemic have shown me how much I appreciate face to face time with this group."

More information will be available soon on the BDFNC website, or contact Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org if you have any questions.

Attention TEENS: Join the Carolina Crew this AUGUST!

August 10-13, 2023
Rock Hill, SC

Save the date for the annual Teen Retreat, scheduled for August 10-13, 2023 at Camp Canaan in Rock Hill, SC!

Continued next page



Attention TEENS: Join the Carolina Crew this AUGUST!

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Wondering who can go to the Teen Retreat? Of course, you know it's for teens. But did you know that it's for ALL teens in the community, ages 13-18?

- Teens diagnosed with a bleeding disorder
- Siblings of someone with a bleeding disorder
- Children of someone with a bleeding disorder

Teens will be allowed to bring one friend or family member with them as long as that person is also a teen.

The Bleeding Disorders Foundation of North Carolina (BDFNC) will once again partner with the Bleeding Disorders Association of South Carolina (BDASC), to provide this fun, educational, and interactive weekend designed with the specific needs of teens in the community. This is a great opportunity to meet new friends, share laughs, challenge yourself, and prepare for your future. If you've never been to one of the NC/SC Teen Retreats, please check out the BDFNC Facebook page for photos.

Be on the lookout for an announcement soon. BDFNC will provide busing from the East Carolina University Hemophilia Treatment Center in Greenville and the BDFNC office in Morrisville to Rock Hill, SC.

Enjoy a Weekend at the Beach: Blood Brotherhood & SOAR Weekend

September 22-24, 2023

Pine Knoll Shores, NC



If you are a man or a woman with a bleeding disorder, you won't want to miss out on the Blood Brotherhood & SOAR Weekend. The Bleeding Disorders Foundation of North Carolina (BDFNC) will be heading back to the Trinity Center on the Crystal Coast of North Carolina for a weekend to make important connections with others who get what it's like to live with a bleeding disorder. There will be separate tracks for men and women, plus programs to support partners & spouses. Stay tuned to the BDFNC website this summer for more information.

Providing Families HOPE: Family Day

November 4, 2023

Concord, NC

There are so many challenges in raising a child, especially when that child has a bleeding disorder. Join the Bleeding Disorders Foundation of North Carolina for the HOPE Family Day at the Great Wolf Lodge in Concord this fall. The event will be aimed at families who have a child with a bleeding disorder. More information will be announced in the summer but until then, save the date!



Community Conversations Third Tuesday of the Month

The Bleeding Disorders Foundation of North Carolina (BDFNC) knows how important personal connections are for people affected by bleeding disorders. One way that BDFNC provides this support is through a monthly, virtual meet-up called Community Conversations. Always held on the third Tuesday of the month at 7:00 pm, these informal meetings are facilitated by longtime community member, Alisha Curtiss. Alisha is the mom of two teen boys with hemophilia and is diagnosed with hemophilia herself. Each month, she leads a conversation. Community Conversations are meant to be FOR YOU, about topics that are relevant to what you deal with.



Whether you want to think of it as a support group or just a monthly chat with fellow community members is up to you, but whatever you think, BDFNC hopes that it provides you with the support and community that you are looking for. More information can be found on the BDFNC website or by emailing Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org.

Expect the Unexpected: Prepare for Anything

January 14, 2023
Morrisville, NC

Community members gathered in Morrisville for a Unión Latina Program focused on preparing for the unexpected. Takeda's session focused on helping people avoid and prepare for a possible trip to the Emergency Room (ER) anytime, anywhere – even when traveling or during a natural disaster. ER staff, including physicians, may have little experience in the management of patients



with bleeding disorders because they are rare conditions. This information sparked a lot of discussion from community members who have either had experiences or wondered about possible situations.

After lunch and the presentation, participants enjoyed making their own one-of-a-kind painting with the help of Wine & Design. These paintings serve as a reminder of another fantastic event focused on education, empowerment, and support.

Educational Weekend Was One for the Books – Consumer Medical Symposium

March 4-5, 2023
Raleigh, NC

The Bleeding Disorders Foundation of North Carolina (BDFNC) hosted a weekend of education, networking, and connection March 4-5, 2023, at the Hilton Raleigh North Hills. The Consumer Medical Symposium is BDFNC's largest educational event held each year that brings together experts from around the country to provide information about the world of bleeding disorders.

This year's theme was "The Future is HERE," with a big focus on new and emerging treatments for bleeding disorders. With the approval of the first gene therapy for hemophilia B (the first for any bleeding disorder), this was a major topic of the weekend. There were several

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Educational Weekend Was One for the Books – Consumer Medical Symposium continued from previous page



presentations from doctors and nurses, and a panel facilitated by Kristy Lee, genetic counselor at the UNC Chapel Hill Hemophilia Treatment Center. The panel featured Dr. Nigel Key, who has administered gene therapy in the clinical trial setting, and Scott Andrews, a past BDFNC board member and a patient with hemophilia who has received gene therapy.

There were also sessions for patients with von Willebrand disease, platelet disorders and ultra-rare factor deficiencies,

clinical trials, joint health, intimacy for women with a bleeding disorder, fitness, advocacy and insurance, and sessions for BDFNC programs, including the Blood Brotherhood for men with bleeding disorders, HOPE for families of children with bleeding disorders, SOAR for women with a bleeding disorder, a session for partners & spouses of someone with a bleeding disorder in English, and for the Unión Latina in Spanish, as well as several sessions simultaneously interpreted into Spanish.

Children and teens weren't left out. Teen programs were facilitated by Beyond Recreation. Children had a visit to a game truck, learned about animals from the NC Museum of Natural Sciences, and other activities led by child care providers from Nannys Plus.

Of course, the weekend wasn't all serious. There were many opportunities to network and connect with other community members. On Saturday night, attendees were wowed by the magic and illusions of Joshua Lozoff. That is, if they weren't watching the UNC-Duke basketball game!

One community member said that the weekend "helped me understand my bleeding disorder better. [BDFNC] treats me like family!!"

Thank you to the sponsors who helped to make the weekend possible, as well as the Hemophilia Federation of America and National Hemophilia Foundation, which supported the event.



Women with Hemophilia – SOAR Luncheon

February 11, 2023
Winston-Salem, NC



On February 11, the Bleeding Disorders Foundation of North Carolina (BDFNC) held a SOAR Luncheon for women with a bleeding disorder. While eating a delicious picnic lunch, the women heard from Xaviette Pointer-Kincy, Sanofi CoRe Manager, about "Factor Fiction: Women with Hemophilia." The presentation described how women are affected by hemophilia and explored strategies on how to have productive conversations with doctors about healthcare needs, especially how to continue advocating for proper care for women with bleeding disorders. Following the presentation, attendees made beautiful suncatchers to commemorate the luncheon.



Bleeding Disorders Awareness Month



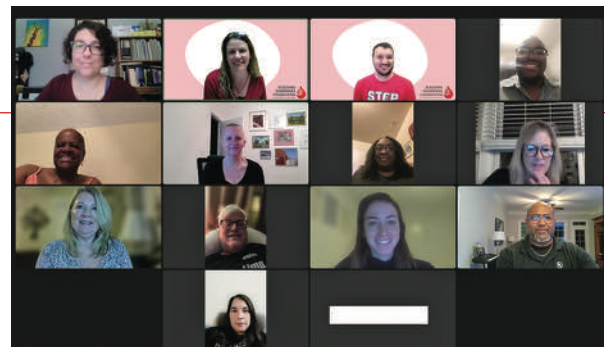
Thank you to the 11 cities, towns, and State of NC for proclaiming March as Bleeding Disorders Awareness Month

How to Tell Your Story

February 28, 2023
Virtual

A dozen participants tuned into this interactive Zoom session focused on “elevator speeches.” An elevator speech is a brief summary of someone’s story that will leave another person with new, impactful information. While there are many reasons to use an elevator speech, they are often referred to when advocating. Everyone in the bleeding disorders community should have one.

Charlene and Fernando Andrzejewski, a West Virginia community member, focused on developing an elevator speech so it can always be ready to advocate, no matter the situation. There was a short but fun Kahoot! game, where everyone was a winner. Attendees were given tips and tricks on best practices. Everyone also had an opportunity to share their stories and situations where having an elevator speech was critical.



HOPE Family Cooking Class

March 25, 2023
Charlotte, NC

Did you know that what you eat is important for people living with a bleeding disorder? Maintaining a healthy body gives people with a bleeding disorder the ability to take better care of their joints and muscles.

On March 25, the Bleeding Disorders Foundation of North Carolina (BDFNC) hosted a family cooking class at Flour Power Cooking Studio in Charlotte. Several families gathered to cook healthy – homemade veggie pizzas and fruit kabobs *Continued page 13*



Actualización del Programa Unión Latina



Los integrantes de la Unión Latina estuvieron presentes en el mayor evento educativo que ofrece la Fundación: The Consumer Medical Symposium 2023. Las familias tuvieron la oportunidad de escuchar, mediante interpretación simultánea al español, sobre la variedad de productos disponibles para el tratamiento de diversos desórdenes sanguíneos, las nuevas investigaciones y los últimos avances en tratamientos que son cada día más eficaces. Las familias, también tuvieron la oportunidad de aprender más acerca de las últimas noticias sobre Medicaid y de seguros médicos privados, y consejos sobre cómo administrarlos de forma más eficiente para la cobertura de personas con algún desorden sanguíneo. Mientras los adultos aprendían, las niñas, los niños y los adolescentes participaban en divertidas actividades para promover sus habilidades sociales.



Uno de los talleres del Simposio fue dirigido específicamente a la comunidad latina, atendiendo la importancia de estar preparados para cualquier emergencia médica derivada de algún desorden sanguíneo.

Información de importancia acerca de Medicaid y CHIP

BENEFICIARIOS DE MEDICAID
¡Actualiza tu información!

COMUNIQUESE CON SU DSS LOCAL:
ncdhhs.gov/localdss

NCDHHS

Si algún integrante de la familia recibe actualmente Medicaid o NC Health Choice for Children (Programa de Cobertura Médica para Niñas y Niños de Carolina del Norte - CHIP), debes de realizar los siguientes pasos para averiguar si continúas recibiendo la cobertura. Durante la emergencia de salud causada por el COVID-19, los criterios de elegibilidad de detuvieron. Sin embargo, están por reanudarse nuevamente. Por lo cual puede ser que dejes de ser elegible para recibir Medicaid o NC Health Choice Coverage.

Debes de asegurarte que el estado de Carolina del Norte tenga tu información de contacto actual, como dirección, número de teléfono, email, o cualquier otro. Asegúrate de revisar tu email con frecuencia. El Departamento de Medicaid se pondrá en contacto con ustedes para hacerles saber sobre su cobertura. Puedes revisar, actualizar, y leer más información en la página web: <http://tinyurl.com/NCmedicaidunwinding>

Si por alguna razón ya no son elegibles para recibir Medicaid o NC Health Choice Coverage, quizás puedas pagar por cobertura a través de las opciones de seguro médico que ofrece Marketplace (www.healthcare.gov).

Para mayor información consulta la Oficina de Medicaid en el estado: <https://tinyurl.com/NCmedicaidunwinding>

Visita además la página web: medicaid.gov

O llama a Marketplace al 800-318-2596 para saber más acerca del tipo de coberturas disponibles.



Coexisting Women's Health Conditions

Jan 20, 2023

Reprint from National Hemophilia Foundation

Happy New Year, everyone – welcome to 2023! I hope you enjoyed your holiday season, and that this new year has been off to a great start.

Today, I wanted to highlight one of our excellent sessions from the Bleeding Disorders Conference (BDC) in 2022. *Coexisting Women's Health Conditions* was a presentation led by Dr. Kalinda Woods, an OB/GYN. As both a practicing physician and a professor, Dr. Woods had a wealth of knowledge and insight to offer throughout this presentation.

This session discussed how bleeding disorder symptoms can be worsened by other conditions that often affect women, such as endometriosis or polycystic ovary syndrome (PCOS). These are referred to as comorbid conditions. These comorbid conditions may affect the symptoms you experience, so proper care, management, and treatment is crucial for an overall better quality of life.

Dr. Woods walked through a variety of common health concerns that affect women and people with uteruses, explaining what signs and symptoms to look out for. She went on to describe how seeking out a diagnosis can be difficult for women in this community since many assume any abnormal bleeding symptoms are due to their bleeding disorder. This is why it is especially important to journal all your symptoms, as well as when these symptoms begin and how long they last. Your care team will use this journal of symptoms and your medical history to help determine if you have a gynecological condition, in addition to your bleeding disorder.

In her session, Dr. Woods says, "Taking history is especially important for women with bleeding disorders. It may take longer to make these diagnoses because oftentimes people assume the symptoms are just due to their bleeding disorder. It's incumbent upon us, as providers and physicians, to investigate and establish the true issue."

As Dr. Woods emphasized, it is the duty of your care team to help get you the correct diagnoses and care. Help them help you by tracking your symptoms and booking your preventative care appointments for 2023.

Dr. Woods shares some empowering words towards the end of her presentation: "Something I tell my bleeding disorder patients is that if you have a problem that bothers you, no matter what the problem is – it's worth bringing up with your physician. That is something we can treat. You don't have to be living with any symptom that you find disruptive to your lifestyle or undesirable."

The full recording of this information session is linked below. I hope you get a chance to watch it and that you learn something new: <https://www.hemophilia.org/educational-programs/education/online-education/coexisting-womens-health-conditions>



KALINDA WOODS

HOPE Family Cooking Class *continued from page 10*



with homemade whipped cream. While you might be thinking that pizza and whipped cream aren't the healthiest options, attendees also learned about the importance of balanced meals and moderation during the presentation, "Fueling Your Future with Smart Choices," led by Morgan Cook with Takeda.

It was a fun evening out, and everyone left with a full stomach and some new insights on how eating healthy is important for living with a bleeding disorder.

This event was part of BDFNC's HOPE Program, which provides support for families of children with a bleeding disorder.



Blood Brotherhood Program Update

The Bleeding Disorders Foundation of North Carolina (BDFNC) knows the importance of making connections so that you don't feel isolated. The Blood Brotherhood Program does just that – connects men with bleeding disorders to share experiences and camaraderie.

In 2023, BDFNC is looking to strengthen the Blood Brotherhood Program. Whether you have been part of the North Carolina bleeding disorders community for years, are new to North Carolina, or you are a young adult, BDFNC hopes that you will participate in 2023.

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*

Have you seen the HOPE logo and wondered what it is? The Bleeding Disorders Foundation of North Carolina (BDFNC) HOPE Program provides support for families who have a child diagnosed with a bleeding disorder. Most programs are geared towards families with children under twelve.

In 2023, BDFNC is looking forward to providing additional resources for families, whether newly diagnosed with a bleeding disorder or having been part of the community for longer. Infusion support, daycare and school resources, what activities are safe for children with a bleeding disorder, unique needs of undiagnosed siblings, and more are some of the topics and/or resources that BDFNC is planning to provide. There were sessions specifically for families at the Consumer Medical Symposium in March and there will be more for families at the Summer Community Retreat in July. In March, BDFNC also hosted a cooking class for families. Family Day in November will be rebranded as the HOPE Family Day to provide connections and networks for families.

If you are the parent of a child with a bleeding disorder, you know the importance of making connections with other parents. Join the BDFNC HOPE Facebook group by contacting Gillian Schultz, Director of Programs. You can also read more about the HOPE Program, including Gillian's experience raising a now 12-year-old with hemophilia on the BDFNC website.

The mission of HOPE is to improve the quality of life for families of children with a bleeding disorder, so they may HOPE to lead a fulfilling life.

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





Unión Latina Program Update

It is important that people who live with a bleeding disorder find community with others also affected with a bleeding disorder. When your primary language is Spanish, the importance of this is increased since it is important not only to find people to understand your health condition but also your culture and language. The Bleeding Disorders Foundation of North Carolina (BDFNC) Unión Latina Program provides opportunities to get involved and participate in different activities so that you and your family can become informed and educated about bleeding disorders, as well as to provide resources so that you can receive appropriate medical treatment.

The Unión Latina is led by community member Guillermo Sanchez, who is always willing to reach out to you and talk about your experiences. BDFNC looks forward to growing the Unión Latina throughout 2023. If you would like more information or to get involved, contact Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org.



SOAR Program Update

The Bleeding Disorders Foundation of North Carolina (BDFNC) SOAR Program is 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 asymptomatic). 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.

In 2023, BDFNC is planning to provide a variety of programs and support for women with bleeding disorders. There were two SOAR sessions at the Consumer Medical Symposium and a SOAR Luncheon this past February. Other plans for 2023 include additional educational programs, sessions at the Summer Community Retreat, and the SOAR Weekend in September. In addition, to connect with other women diagnosed with a bleeding disorder, request access to the private SOAR Facebook group.

BDFNC would also love to hear from YOU, about your story as a woman with a bleeding disorder, in order to share experiences so other women don't have to feel so alone. Email Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org, to request access to the Facebook group or with your personal story.

Mental Health Initiative

The Bleeding Disorders Foundation of North Carolina (BDFNC) continues to prioritize the importance of mental health among those affected by bleeding disorders. 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.

BDFNC has published a Mental Health Resource Guide to provide resources for individuals in managing their mental health. If you would like a copy, please contact BDFNC at events@bleedingdisordersnc.org so that we can send it to you. Next steps for BDFNC are to continue research into how bleeding disorders affect a person's mental health and to distribute its mental health survey in Spanish and for caregivers.

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>

Gillian Schultz, Director of Programs, is sitting on a national coalition that is addressing barriers to access to inpatient mental health and substance use facilities for patients with bleeding disorders. The coalition was organized after a young man with

Continued page 16



Teen Empowerment Program



The Bleeding Disorders Foundation of North Carolina (BDFNC) realizes that teens have unique needs as they are growing up, becoming independent, and learning to manage their bleeding disorder on their own. BDFNC also recognizes that ALL teens in the bleeding disorders community can benefit from supportive programs, regardless if they are the person in the household with a bleeding disorder. The Teen Empowerment Program supports all teens impacted by a bleeding disorder.

Congratulations to Kayleigh Beeler, who won the Teen Logo Competition and designed the brand new logo for the Teen Empowerment Program. You can learn more about Kayleigh and her logo in this newsletter.

In 2023, BDFNC is planning a variety of events to support teens, including the teen track at the Consumer Medical Symposium and Summer Community Retreat, Teen Retreat, and other events throughout the year.

For more information about the Teen Empowerment Program, please contact Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org or by calling/texting (919) 272-6000.

Teen Empowerment Program Logo Competition

The results are in for the Teen Empowerment Program logo competition! Congratulations to Kayleigh Beeler, whose logo received the most votes. The logo that she designed, “Lifting Each Other Up,” will be the new Teen Empowerment Program logo that will be used for all Teen Program communications. Learn more about Kayleigh:



My name is Kayleigh Beeler, and I was born in Huntersville, NC. When I was 12 years old, I was diagnosed with von Willebrand disease.

In my free time, I enjoy a number of different hobbies — Art, Sublimation Printing (Cups & Clothing), and Photography.

In 2012, after living in Virginia for four years, my family and I moved back to North Carolina. I remember going to a Hot Air Balloon Festival and the joy that brought me. That memory helped inspire the logo I designed.

I am currently a freshman at Langtree Charter Academy. When I finish school, I would like to assist the elderly. I feel like that is my calling.

A Program for Spouses, Partners, and Caregivers

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. During the Consumer Medical Symposium in March, Nick led a well-attended breakout session. This informal session provided a space for community members to share their experiences as a spouse/partner/caregiver. It was really powerful to see the commonalities and fellowship between attendees as they shared. More events will be planned throughout the year, so keep an eye out for these.

Interested in learning more or getting involved? Reach out to Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org or (919) 319-0014 and she can connect you with Nick.



Mental Health Initiative continued from page 14

a bleeding disorder was denied access to residential substance use facilities because of his hemophilia, and tragically, died from an overdose. The Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC) is made up of members from bleeding disorders organizations across the country, the Hemophilia Federation of America, the National Hemophilia Foundation, Hemophilia Treatment Center social workers and nurses, and community members, with a mission of advocating for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders. You can learn more about BD SUMHAC on its website: www.newenglandhemophiliaorg/sumhac

To learn more about BDFNC's mental health initiative, BD SUMHAC, or if you'd like to get involved, please contact Gillian at events@bleedingdisordersnc.org, or by calling/text her at (919) 272-6000.

Scan the QR Code to
SHARE YOUR STORY



Help **END THE STIGMA**
about **MENTAL HEALTH**

Patient Assistance Programs

PATIENT ASSISTANCE PROGRAMS

**RESOURCES EVERYONE IN
THE BLEEDING DISORDERS
COMMUNITY SHOULD
KNOW ABOUT.**



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:

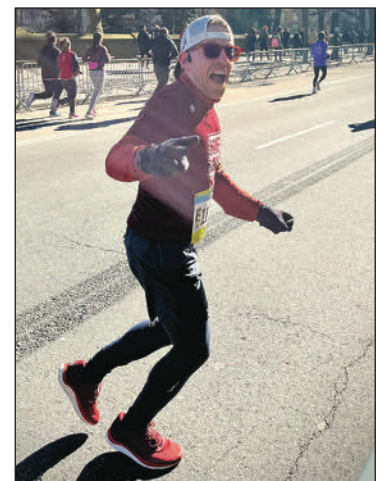
HFA - <https://tinyurl.com/assistancehfa>

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

Dr. Kleiboer Runs Half Marathon for Bleeding Disorders



On March 19, a team of Red Tie Runners took to the streets of NYC for the 2023 United Airlines New York City Half Marathon in support of the National Hemophilia Foundation. One of those runners was none other than Dr. Brendan Kleiboer, practicing pediatric hematologist and the Director of Pediatric Hemostasis & Thrombosis at the Hemophilia Treatment Center of Levine Cancer Institute and Levine Children's Hospital in Charlotte, NC. Congratulations and thank you to Dr. Kleiboer for his commitment to the bleeding disorders community!



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

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.

2023 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
Brent White

General Donations

Julie & Steve Conger
Sue & Allen Heafner
Jessamy Huckel
Linda & Allen Kurtz
Phillip Poovey

In Honor of India Dunn & Family

Adam Wolk

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

Annual Giving Donation

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Lori Conger
Susan & Charles Cowell
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Shannon Elderdice
Sue & Allen Heafner
Stephen Sachs
Gillian & Karl Schultz
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Ann & Gary Skinner
Daryl Steinbraker

Annual Giving Donation

In Honor of Charles & Kathy Register
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Kristina Olson

Annual Giving Donation In Honor of Hayden & Declan Otey

Erin & Kevin Otey

Annual Giving Donation In Honor of our 50th Anniversary

Linda & Allen Kurtz

WRAL Community Cares Donation

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Mental Health Crisis for Teens

By: Rita Colorito

December 7, 2022

Reprint from National Hemophilia Foundation



The last time Jennifer Feldman, R.N., saw Derick, a then 20-year-old with severe hemophilia A, he asked for help to turn his life around. It was late March 2021, and Derick was in the emergency room once again — not for his bleeding disorder, but because of the mental health and substance use disorders he had struggled with since his teens.

“His last ER experience really scared him. He knew this was an uphill battle. The only difference was, this time he was actually ready to get the help he needed,” says Feldman, nurse coordinator for the New England Hemophilia Center at UMass Memorial Medical Center in Worcester, Massachusetts.

At the time, the inpatient psychiatric care beds at UMass Memorial, where Derick had been hospitalized before, were full. Feldman called other rehab facilities throughout central Massachusetts. The ones with openings refused to take Derick.

“I was told that it was not something that they could do because having a patient who required infusions or injections is a liability to them,” Feldman says. After Derick’s death, Feldman sounded the alarm to the National Hemophilia Foundation and other bleeding disorders organizations. Could other teens and adults with bleeding disorders be denied inpatient mental and behavioral health care because they need factor infusion?

Despite Feldman’s best efforts to get him round-the-clock care, by early August 2021 Derick had died from his substance use disorder. Having hemophilia had kept this “big teddy bear,” as Feldman described him, from getting the inpatient care that was his best hope for long-term recovery.

“Derick was discriminated against because of his underlying condition. I thought this can’t be an isolated incident. And sure enough, it certainly wasn’t,” Feldman says. (See below, “Changing Access to Mental and Behavioral Health Care.”)

Like Feldman, Gillian Schultz, director of programs for the Bleeding Disorders Foundation of North Carolina, has faced roadblocks to inpatient care for her 11-year-old son, who has struggled with attention-deficit/hyperactivity disorder and a mood disorder since he was 5.

Two years ago, after an emergency hospital stay, doctors recommended that Schultz’s son receive inpatient care. Knowing such facilities are often fully booked, Schultz tapped her connections. Even when she could find an opening, her son’s hemophilia tripped an automatic denial. Her hemophilia treatment center (HTC) social worker and nurse made calls and wrote letters. “Nobody was able to help,” she says.

Schultz’s son was eventually placed in a weekday day program. “They would accept him there because he didn’t need infusions while he was there,” Schultz says. “But it was not an ideal situation because he needed a more intense level of care. And he fought with us when it was time to go each day.”

Day programs are a transitional step after someone reaches stability with inpatient care. Without inpatient care, it took her son nearly a year for his mental health to stabilize, says Schultz, who worries about what may happen as he gets older.

Schultz’s experience prompted her state bleeding disorders chapter to launch a mental health initiative. Its subsequent survey of people with bleeding disorders across North Carolina found that 37% of 11- to 19-year-olds deal with a mental health issue. Schultz, who develops programs for teens at her chapter, wasn’t surprised by the findings.

A Nationwide Mental Health Emergency

Derick’s and Schultz’s stories illustrate the escalating mental health crisis among the nation’s children and adolescents — and the extra hurdles that people with bleeding disorders face when seeking care.

According to the Substance Abuse and Mental Health Services Administration (SAMHSA), 15.7% of adolescents ages 12 to 17 experienced a major depressive episode in 2019, up significantly from 8.1% in 2009.

Continued next page



Mental Health Crisis for Teens continued from previous page

Of these, 11.1% experienced a depressive episode so severe that it interfered with their school, home, and social lives. By comparison, 5.8% of teens in 2009 reported having major depression with such severe impairment.

The COVID-19 pandemic placed additional mental health burdens on children and teens. According to the Centers for Disease Control and Prevention, 37% of high school students in 2021 reported experiencing poor mental health during the pandemic. In the 12 months before the survey, 44% had felt persistently sad or hopeless.

Among her child and teen patients at Rush Hemophilia and Thrombophilia Center in Chicago, Lucy Ramirez, MSW, LCSW, has seen the mental health effects of living through the pandemic. “A lot of them were not happy about virtual learning. That was the main impact,” she says. “Some of them seemed to give up on it. They became more depressed and more anxious about that aspect.”

Missing out on milestones such as school dances and graduation also affected kids’ mental well-being, Ramirez says. And even returning to school proved difficult for some. “They were kind of out of practice being with friends and socializing again,” she says.

For children and teens who already had depression, lockdown and isolation measures compounded their symptoms, Ramirez says. “More of the adolescents that we work with were a bit more withdrawn socially,” she says. “They were having a harder time communicating with their family members, and with their friends especially.”

Ramirez also saw an uptick in teens and young adults not following their normal prophylaxis schedules. “They weren’t doing anything or going anywhere, so they didn’t feel the need to treat,” she says. “But doing a deeper dive into what those emotions were, it was an overall neglect of self-care.”

Like many who struggle with mental health and substance use disorders, Derick stopped taking care of his physical health, often missing his HTC appointments. A change in physical health, appearance, and hygiene are often signs of depression and other mental health issues, says Denise Lowery, LCSW, who works with teens at the UC Davis Hemostasis and Thrombosis Center in Sacramento, California.

Safeguarding Your Child’s Mental Health

The sooner children receive treatment for a mental or behavioral health issue, the better their chances at managing the disorder and preventing it from getting worse. That’s why it’s important to recognize how widespread and interconnected these issues are for children and teens.

Like Schultz’s son, mental and behavioral health issues can start well before the teen years. One in 6 U.S. children ages 2 to 8 has a diagnosed mental, behavioral, or developmental disorder, according to the CDC.

The latest data from the National Survey of Children’s Health found that 22.6% of children ages 3 to 17 had at least one reported mental, behavioral, emotional, or developmental problem or needed a related screening. As they enter their tween and teen years, diagnoses of ADHD, depression, and anxiety increase, according to the CDC.

Before prophylaxis treatment became available, Lowery says her patients experienced more anxiety and depression related to their bleeding disorders.

To help kids and teens maintain their mental health, HTC social workers and nurses often recommend that parents encourage them to participate in programs offered through NHF, their local chapters, and other organizations. At the height of the pandemic, many of these events took place virtually. Bleeding disorders summer camps — which help kids and teens feel a sense of belonging — went remote.

Schultz’s son, who looks forward to summer camps every year, refused to go to virtual camp. She’s seen a change in his attitude for the better since he could attend in person this year.

To get teens to connect during the pandemic, Lowery held a virtual teen group. “They were chatting, playing their video games, and I think it was really helpful for them to just talk about nothing, because they were just interacting,” she says.

Advocating for your child’s mental health needs is as important as advocating for care for their bleeding disorder, Lowery says. While she’s seen an increase in anxiety and depression among children and teens, Lowery says that may be the result of feeling more comfortable talking about mental health issues now than in the past. When they don’t talk about it, she says, children and teens struggle with these issues longer than necessary, simply because it takes so long to get a diagnosis and then treatment.

For parents who are concerned about their child’s mental health, Lowery recommends first reaching out to their HTC social workers and nurses.

And because mental health issues can strain parents and families, Schultz advises parents to focus on their own self-care. “Seeking community and support from others who are in similar situations — especially for parents — is really important, too,” she says.

Continued next page



Mental Health Crisis for Teens

continued from previous page

As was the case with Derick, substance use disorder often coexists with mental illness. According to SAMHSA, nearly 3% of adolescents ages 12 to 17 struggle with both major depression and substance use disorder (illicit drug or alcohol use or both).

Often, teens will use drugs or alcohol as a coping mechanism. Experiencing a major depressive episode increases the chances that teens will use illicit drugs. The most recent SAMHSA data from 2020 found that 28.6% of adolescents ages 12 to 17 who had a major depressive episode reported using illicit drugs within the past year, compared with 10.7% of those with no such episodes.

Feldman says she wishes she could have done more for Derick, who wanted to go back to college to study forensic science. He had attended college briefly in 2018 on an academic scholarship.

“He was just a really nice kid, super smart. He definitely could have gone places,” Feldman says. “You just never think you’ll run out of time.”

Changing Access to Mental and Behavioral Health Care

Concerned that people with bleeding disorders are being denied critical care for their mental health and substance use disorders, the National Hemophilia Foundation joined with the Hemophilia Federation of America, local bleeding disorders chapters, several hemophilia treatment center (HTC) nurses and social workers, and community members to form the Bleeding Disorders Substance Use and Mental Health Access Coalition. Gillian Schultz and Lucy Ramirez both serve on the coalition.

To get a handle on the problem, the coalition conducted a nationwide survey of HTC doctors, nurses, social workers, and staff. The results were sobering: 78% of those who had tried to secure placement for their patients at a mental health or substance use residential treatment facility had been denied care. They often came across outdated concepts of what it means for someone to have a bleeding disorder and concern over infusion needles being used for substance use or self-harm.

“We found that it was an issue across the country,” says Kate Reinhalter Bazinsky, MPH, the coalition’s chair and a board member of the New England Hemophilia Association. “We had cases in 16 different states, and we had 28 different individual provider reports of this happening. And often the providers had multiple patients who had been denied care.”

The American Society of Addiction Medicine (ASAM), which sets admission criteria for substance use treatment centers, is expected to release new guidelines in 2023. So, the coalition decided to tackle substance use care first, says Bazinsky, providing its own set of recommendations in hopes of addressing concerns and misinformation over admitting people with bleeding disorders. Because it’s not an accrediting organization, ASAM can’t force facilities to implement the guidelines, but many states incorporate ASAM’s criteria into their regulations, so it’s an important step to get the organization to rethink its policies, Bazinsky says.

“Basically, we defined what medical stability means for a bleeding disorders patient. They are safe within an inpatient facility as long as they have the ability to infuse, they have access to their medications, and there’s somebody to monitor them during the infusion,” Ramirez says. To make sure its proposed recommendations to ASAM passed medical muster, the coalition submitted them to NHF’s Medical and Scientific Advisory Council (MASAC), which drafted a letter to ASAM endorsing the group’s work.

Through the survey, the coalition also learned what worked for providers who were able to get their patients into residential mental health and substance use facilities. The coalition developed these best practices into a resource guide, which providers received in August during NHF’s Annual Bleeding Disorders Conference. “It gives providers a blueprint for what they should say and not say when talking with facilities to maximize their chances of getting residential care for their patients,” Bazinsky says.

In the meantime, if you or your child needs residential mental health or substance use services, don’t give up, Ramirez says. “We have had some patients who have been successful getting treatment for substance use on their own, who made the calls to get into rehab. One adult was even able to bring his infusions to treat himself. So, it can be done,” she says. “But we’re trying to increase those success stories so that all people with bleeding disorders are able to get into treatment when they need it.”

If you or your provider has been denied access to inpatient mental health or substance use care, the Bleeding Disorders Substance Use and Mental Health Action Coalition wants to hear from you. Email bdsumhac@gmail.com, or contact Marla Feinstein, NHF’s senior policy and healthcare analyst (mfeinstein@hemophilia.org or 212-328-3734) or Mark Hobarzck, senior manager for policy and advocacy at the Hemophilia Federation of America (m.hobarzck@hemophiliafed.org or 813-965-2127).

<https://hemaware.org/life/behavioral-care-mental-health-crisis>



NC Advocates Travel to DC

March 8-10, 2023

Washington, DC



It was a quick couple of days as 17 Bleeding Disorders Foundation of North Carolina (BDFNC) members took to Washington, DC to advocate for the bleeding disorders community. The National Hemophilia Foundation's (NHF's) Washington Days is an excellent opportunity for the community to speak with their representatives about issues that are important to them.

This year the two big talking points involved legislation to ban Copay Accumulator Adjusters and maintaining funding for the Hemophilia Treatment Centers (HTCs). Advocates asked members of Congress and their staff to take action against Copay Accumulator Adjustment Programs by supporting HR 830, the Help Ensure Lower Patient Copays Act (HELP Copays Act). The HELP Copays Act is a two-part solution that eliminates barriers to treatment

for some of the most at-risk patients. This legislation would allow additional payments, discounts, and other financial assistance to apply to the cost-sharing requirements of health insurance plans. The annual treatment costs can exceed \$350,000 per year for a person with severe hemophilia. Therefore, people with bleeding disorders hit their health insurance's annual out-of-pocket (OOP) maximum each year, often in January. Many families need financial assistance to pay these OOP costs and receive it from nonprofit organizations or pharmaceutical companies.

An increasing number of private health insurance plans are implementing copay accumulator programs that don't allow copay assistance to count towards a patient's OOP maximum. When copay assistance is not allowed, many patients cannot afford their treatments and stop taking them or reduce the prescribed dosage. This often leads to complications and has unintended consequences (e.g., increased visits to the emergency room, joint bleeds/damage, and missed days from work/school) that harm patients and increase overall costs. The bleeding disorder community believes that plans should be required to count all copays (regardless of who pays) towards a person's OOP maximum.

Advocates also asked that federal funding for HTCs and bleeding disorders research remain the same. This includes funding from three agencies:

- **National Institutes of Health (NIH):** Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
- **Centers for Disease Control and Prevention (CDC):** Funds HTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
- **Health Resources and Services Administration (HRSA):** Provides funding for HTCs to provide multidisciplinary services



not typically covered by insurance, such as PT and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all of their patients.

The comprehensive care the HTCs offer is essential. As more people are being diagnosed with bleeding disorders and patient populations are growing, the HTCs need to have the funding to keep up.

With nine meetings, it was a busy and productive day on Capitol Hill. For anyone who has never been, there is no better time to start advocating for you and your loved ones. Interested in getting involved in advocacy or learning more about this year's talking points? Reach out to Charlene at (919) 319-0014 or email advocates@bleedingdisordersnc.org.



The HELP Copays Act Moves Forward

COPAY ACCUMULATORS HARM PATIENTS

Patients are being harmed by copay accumulator adjustment policies (CAAPs) that bar copay assistance from counting towards a patient's deductible or out-of-pocket maximum. These policies hurt patients who depend on medicines by:

- Exposing Vulnerable Patients to Large, Unexpected Costs**
CAAPs disproportionately impact patients suffering from serious illness, particularly those who are low income or persons of color. These patients rely on copay assistance, but accumulators cut that lifeline and leave patients exposed.
- Interrupting Necessary Treatment**
Nearly all copay assistance is used to pay for medicines without generic alternatives. When more costs are transferred to the sick and vulnerable, those patients often lose access to needed medications—driving down drug adherence and resulting in other more costly health issues. CAAPs create an unnecessary barrier that interrupts the course of critical treatment for patients.
- Undermining Patient Protections**
The Affordable Care Act provided minimum standards for coverage and protections against high out-of-pocket costs, particularly for those with pre-existing health conditions. CAAPs erode these protections and harm patients with serious, chronic health conditions.

Protections for people who rely on copay assistance have been a top priority for the bleeding disorders community and many other patient groups for several years. That effort took a big step forward in April with the introduction of a first-ever Senate version (S. 1375) of the HELP Copays Act.

Sponsored by Sens. Kaine, Marshall, Markey, and Ernst, S. 1375 (identical to its House counterpart, H.R. 830) is bipartisan legislation that would prohibit copay accumulator adjusters. The bill would require health plans to count copay

assistance towards a beneficiary's deductible and out-of-pocket maximum. It would also close the so-called "non-essential health benefits loophole" that health plans and pharmacy benefits managers (PBMs) currently exploit to justify the imposition of copay maximizers. These reforms will help people with bleeding disorders and other costly health conditions to afford their medications and stay on their treatment regimens.

NC is Close to Expanding Medicaid!

Thirteen years (to the day) after the Affordable Care Act was signed into law, the North Carolina General Assembly passed Medicaid Expansion and sent this historic legislation to be signed into law by Governor Roy Cooper. Medicaid expansion will begin in North Carolina after the federal government approves North Carolina's Medicaid expansion plan and a state budget for FY 2023-24 is in place. What an exciting time for North Carolinians! According to the National Hemophilia Foundation (NHF), an estimated 30% of people with a bleeding disorder are enrolled in Medicaid in a typical year. As a safety net program, Medicaid covers some of the most vulnerable members of the bleeding disorders community.



Bleeding Disorders Foundation of North Carolina 2023 Calendar of Events Highlights

May 22, 2023

Educational Dinner - Charlotte, NC

June 3, 2023

Ultra-Rare Bleeding Disorders & von Willebrand Disease Day - Chapel Hill, NC

June 20, 2023

Community Conversations - Virtual

June 24, 2023

Unión Latina Event - Greenville, NC

July 8-9, 2023

Summer Community Retreat - Morehead City, NC

August 10-13, 2023

NC/SC Teen Retreat - Rock Hill, SC

August 17-19, 2023

NHF Bleeding Disorders Conference - Baltimore, MD

August 26, 2023

Welcome to BDFNC - Virtual

September 22-24, 2023

Blood Brotherhood & SOAR Weekend - Pine Knoll Shores, NC

October 14, 2023

Raleigh Festival & Walk - Morrisville, NC

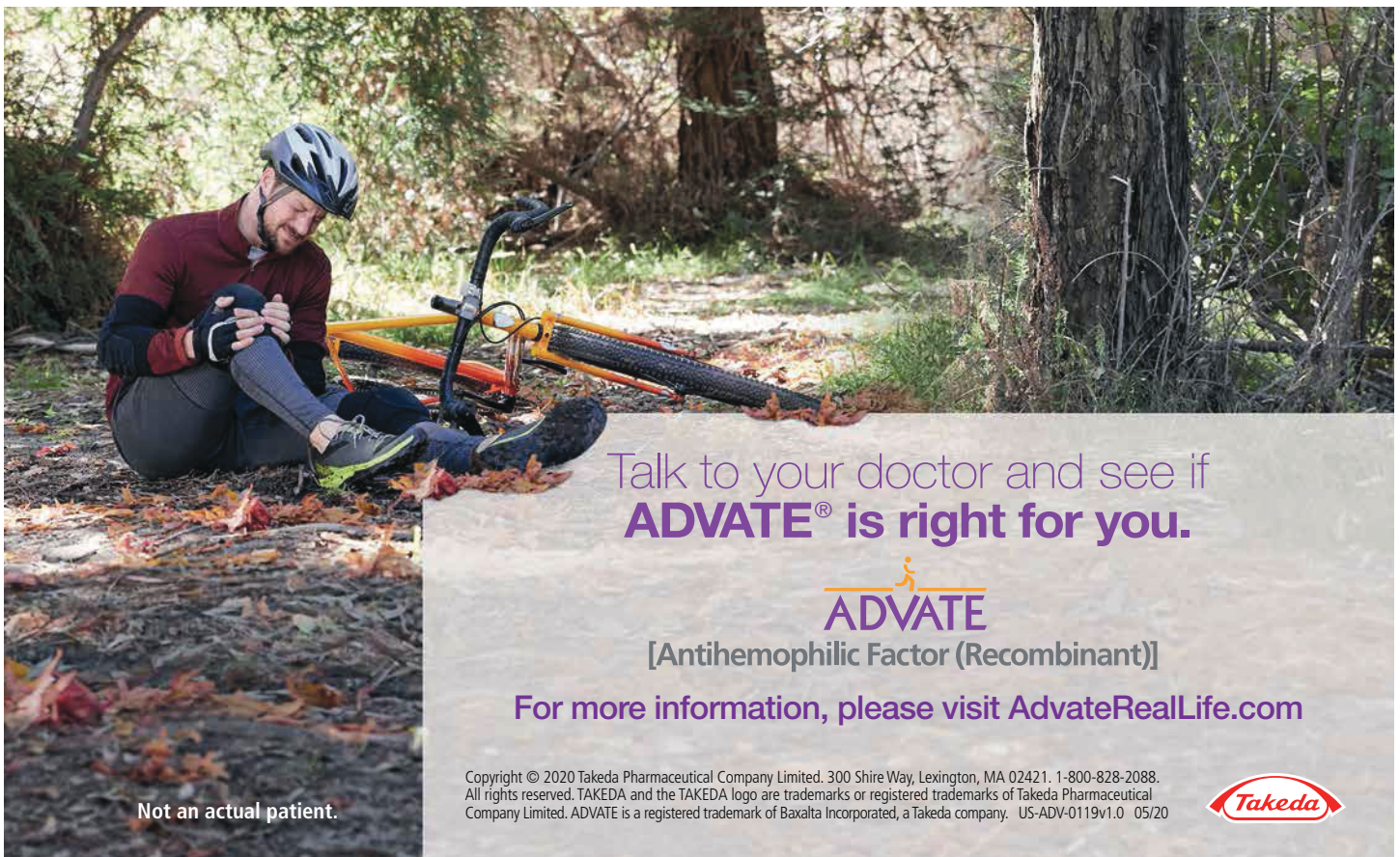
November 4, 2023

HOPE Family Day - Concord, NC

December 2, 2023

Holiday Celebration - Location TBA

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




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Not an actual patient.





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mark your calendars!



RALEIGH

Saturday, October 14, 2023

Lake Crabtree County Park
Morrisville, NC



**Entertainment • Music & Games
Breakfast & Lunch
Photo Booth • Face Painting
Dog Friendly • And More!**



Fun for the entire family!
bleedingdisordersnc.org/festival