

THE C NCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Fall 2023

A National Conference to Remember!

August 17-19, 2023
National Harbor, MD

The National Hemophilia Foundation (NHF) 75th Annual Bleeding Disorders Conference (BDC) was one for the books! After seven decades, NHF leadership announced at the conference that they are changing their name to the National Bleeding Disorders Foundation (NBDF)! In addition to this major announcement, there were plenty of other noteworthy moments. From the educational sessions to the opportunities to connect with others from around the country, attendees gained a lot. Bleeding Disorders Foundation of North Carolina Director of Programs, Gillian Schultz, presented in two different sessions related to her important work in the areas of mental health and substance use for patients with bleeding disorders. See page 23 to hear from NC community members about their experience attending this fabulous national conference!



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Did You Know? Insurance “Family Glitch” Fixed in 2023



While this change took effect at the beginning of 2023, the Bleeding Disorders Foundation of North Carolina (BDFNC) has heard that not everyone was aware of this important adjustment.

Before the fix, if your employer offered “affordable” health coverage, you were not eligible for premium tax subsidies to purchase insurance in the Health Insurance Marketplace (aka ACA or Obamacare). Employer plans are not considered affordable if an employee must contribute more than 9.5% of their income (adjusted for inflation) toward insurance premiums.

Prior to the change in 2023, there was what is known as the “family glitch” due to an Internal Revenue Service (IRS) interpretation of the law. The interpretation based the affordability of a plan on the cost of employee-only coverage, rather than the cost of family coverage. In other words, this interpretation did not consider the additional premium costs for family-based coverage. If the

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Save The Date

**Educational Dinner
– Health Insurance
Roadmap**
November 6, 2023
Virtual

**Educational Dinner –
Gene Therapy**
November 9, 2023
Charlotte, NC

**Teen Empowerment
Event**
November 18, 2023
Raleigh, NC

**Community
Conversations**
November 21, 2023
Virtual

Holiday Celebration
December 2, 2023
Gastonia, NC

March 16-17, 2024
Consumer Medical
Symposium
Charlotte, NC

April 27, 2024
Charlotte Festival & Walk
Charlotte, NC

**Many more events
coming up.**

**BLEEDING
DISORDERS
FOUNDATION**
OF NORTH CAROLINA



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Morrisville, NC 27560
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info@bleedingdisordersnc.org
www.bleedingdisordersnc.org

MISSION STATEMENT

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

Contact Numbers

Bleeding Disorders Foundation of NC

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

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

National Bleeding Disorders Foundation

(888) 463-6643
www.hemophilia.org

About This Publication

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

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

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

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

Hemophilia Treatment Centers

East Carolina University Health Hemophilia Treatment Center

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

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

ADULT:

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

PEDIATRIC:

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

Novant Health Center for Bleeding Disorders

125 Queens Road, Suite 600
Charlotte, NC 28204
Phone: (980) 302-6600

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

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

UNC Hemophilia and Thrombosis Center

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

Wake Forest University School of Medicine

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

Additional Medical Resources

Duke University Medical Center Hemostasis and Thrombosis Center

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

Mission Hospital Pediatric Hematology/ Oncology Program

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

Resource Information

National 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.

LA Kelley Communications

1-978-352-7657

www.kelleycom.com

PAN Foundation

Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.

1-866-316-7263

panfoundation.org

Patient Notification System

The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.

1-888-UPDATE-U

www.patientnotificationsystem.org

World Federation of Hemophilia

1-800-520-6154

www.wfh.org

VISION STATEMENT

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

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



A Tribute to Linda

By: Cheri Clark, BDFNC Community Member



Affectionately known as the lady with the Carolina blue hair, Linda Woodard was UNC-Chapel Hill's biggest fan. Linda studied at UNC, played basketball at UNC, and worked her entire career as a laboratory technologist at UNC Hospital. After retirement, she gave many years of volunteer service to the UNC Hospital Cancer Center. In 2014, when I told Linda my oldest son, Brandon, had just started college at UNC, she insisted on taking him to dinner at the Carolina Club so she could welcome him to the Carolina community. She had never met him before this gracious offer. The dinner and conversation were an experience my son recalls fondly.

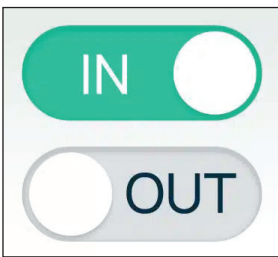
Linda was also a devoted member/volunteer of the Bleeding Disorders Foundation of North Carolina (BDFNC) for over a decade and attended many events throughout the years. Her camera usually accompanied her, and she shared many of her photos along with her journey as an advocate on social media. Linda's smiling face was frequently the first to greet the newest members in the bleeding disorders community, especially the women involved with SOAR. Our designated tutu-making extraordinaire, Linda taught us how to make the colorful tulle creations

that often graced our booth at the Raleigh Walks. She was always passionate about sharing her own story of living with VWD and could offer oodles of advice on aging with a bleeding disorder. To Linda, nobody was a stranger but just a friend she hadn't spoken to yet. She was truly one of a kind.

BDFNC was shocked by Linda's sudden passing on August 4, as her life was unfairly cut short. Her words of wisdom, purple attire and infectious personality will be truly missed by our community. We will take the happiest memories of our times with Linda with us along the way as we advocate for ourselves and others with bleeding disorders, just as she would have done. Sincere condolences go out to friends and family for their great loss.



Opt In to Get Newsletter Mailed to You



Do you enjoy receiving this newsletter delivered directly to your home, or would you prefer reading this newsletter online?

Contact the BDFNC office to OPT IN to home delivery of *The Concentrate* by December 1 if you want to continue to receive your copy of *The Concentrate* delivered by mail to your home address. **Only members who OPT IN to receiving this newsletter by mail before December 1 will continue to receive *The Concentrate* by mail in 2024.** If you don't OPT IN you will receive a link to read the newsletter online through a downloadable version of *The Concentrate* on the BDFNC website.

By informing the Bleeding Disorders Foundation of North Carolina (BDFNC) of your preference, you can help BDFNC conserve valuable resources by providing home delivery only to those who select it.

To OPT IN, please do one of the following:

- Update your membership application on the BDFNC website (www.bleedingdisordersnc.org/membership) and confirm your communication preferences,
- Send an email to info@bleedingdisordersnc.org,
- Text BDFNC at (919) 271-4171 with your name and address,
- Call the BDFNC office at (919) 319-0014.



Did You Know? Insurance “Family Glitch” Fixed in 2023

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coverage was considered affordable for the employee, other family members could not get financial assistance to pay for a marketplace health plan even if the employer’s family-coverage cost was unaffordable.

The new IRS interpretation eliminates the family glitch by basing the affordability test for employee’s family members on the premium cost for family coverage, rather than employee-only coverage. This change allows millions of family members to receive federal financial assistance toward the cost of premiums and deductibles.

Event Attendance Policy

The cost of attending an event should never be a barrier for someone impacted by a bleeding disorder to be able to receive the education and resources that they are looking for. That is why the Bleeding Disorders Foundation of North Carolina (BDFNC) is pleased to offer all events and activities (except fundraisers) FREE OF CHARGE for your participation. While they are free for you to attend, there are significant costs associated with events. Many of these costs have increased significantly since the COVID-19 pandemic. 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. Please know that if BDFNC has to enforce this policy, it is only to make sure that the money that is raised and donated to fund events is being used effectively.

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!

Community Conversations

Third Tuesday of the Month

Are you looking to make meaningful connections in the bleeding disorders community? Then look no further than the Bleeding Disorders Foundation of North Carolina’s (BDFNC) Community Conversations. Held on the third Tuesday of every month at 7:00 PM, Community Conversations brings together adults with bleeding disorders for meaningful conversations about things important to the community. The chats are facilitated by longtime community member Alisha Curtiss. Community Conversations are meant to be FOR YOU, about

topics relevant to you.



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 Community Conversations 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.

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THERAPEUTICS

Understanding Health Insurance

October 17, 2023

Raleigh, NC

November 6, 2023

Virtual

Open enrollment is about to start, so it's the perfect time to get a refresher and ask questions about health insurance. *What are the different insurance options? What insurance plan is best for me? Why might my insurance deny my coverage?* Join the Bleeding Disorders Foundation of North Carolina (BDFNC) at Rey's Restaurant in Raleigh on October 17 or join virtually on November 6 to find out more about health insurance!

Morgan Cook, Takeda Community Education Specialist will lead the presentation, *Health Insurance Roadmap*. This program will provide attendees information about health insurance, including an overview of insurance options, transitions that impact coverage, and insurance denials of coverage.



HOPE Family Day at the Great Wolf Lodge

November 4, 2023

Concord, NC



The Bleeding Disorders Foundation of North Carolina (BDFNC) invites families who have a child 12 or under who is diagnosed with a bleeding disorder to the HOPE Family Day on November 4 at the Great Wolf Lodge in Concord. There will be a fun, hands-on activity about how blood clots, lunch, and a visit to the waterpark.

More information and registration are available on the BDFNC website. Please note that this is a one-day event, and hotel rooms will not be provided.

The HOPE Program is BDFNC's program to support families with children diagnosed with a bleeding disorder.

Dinners Around North Carolina

October 26, November 9

Asheville, Charlotte

The Bleeding Disorders Foundation of North Carolina (BDFNC) will be bringing different educational topics around the state this fall with dinner programs for you to enjoy. In addition to the September 7 program in Greensboro and the October 17 program in Raleigh, BDFNC will also be holding an educational dinner on October 26 in Asheville about health insurance and, on November 9 in Charlotte about gene therapy.

More information about these educational dinners can be found on the BDFNC website.

Ring in the Holidays with BDFNC

December 2, 2023

Gastonia, NC

Celebrate the holidays with the Bleeding Disorders Foundation of North Carolina (BDFNC). Join BDFNC on December 2 at the Gastonia Conference Center for a festive holiday luncheon. There will be crafts and activities for kids and time to reconnect and socialize with your BDFNC family. BDFNC has already been in touch with the North Pole, and Santa is hoping that he isn't too busy to visit

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Ring in the Holidays with BDFNC

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everyone to spread his holiday cheer. The day's presentations will also be simultaneously interpreted into Spanish so language is not a barrier for the Latino community.

Registration for the Holiday Celebration will open in October. For more information, visit the BDFNC website.



Community Conversations

July 18, 2023

Virtual on Zoom

By: Alisha Curtiss

During our last Community Conversations, participants discussed their personal challenges with having a bleeding disorder or supporting others with a bleeding disorder. Challenges were unique to each person and we all gleaned insights from the strength shared. The group openly shared their perspectives and what has helped them conquer barriers.

A Crystal Coast Weekend: Summer Community Retreat

July 7-9, 2023

Morehead City, NC

This past July, the Bleeding Disorders Foundation of North Carolina (BDFNC) held the Summer Community Retreat at the Crystal Coast Civic Center in Morehead City, North Carolina. Located on the Southern Outer Banks, the Civic Center overlooks the Intracoastal Waterway. The Summer Community



Retreat combines the Adult Retreat and Family Retreat, two popular events held in the past, into one event of fun for everyone.

Community members from across North Carolina gathered together for two nights and three days of connection, education, community building, and fun. There were sessions for adults with bleeding disorders and parents of children diagnosed with a bleeding disorder, including sessions called "Spotlight on Siblings" and "Bleeding Disorders in the Workplace." There was an amazing music therapy session led by Tim Ringgold, in which participants learned about self-care through music therapy. Community members also got to visit the North Carolina Aquarium at Pine Knoll Shores and participate in a movie night. Thank you to all of the community members who attended and made this weekend wonderful!

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A Crystal Coast Weekend: Summer Community Retreat

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One community member said, "The best part of the weekend was families opening up and sharing their difficulties, and how they overcame them." Another person said, "It was great seeing that there are other people who are living with a bleeding disorder like me. I no longer feel like I am alone."

BDFNC looks forward to hosting this event again next year!

Carolina Crew Together Again - NC/SC Teen Retreat

August 10-13, 2023

Rock Hill, SC



Teens from the Bleeding Disorders Foundation of North Carolina and the Bleeding Disorders Association of South Carolina united for the NC/SC Teen Retreat at Camp Canaan in Rock Hill, South Carolina for four days this past August. Also known as the "Carolina Crew," teens diagnosed with a bleeding disorder and teens who have a sibling or a parent with a bleeding disorder were able to bring a friend to the Retreat where they learned about each other, independence, and how to overcome barriers of living with a bleeding disorder. Teens were able to choose among activities including a high ropes course or ziplining, and also went kayaking and swimming.



Joe Torrey from GutMonkey led the teens through team-building activities as part of their Leading Edge Program.



The teens had to work together to achieve common goals through games and other exercises.

While many of the teens didn't know each other at the beginning of the Retreat, by Sunday they left with new friendships and connections that will last for years to come!



Blood Brothers Chat

August 15, 2023

Virtual

The Bleeding Disorders Foundation of North Carolina's (BDFNC) first Blood Brothers Chat was held on Zoom on August 15. The meeting was facilitated by Guillermo Sanchez, a Blood Brother from North Carolina. Five men joined the chat and talked about various topics. They also talked about future meetings including more virtual opportunities, cookouts, campfires, and more. Longtime Blood Brotherhood member Reid Coleman said, "It felt really good to see each other and reconnect with old friends, plus make plans for the future."

Save the date for the next Blood Brothers Chat: October 24 on Zoom. You will find more information on the BDFNC website.



Welcome to BDFNC!

August 26, 2023

Virtual on Zoom

Individuals who have been connected with the Bleeding Disorders Foundation of North Carolina (BDFNC) by completing a membership application or getting a Medical ID sent to them may not know all of the programs and services that are available to them. On August 26, Gillian Schultz, Director of Programs, led an overview with new community members about the ways BDFNC can support them. An overview of the organization through an interactive Kahoot! game and a discussion about programs provided a comprehensive overview of BDFNC. The hour-long program ended with a community member who has been part of BDFNC for years sharing the ways that BDFNC has helped her. Everyone who joined the event was sent a BDFNC mug.



Setting Educational Expectations

September 7, 2023

Greensboro, NC

The setting educational expectations dinner in Greensboro was an incredible experience. Attendees learned so much about preparing for back to school and things to consider when having a school aged child with a bleeding disorder. For example, some schools might be hesitant to let students with bleeding disorders participate in gym class, so learning about that and how to navigate those situations was helpful and insightful. Hearing from community members about their experiences with the school systems and the struggles they have faced due to the school not being accommodating about their child's bleeding disorder was very impactful. Community members at the event appreciated getting to learn from fellow members and from Xaviette Pointer-Kincy, a Sanofi CoRE Manager, who led the presentation.

A Weekend for Men and Women Diagnosed with a Bleeding Disorder

September 22-24, 2023

Pine Knoll Shores, NC

The weather had other plans for the Bleeding Disorders Foundation of North Carolina's (BDFNC) Blood Brotherhood & SOAR Weekend in September. Unfortunately, Tropic Storm Ophelia made landfall not far from the event venue and the weekend had to be postponed. While the event is postponed, several men and women signed onto Zoom on Saturday to hear Melissa Geraghty, PsyD present *Bleeding Disorders: The Intersection of Chronic Health and Mental Health*. Stay tuned for an announcement of when the event will be rescheduled.



Unión Latina Event in Charlotte

September 30, 2023

Charlotte, NC

On September 30, nearly 20 community members got together for a Unión Latina event at the Matthews Community Center celebrating Hispanic Heritage Month and learning about health insurance. Kids decorated cookies and made crafts, and everyone enjoyed a delicious lunch. It was also a great opportunity for families to connect with each other.





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Anne Lowish, RN, Territory Manager

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Kathy Robinette, Regional Sales Director

Mobile: (410) 952-9080

Actualizar de la Unión Latina

Por: Guillermo Sanchez

La presencia de familias latinas dentro de la comunidad de desórdenes sanguíneos a lo largo del país, es más fuerte cada día. Los laboratorios, las farmacias especializadas, el personal médico y las organizaciones sin fines de lucro que apoyan a esta comunidad, ofrecen más servicios y oportunidades de aprendizaje en español.

La BDFNC realiza este compromiso a través del Programa de La Unión Latina, con el cual ofrece distintas oportunidades de aprendizaje en español y con un enfoque cultural adecuado. Los participantes del Programa tienen la oportunidad de asistir a reuniones educativas presentadas por especialistas bilingües en distintos temas que van, desde la prevención y tratamiento de sangrados hasta estrategias para actuar durante una emergencia.

Durante las conferencias que ofrece la BDFNC se tienen disponibles los servicios de interpretación simultánea, con los cuales las personas que hablan español aprenden y participan sin la barrera del lenguaje. Como parte del Programa de la Unión Latina, nuestro Staff y voluntarios bilingües brindan apoyo a las familias latinas durante todo el año con el propósito de asegurar su participación en todas las actividades que ofrece la Fundación.

Otras noticias:

¡Queremos celebrarte! ¿Tienes algún cumpleaños para festejar, o aniversario, o algún otro logro? ¿Tú o tu hijo han aprendido a auto-infundirse? Podemos compartir tu logro en nuestras próximas ediciones de The Concéntrate. Mándanos la información al correo electrónico: info@bleedingdisordersnc.org

Evento de Unión Latina en Charlotte

30 de Septiembre de 2023

Charlotte, NC



El 30 de septiembre, unos 20 miembros de la comunidad se reunieron en el Centro Comunitario de Matthews para celebrar el Mes de la Herencia Hispana y aprender sobre seguros de salud. Los niños decoraron galletas e hicieron dibujos, y todos disfrutaron de un delicioso almuerzo.

También fue una gran oportunidad para que las familias se conocieran y relacionarán con otros miembros de la comunidad.



Celebre los días festivos con BDFNC

2 de Diciembre de 2023

Gastonia, NC

Celebre los días festivos con The Bleeding Disorders Foundation of North Carolina (BDFNC). Celebre con BDFNC el 2 de Diciembre en el Centro de Conferencias de Gastonia para un almuerzo festivo. Habrá artesanías y actividades para los niños. También habrá tiempo para conectarse y socializar con su familia de BDFNC. BDFNC ya se ha puesto en contacto con el Polo Norte, y Papá Noel espera no estar demasiado ocupado para visitarnos a todos y contagiarnos con su alegría navideña. Las presentaciones del día también se interpretarán simultáneamente en español para que el idioma no sea una barrera para la comunidad latina.

La inscripción para la Celebración de los días festivos se abrirá en Octubre. Para más información, visite el sitio web del BDFNC.



Menstrual Toolkit from HFA

Tools that track menstruation can be invaluable when having conversations with medical providers about heavy menstrual bleeding. The Hemophilia Federation of America (HFA) has recently launched a new toolkit, designed by women with bleeding disorders, for women with bleeding disorders.

Included in the toolkit are printable and digital tracking tools for women, girls, and people with the potential to menstruate. They can be used by people with bleeding disorders and for those who have not yet been diagnosed to track their bleeding experience during menstruation. There are two ways included to track menstruation: measuring by volume and measuring with pictorial blood assessment charts (PBAC). Each of these tools includes a menstrual tracker guide with instructions on how to use, notes, tips, definitions, and links to other resources, plus a daily log, weekly log, monthly log, and an annual log.

Other tools in the kit include handouts for providers and patients by the Foundation for Women & Girls with Bleeding Disorders, including a *Let's Talk Period* and a *Patient Pain and Bleed Diary* handout; videos; links to podcasts, and other articles.

You can find the Menstrual Toolkit on the HFA website: www.hemophiliafed.org/resource/menstruation-tracking



Raising Awareness about Women and Girls with Bleeding Disorders

Throughout the fall months, the Bleeding Disorders Foundation of North Carolina (BDFNC) participates in several nurse conferences to raise awareness about the signs and symptoms of women and girls with bleeding disorders. According to the CDC, **it takes an average of 16 years from the onset of symptoms for a woman to receive a diagnosis**. There are an estimated 44,000 women and girls in North Carolina who have a bleeding disorder, but most are not diagnosed. Women and girls with undiagnosed bleeding disorders face painful and heavy periods, unnecessary hysterectomies, hemorrhaging after childbirth, and other complications that are preventable. By raising awareness about bleeding

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Raising Awareness about Women and Girls with Bleeding Disorders

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disorders at nurse conferences, BDFNC can help to provide information and resources to those who are often the first to hear about the symptoms of a bleeding disorder in women and girls.

In September, BDFNC exhibited at the North Carolina Nurses Association Annual Convention in Winston-Salem. This large conference brings in hundreds of nurses from various specialties. The exhibit hours are always bustling. BDFNC staff and volunteers provide information about women with bleeding disorders and raise awareness about the frequency of bleeding disorders, especially von Willebrand disease. Every year that BDFNC has exhibited, a nurse has come up to the booth and remarked how either they were diagnosed or a patient of theirs was diagnosed because of the information that BDFNC provided.

In December, BDFNC will be exhibiting at the North Carolina School Nurse Conference in Greensboro. School nurses from around North Carolina attend this conference. BDFNC focuses

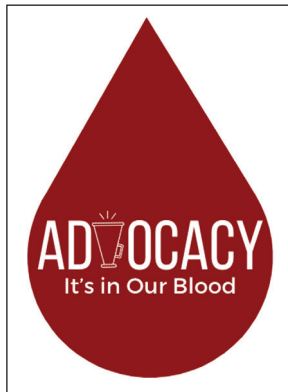
on the signs and symptoms of girls with bleeding disorders, especially once they start menstruating. Alerting school nurses about what they should be looking out for and providing them with resources that can be shared with students' parents can hopefully help a girl with an undiagnosed bleeding disorder receive the treatment and care that they need to improve their quality of life.

In addition to the conferences that BDFNC exhibits at as part of the mission of the SOAR Program, BDFNC also exhibits at the North Carolina Dental Hygienists' Association Conference, the North Carolina Emergency Nurses Association Conference, and the North Carolina EMS EXPO to raise awareness about bleeding disorders.



Advocacy Program Updates

By: Genevieve Skinner, BDFNC Advocacy Director



The Bleeding Disorders Foundation of North Carolina (BDFNC) has been busy with advocacy on several issues that impact the bleeding disorders community.

North Carolina Medicaid Expansion Continues to Be Delayed

Beginning December 1, 2023, more North Carolinians will be able to get health coverage through NC Medicaid. This will be a game changer for the more than 600,000 people who will be able to access health care and is the most significant investment in the health of our state in decades. There is a new website, bilingual toolkit, and a sign-up form to stay updated on the most current information about how more North Carolinians will be able to get health coverage through NC Medicaid. For more information, visit: medicaid.ncdhhs.gov/north-carolina-expands-medicaid

Medicaid Unwinding is Continuing

Medicaid Unwinding is continuing across the country. Over 5.5 million patients have been disenrolled from Medicaid by the end of August. Sixty-eight thousand of those patients were in North Carolina. Eighty-seven percent of disenrollments in the state of North Carolina have been due to procedural reasons. This is avoidable. Please make sure Medicaid has your current contact information and that you are regularly checking that phone, email, or mailbox.

The Fight Against Building a Casino Next to Camp Carefree

Rockingham County commissioners approved the rezoning of the land next to Camp Carefree. This land will be rezoned from residential agricultural to highway commercial. This is step one on the way to a casino being built on that land. The residents of Rockingham

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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 – it connects men with bleeding disorders to share experiences and camaraderie. Whether you are a young adult or have retired, if you are an adult man diagnosed with a bleeding disorder, you are invited to join BDFNC's Blood Brotherhood.

Though many activities and functions were canceled during the worst of the COVID-19 pandemic, BDFNC is open and looking to re-energize the Blood Brotherhood Program! In August, the first BDFNC Blood Brothers Community Chat was held on Zoom. Participants talked about what they would like to see from the Blood Brotherhood Program moving forward. The next Blood Brothers Community Chat will be on October 24 on Zoom.

In addition to virtual opportunities, Blood Brothers would have met during the Blood Brotherhood & SOAR Weekend, that had to be postponed due to Tropical Storm Ophelia. Ideas for other in-person events include fishing or going to a sporting event. Stay tuned to the BDFNC website for dates of other events coming soon.

BDFNC also just created a private Facebook group for men with a bleeding disorder to connect. On Facebook, search for BDFNC Blood Brotherhood or visit: www.facebook.com/groups/958504228600067.

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's) 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*

The needs of parents raising a child with a bleeding disorder have changed over the years. Whatever your experience is, connecting with other families who have a child with a bleeding disorder can make the difference between living with hope or fearing the worst. The Bleeding Disorders Foundation of North Carolina's (BDFNC) HOPE Program provides support for families who have a child diagnosed with a bleeding disorder. Most programs are geared toward families with children 12 and under.

HOPE resources include a "Back to School" toolkit and a mentoring program. BDFNC also has a private Facebook group for families to connect and find support. You can search BDFNC HOPE or visit www.facebook.com/groups/561099897299679. In November, the HOPE Family Day will provide opportunities for families to connect with each other and learn more about clotting and how a bleeding disorder affects their child.

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 Schultz, Director of Programs (and also the mom of a 12-year-old son with hemophilia), at events@bleedingdisordersnc.org or by calling (919) 319-0014.



Unión Latina Program Update

By: Guillermo Sanchez

The presence of Latino families within the bleeding disorders community throughout the country is stronger each day. Laboratories, specialty pharmacies, health providers, and nonprofit organizations that support this community are offering more services and learning opportunities in Spanish.

The Bleeding Disorders Foundation of North Carolina (BDFNC) implements this commitment through the Latin Union Program, which offers different learning opportunities in Spanish and with an appropriate cultural approach. The participants in the Program have the opportunity to attend educational sessions presented by bilingual specialists on different topics, from bleeding prevention and treatment to strategies about how to react during an emergency.

Continued next page



Unión Latina Program Update continued from previous page

Simultaneous interpretation services are available during the conferences offered by BDFNC, providing our Spanish-speaking members the opportunity to learn and participate without the language barrier. As part of the Latin Union Program, our bilingual staff and volunteers provide support to Latino families throughout the year with the purpose of ensuring their participation in all the activities offered by the Foundation.

Soar SOAR Program Update

Connect with other women and girls diagnosed with a bleeding disorder through the Bleeding Disorders Foundation of North Carolina (BDFNC) SOAR Program. Through educational opportunities throughout the year, including the Blood Brotherhood & SOAR Weekend this fall, connections made between women can be vital in helping women and girls receive accurate diagnoses and appropriate treatments. You can also connect with other women on the private BDFNC Facebook Group. Search BDFNC SOAR on Facebook or visit www.facebook.com/groups/ncsoar.

As part of the SOAR Program, BDFNC also plans on exhibiting at several conferences this fall, which you can read more about in the SOAR Supplement on p. 12.

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 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.

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, to request access to the Facebook group or with your personal story at events@bleedingdisordersnc.org.

Teen Empowerment Program



From summer into later this fall are busy times for teens in the bleeding disorders community. From the Teen Retreat that was held in August, to other Teen Empowerment events that are being held later this fall, there are many opportunities for teens to get involved with the Bleeding Disorders Foundation of North Carolina (BDFNC).

What is important for you as a teen? Is it connecting with other teens who have a bleeding disorder? Is it learning about how to prepare for getting a job or going to college? What about helping to plan future teen activities? Let us know how you'd like to get involved!

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.

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

A Program for Spouses, Partners, and Caregivers

While the last few months have been quiet in developing programming and support for spouses, partners, and/or caregivers of someone with a bleeding disorder, please know that the Bleeding Disorders Foundation of North Carolina (BDFNC) continues to think about ways to support you.

Nick Henry, who is the partner of someone with a bleeding disorder, was planning to lead a session at the Blood Brotherhood & SOAR Weekend for partners, spouses, and caregivers. Unfortunately, the event was postponed due to Tropical Storm Ophelia. Stay tuned to when that session will take place. Nick is also helping to develop the program.

BDFNC also encourages you to join a Community Conversations Support Group meeting. Held on the third Tuesday of the month, these informal meetings on Zoom can help to provide you with support and resources.

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

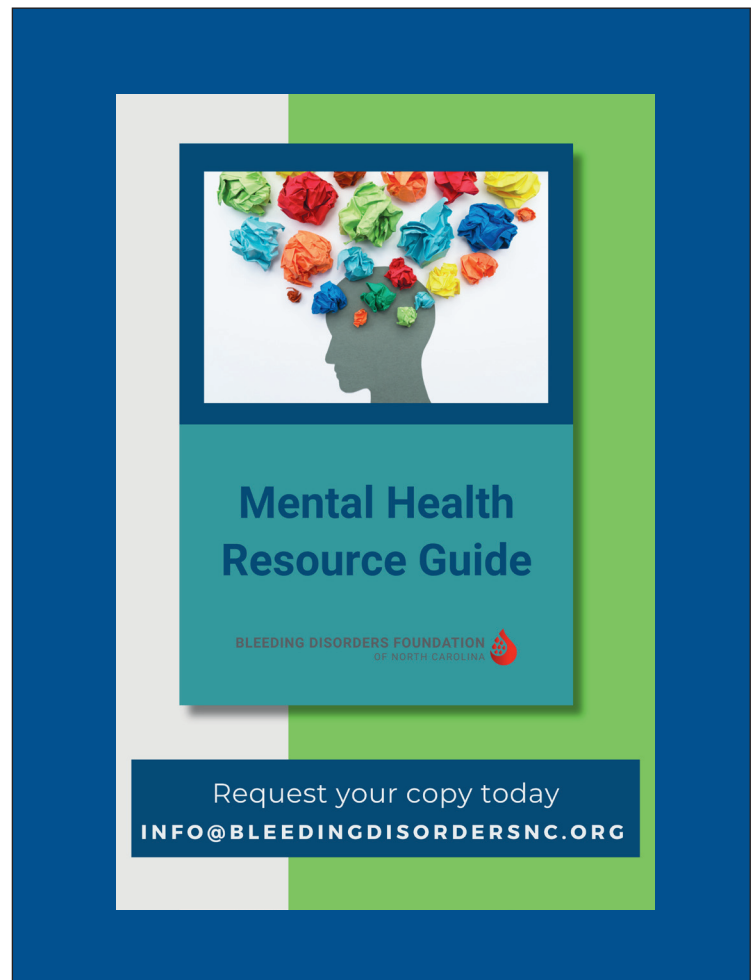
Taking care of your own or someone you love's mental health is equally as important as taking care of a bleeding disorder. Based on the Bleeding Disorders Foundation of North Carolina's (BDFNC) research investigating the prevalence of mental health conditions in the bleeding disorders community as well as published studies, it is known that people with bleeding disorders have higher rates of depression and anxiety than the general public.

You don't have to manage a mental health condition in silence. Help BDFNC normalize the conversation and help end the stigma about mental health by sharing your story. You can share your story (either with or without your name) here: www.surveymonkey.com/r/WRB6GTH.

BDFNC also has resources that can be helpful for you if you are living with a bleeding disorder and a mental health condition. The "Mental Health Resource Guide" provides information about how you can manage a mental health condition. If you would like a copy, please contact BDFNC at info@bleedingdisordersnc.org.

There is also a newly available resource provided by the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), of which BDFNC is a proud supporter. With a mission of removing barriers to inpatient mental health and substance use disorder treatment, BD SUMHAC has put together an "Access Toolkit" for patients, a "Provider Toolkit" for care providers, and other resources. You can find them all on the BD SUMHAC website: www.bdsumhac.org.

To learn more about BDFNC's mental health initiative, BD SUMHAC, or if you'd like to get involved, please contact Gillian at 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 2023. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

Employee Giving Programs (various)

Anonymous
April Lindsey Evans
Brent White

General Donations

Sue & Allen Heafner
James Jarratt
Linda & Allen Kurtz
Dr. Randolph & Mrs. Catherine Lambe
Carrie Regler
Nancy Smoak
Dorice Winston

Facebook Fundraisers

Carol Hill
April Lindsey Evans
Linda & Allen Kurtz

George D McCoy Scholarship Donation

Emily Balance
Charlene Cowell
Facebook Donors
Betty Hansen

In Memory of James Smith

The Cowell Family
Anonymous
Shannon Taylor

In Memory of Kevin Transou

Gary Church
Judy & Michael Haran
Sam Kalat

Wine Tasting Raffle

Lucia Coppola
Kimberly Davenport
Karyn & Kyle Davis
Boyd Furr
Peter Gioia
Ellen Jefferson Kearney
Ann Skinner
Lizzie Weeden

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



FACTOR **UP** with ALTUVIIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range (**over 40%**) for most of the week

ALTUVIIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl



HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).^{*†}

48

HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7

BLEEDS PER YEAR[‡]

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[‡]

In people taking ALTUVIIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

^{*}Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†]159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡]Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIIO, living with hemophilia, and treatment options from your local CoRe.



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INDICATION

ALTUVIIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIIO?

You should not use ALTUVIIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIIO?

You can have an allergic reaction to ALTUVIIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIIO. This can stop ALTUVIIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full [Prescribing Information](#).

sanofi

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MAT-US-2301368-v1.0-03/2023

Rest in Peace, James

James Morrison Smith (74), better known as Jim or Papaw, was born on September 15, 1948 in Little Rock, Arkansas. He lived in foster homes until the age of 11, when he was adopted by his forever parents Valerie & Joseph Smith, who lived in Louisiana. He would gain five siblings: Mathew, Alec, Barbara, Robin, and Marshall, and in Louisiana he would eventually meet his wife Louann. In 1971, after graduation, they left to build a home in North Carolina. This is where they would raise their children; Tracey, Tiffany, James, and Joel.

In life, although his disorder would prevent him from physically participating in sports, it could not stop him from being heavily involved in his communities' recreational sports and all of the sports in which his children would participate. Most of all, he was an avid supporter of the North Carolina State Wolfpack. He was a collector of many things, but most of all, an extensive coin collection, duck decoys, and prints. He also collected classic cars, with his prized car being a 1955 Thunderbird. Although he had left Louisiana, he was still very passionate about eating crawfish. He hosted a two-day cajun style crawfish boil every year on Memorial Day weekend, sometimes amassing a crowd of family and friends that would reach nearly four hundred people.

In work, Jim was a founding partner of HRF Inc., started in 1986, a USlicensed specialty human plasma center that provided rare plasma for research and diagnostic controls to an international market. He served as a member of the board of directors and officer for the company until his retirement. His contributions undoubtedly improved the quality of life of many in the hemophilia community and others with rare blood disorders. He and his wife together created many happy families through their multiple exotic pet stores as well as a grooming and boarding shop.

He passed on June 25 surrounded by his loved ones. His death is attributed to a lifelong battle with hemophilia and a recent diagnosis of cancer. He will be dearly missed by all who knew him.



Has Your Teen Gone Off to College?

If your teen has gone off to college, please have them send their updated contact information so that the Bleeding Disorders Foundation of North Carolina can send them information about upcoming events and news that may be relevant to them!

Also, please have them complete a membership application: www.bleedingdisordersnc.org/membership

Lora Joyner Honored as National Physical Therapist of the Year



Lora Joyner, Physical Therapist (PT) and Hemophilia Treatment Center Coordinator for East Carolina University, was honored at the National Bleeding Disorders Foundation conference as the 2023 PT of the Year. Lora's impact on colleagues within the medical community, the bleeding disorders community, patients, and families is evident through heartfelt nominations submitted on her behalf from those she has worked with throughout the years. Congratulations on a well-deserved award, Lora!

"It is an honor to be recognized for my life's work as a Physical Therapist in the Bleeding Disorder community by fellow therapists, health care professionals, patients, families, and HTC colleagues. As I near retirement

from a full-time career in a Hemophilia Treatment Center, I will look back on this achievement with a mix of pride and humility. I am grateful that my name will be associated with Donna Boone and previous award winners and recognized as a role model and mentor for current and future healthcare professionals in the Bleeding Disorder community." - Lora Joyner

2023 George D. McCoy Education Scholarship & Optum® Infusion Pharmacy Education Scholarships Winners



Pavri Porus
Allendale, NJ



Alexanderia Shaw
St. Louis, MO

2023 Optum® Infusion Pharmacy Education Scholarships Winners



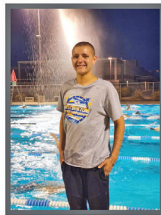
Peyton Brush
Southlake, TX



Luc Chapall
Sewel, NJ



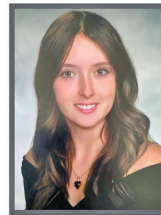
Jaden Cook
Kernersville, NC



James Cosman
Fallon, NV



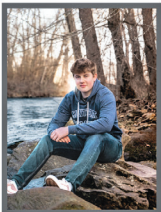
Jack Davis
San Antonio, TX



Jocelyn Doerr
Blandon, PA



Karissa Doerr
Blandon, PA



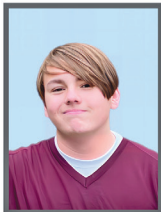
Matthew Fowler
Murphy, NC



Kayla Gregory
Danville, CA



Garrett Hayes
Plano, TX



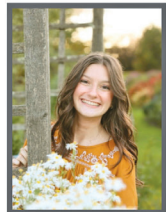
James Hensley
Frederick, MD



Ryan Holland
Hudsonville, MI



Anaya Johnson
Kissimmee, FL



Mikaela Kottelich
Irwin, PA



Paul Lewis
Marshallberg, NC



Elias Linn
Goodyear, AZ



Catherine Lyons
Higginum, CT



Ashlyn McGarry
Averill Park, NY



Kandhan Nadarajah
Brighton, MI



Zachary Oatley
North Canton, OH



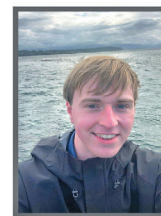
Benjamin Pethe
Metairie, LA



Olivia Reilly
Northglenn, CO



Davis Routh
Hartselle, AL



John Waters
Pensacola, FL



Ella Wood
Cuba City, WI

Not Pictured:

Anonymous
Longwood, FL

Anonymous
Landrum, SC

For more information regarding Education Scholarships, visit bleedingdisordersnc.org/resources/educational-scholarships

Advocacy Program Updates *continued from page 14*

County and people concerned about Camp Carefree encouraged commissioners to vote 'no' on this rezoning. A casino would bring noise, pollution, traffic, and change what is an otherwise quiet and safe community. It would change the peaceful atmosphere that is important to the campers and families at Camp Carefree (a camp that provides a free week of camp for children with chronic illness and disabilities). The next step of this process is for the NC legislature to allow the construction of casinos on non-tribal lands. BDFNC is reaching out to Senator Phil Berger to express concern about how these casinos could affect Camp Carefree.

Helping Patients Avoid Step Therapy

In 2020 the North Carolina Legislature successfully passed a bill that required insurers to provide patients and providers with access to a step therapy exemption. This was very important to many disease communities because step therapy is a process that requires a patient to try and fail on a lower-cost medication before they can "step up" to the treatment prescribed by their physician. Unfortunately, patients continue to be told to follow step therapy protocols, despite the law. BDFNC is reaching out to the insurance commissioner and healthcare providers to help educate the community and tell patients that there are now ways to avoid having to go through step therapy protocols.

You Can Get Involved in Advocacy

If you are passionate about any of these issues or interested in getting involved in advocacy with BDFNC, there are many ways to do so! If you want to get advocacy updates or join our monthly advocacy call, please email advocacy@bleedingdisordersnc.org. Save the date for Washington Days with the National Bleeding Disorders Foundation (NBDF), formerly National Hemophilia Foundation (NHF), from March 6-8, 2024. Keep an eye out for the date announcement of BDFNC's 2024 State Advocacy Days in Raleigh.



National Hemophilia Foundation Has a New Name

Reprinted from the National Bleeding Disorders Foundation



NATIONAL
**BLEEDING
DISORDERS**
FOUNDATION

In 1948, the foundation got its start as simply "The Hemophilia Foundation" – then in 1956, the foundation formally incorporated into what is known today as – the National Hemophilia Foundation. Even then, it was important to capture the organization's expanding footprint across the U.S.

Now, in 2023, the time for change has come again.

Because of our longstanding name, the National Hemophilia Foundation is best known for helping people with hemophilia and also for serving the individuals and professionals who care for that community.

However, in the foundation's many decades, we have also long served those facing other blood and bleeding disorders such as von Willebrand disease, rare factor deficiencies, platelet disorders, and more. Over the past 75 years, our powerful combination of research, education, and advocacy has improved the lives of people and

families with a range of conditions – yet our name and image has not reflected that.

Now, as the National Bleeding Disorders Foundation (NBDF), we can be more inclusive of everyone we serve. Although hemophilia remains a major focus, our name ensures that all people with VWD and rare and ultra-rare deficiencies know that they can find a home within NBDF.

Although we're adopting a new name and a new look, our work will not change in the short term. We remain dedicated to supporting our network of over 50 chapters across the country and channeling funds into blood and bleeding disorders research. And we will continue to educate and support families with these disorders as we work tirelessly to protect access to health care on the state and local level.

Over the long term, our new name will challenge us to explore how we can harness our resources and networks to help people facing other blood and bleeding disorders – because after all, bleeding disorders are blood disorders. In the same way that the National Hemophilia Foundation evolved to help people facing blood and bleeding disorders beside hemophilia, we can evolve once again to assist more families in need. Many rare blood and bleeding disorders don't have a national support and advocacy network like ours — and together, we have a historic opportunity to change that.

As the National Bleeding Disorders Foundation, we will use our longtime legacy to inspire a future where even more people have access to the treatments and support they need to thrive. We will remain true to our core vision while raising awareness, expanding reach, and continuing to build upon 75 years of history, hope, and progress.

More information and FAQ can be found here: www.hemophilia.org/who-we-are/our-story/the-national-hemophilia-foundation-has-a-new-name



A National Conference to Remember!

continued from page 1



"The Bleeding Disorder Conference is exciting because you network with people from different states and hear their stories. You also gain a wealth of knowledge, resources and support from people that can empathize with your specific needs and situations."

Vicky

"I believe everyone in the bleeding community should attend the National meetings if they can because there is so much information to get about the bleeding community. Each year there is always new information and everybody has something different to tell. It's amazing to see the bleeding community come together as one."

Betty



"My name is Carol Hill and I am a volunteer and member, and I cared for my mother Lillian Elaine Jones who had an acquired bleeding disorder, factor VIII deficiency. I would like to tell you all since my mom and I were introduced to our new family, things have been extraordinarily positive. We both gained a wealth of education about her condition and many others. Since her passing I continue to learn from this community to be empowered as I grow in strength with advocacy. This National conference really let me know that it truly is making a change to include every bleeding disorder. There was a class related to my mom's acquired hemophilia condition, and I was so happy to see this topic added. And so many other topics, 45-50 sessions a day, a wealth of information, and I am so blessed our BDFNC blessed me to come and have not just the hotel accommodations, but also meet new people and friends. I hope to continue to raise awareness for years to come."

Carol



"What a wonderful experience at the BDC 2023!!! It was so nice meeting and seeing members of the bleeding disorder community from North Carolina and across the country. It was wonderful to share life experiences and create friendships with other families, healthcare providers, industry partners, and chapter leaders. My biggest takeaway was how impactful all the sessions were. I was able to choose from dozens of education sessions on a host of topics over a couple of days. This is my fourth BDC, and I continue to learn so much! The best part is that the sessions are equally educational and emotional with all the testimonials. If you have never been or have not attended a BDC in a while, please go in 2024! Our community is stronger when we are all together!"

Ryan



"We are very happy for the opportunity to attend the #BDC23 where we listened to knowledgeable speakers addressing different topics, from genetic treatments to strategies to become better advocates for our community. My wife had a reflective time sharing with other caregivers, getting tips about how to keep good mental and physical health while giving support to a family member to better overcome bleeding episodes and treatments. As a person with a bleeding disorder, I had the opportunity to share and learn from other people impacted by different types of bleeding disorders to better cope and juggle with our health and the day-to-day life challenges. My daughters were fascinated with how big and caring is the bleeding disorder community. My family came home with a new set of tools and knowledge to empower others community members to achieve and maintain a better quality of life."

Guillermo



**BLEEDING
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So we can better serve you, tell us about

- ***your bleeding disorder (BD)***
- ***other members of your family with a BD***
- ***what kinds of programs interest you***
- ***what kinds of services you need***
- ***how we can best communicate with you***

**FREE
MEMBERSHIP**



Let us hear from you!
bleedingdisordersnc.org/membership

