

THE NCENTRATE

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA'S OFFICIAL NEWSLETTER

Winter 2022

Who's Who in the Bleeding Disorders Community

Whether you are new to the bleeding disorders community or have been part of the community for years, it can be difficult to keep track of all the organizations and companies that you may encounter. The information below will help you to better understand who everyone is.

Nonprofit Organizations

As nonprofit organizations, the groups below help patients and their families affected by a bleeding disorder by providing education, support programs, resources, and advocacy for the special healthcare needs of the bleeding disorders community.

Bleeding Disorders Foundation of North Carolina (BDFNC)

BDFNC is the only nonprofit organization in North Carolina that serves individuals impacted by a bleeding disorder. Anyone can become a member, and membership is free for all. BDFNC has special programs for men with a bleeding disorder, women with a bleeding disorder, families affected by a bleeding disorder, teens affected by a

Continued page 4



Anita Smith Retires After 39 Years



For nearly four decades, Anita Smith, CPNP, has been a welcoming face at the Wake Forest Baptist Hemophilia Treatment Center (WFU HTC). After a long and wonderful career as a nurse, Anita is retiring at the end of 2022. Anita plans to spend more time with her family and also remain involved with her bleeding disorders family as a supporter and volunteer.

It's impossible to describe what Anita's contributions have meant to the bleeding disorders community. She has been committed way beyond

what would be expected from a job, working countless hours to make sure that her patients had the best care possible. In typical Anita fashion, she has gone above and beyond in serving the bleeding disorders community through her volunteerism at Victory Junction. Anita is a founding committee member of

Continued page 9

In this Edition:

UPCOMING EVENTS	Page 5
RECENT EVENTS	Page 7
SUPLEMENTO DE LA UNIÓN LATINA	Page 11
SOAR SUPPLEMENT	Page 12

Save The Date

Community Conversations
February 21, 2023
Virtual

Welcome to BDFNC!
February 25, 2023
Virtual

Consumer Medical Symposium
March 4-5, 2023
Raleigh, NC

Charlotte Festival & Walk
April 22, 2023
Charlotte, NC

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

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

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

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

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

BLEEDING DISORDERS FOUNDATION
OF NORTH CAROLINA



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Morrisville, NC 27560
(919) 319-0014
info@bleedingdisordersnc.org
www.bleedingdisordersnc.org

MISSION STATEMENT

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

Contact Numbers

Bleeding Disorders Foundation of NC

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

National Hemophilia Foundation

(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

Community Health Charities

(919) 554-3272
www.healthcharities.org

About This Publication

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

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

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

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

Hemophilia Treatment Centers

East Carolina University 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.





Looking Forward to 2023

It's hard to believe that I'm writing this article; it feels like only a few months ago I was writing a recap from 2021. Time flies when you're having fun! Speaking of fun, we've been so fortunate to host dozens of events this year, many of them back in person. We've learned how to run hybrid events so we can offer virtual options, including a virtual audience and speakers. We were able to finally meet community members whom we had only seen via computer. I think this re-introduction to in person and hybrid events has had a positive impact on everyone's mental health; I know it has for me.

As we look forward to 2023, the Bleeding Disorders Foundation of North Carolina (BDFNC) remains committed to our mission of serving the bleeding disorders community across North Carolina. That said, we are all ears if there are ways we can better serve you. Some of our 2023 plans, aside from the many programs and services we offer, include:

- Growing our staff and board of directors strategically to meet the current and future needs of the community.
- Building upon our advocacy program and efforts.
- Conducting mini "needs assessments" geared toward getting your thoughts on how BDFNC can best support you.
- And much more!

Warm wishes,
Charlene



Who's Who in the Bleeding Disorders Community continued from page 1

bleeding disorder, and Spanish speakers. It also provides dozens of free educational and supportive events throughout the year and across the state, resources, financial assistance programs, scholarships, and advocacy.

Hemophilia Federation of America (HFA)

HFA is a national community-based advocacy organization that serves all people living with bleeding disorders and their families across the United States. Each year, it hosts a symposium that brings together bleeding disorders community members from across the country.

National Hemophilia Foundation (NHF)

NHF is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing complications of these disorders through education, advocacy, and research. NHF events include the Bleeding Disorders Conference and Washington Days.

Hemophilia Treatment Centers

Hemophilia Treatment Centers (HTCs) are **medical facilities** that provide specialized, comprehensive care for those affected by bleeding and clotting disorders. North Carolina is lucky enough to have five HTCs across the state: Atrium Health Wake Forest Baptist in Winston-Salem, East Carolina University Health Hemophilia Treatment Center in Greenville, Harold R. Roberts Comprehensive Hemophilia Diagnostic and Treatment Center in Chapel Hill, Hemophilia Treatment Center of Levine Cancer Institute and Levine Children's in Charlotte, and St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital and Adult HTC in Charlotte.

HTCs provide you with medical care. They provide treatment for your bleeding disorder and prescribe the appropriate medications and interventions needed for your condition.

Pharmaceutical Companies

Pharmaceutical companies make medications/treatment products for bleeding disorders. They do not sell directly to patients. Many of the pharmaceutical companies that produce treatments for bleeding disorders support nonprofit organizations by making donations or sponsoring educational events. Company representatives may attend these events to provide you with education about their products; however, it is between you and your medical provider to determine the best product for your situation.

BDFNC does not endorse any pharmaceutical products or services.

Specialty Pharmacies (also called Home Care Companies)

Specialty pharmacies sell medication and supplies to patients with bleeding disorders. Unlike the corner pharmacy, specialty pharmacies carry specialty medications, like clotting factor. Many of these companies may provide additional services including home nursing and infusion services. Specialty pharmacies **do not** prescribe medications or provide medical advice. Some of the specialty pharmacies support nonprofit organizations by making donations or sponsoring educational events. Company representatives may attend these events to provide you with education about their services; however, it is between you, your medical provider, and often your insurance company to determine which specialty pharmacy you can use.

BDFNC does not endorse any specialty pharmacy.

Other Organizations

In addition to the nonprofit organizations, pharmaceutical companies, and specialty pharmacies listed above, there are a variety of other nonprofit and for profit organizations that provide services to the bleeding disorders community. You can learn about all of these companies and more by visiting the BDFNC website at bleedingdisordersnc.org/the-who-what-guide.

Please note that no organization should be contacting you without your express written permission. When you attend a BDFNC event that is sponsored by pharmaceutical companies and/or specialty pharmacies, you may be asked to fill out a "Company Request for Information Form" by the company representative in attendance during scheduled exhibit times. Completion of this form is optional. If you do complete the form, they will follow up with you. If you are being solicited by a company and have not given them permission to communicate with you, please contact the BDFNC office at (919) 319-0014 or at info@bleedingdisordersnc.org.

While it can be very confusing to keep track of who is who, all of the different organizations and companies exist to help you successfully navigate living with a bleeding disorder.

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 that you must agree to every time you register for an event. When deciding whether to register, carefully consider the audience the event is geared towards and how far the event is from where you live.

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 does expect that you will attend. However, sometimes things come up, and if you are unable to attend for any reason, please contact BDFNC. As a community affected by unpredictable bleeds, BDFNC understands that changes may happen at the last minute. With the ongoing COVID-19 pandemic and spread of other illnesses, if someone in your party gets sick, please stay home and let BDFNC know that you will not be attending. Bleeds, unexpected illnesses, or other emergencies are understandable reasons to cancel, and your ability to register for future events will not be put in jeopardy as long as you let BDFNC know that you cannot attend before the event happens. However, BDFNC will begin placing registrants on a waiting list and possibly charging a hotel deposit (if applicable) if you 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!

Is your Primary Language Spanish? Save the Date for the Next Unión Latina Event

January 14, 2023
 Morrisville, NC

If your primary language is Spanish, we hope that you will join the Bleeding Disorders Foundation of North Carolina (BDFNC) for the upcoming Unión Latina event on January 14 at the BDFNC office in Morrisville. Learn about the importance of being prepared with the program *Expect the Unexpected: Prepare for Anything*. More information and registration is available on the BDFNC website.



Charlotte Festival & Walk Back this Spring

April 22, 2023
 Charlotte, NC



Save the date for the 2023 Bleeding Disorders Foundation of North Carolina (BDFNC) Family Festival & Walk in Charlotte! On April 22, BDFNC will be setting up on the streets in Uptown Charlotte for a block party that brings together the bleeding disorders community. As part of BDFNC's largest fundraiser, YOUR help is needed to make it a success. Start thinking about your Walk team and how you will fundraise for the 2023 event. There are some exciting changes coming this year, so stay tuned in early January for the official kick-off announcement!

BDFNC is seeking people to serve on the Charlotte Walk Committee. If you have experience with event planning, fundraising, or just a desire to help, please contact Gillian Schultz, Director of Programs, at g.schultz@bleedingdisordersnc.org.



Largest Educational Event Year: Consumer Medical Symposium

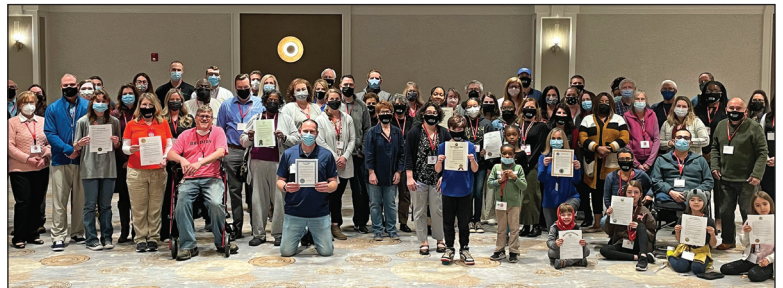
March 4-5, 2023

Raleigh, NC



Save the date for the Bleeding Disorders Foundation of North Carolina's (BDFNC) largest and most attended educational event of the year. The Consumer Medical Symposium will be held March 4-5 at the Hilton Raleigh North Hills. This year's event, "The Future Is Here," will address questions about gene therapy and other up-and-coming treatments for bleeding disorders, as well as the ongoing need to advocate for access to healthcare in the bleeding disorders community. There will also be sessions for ultra-rare bleeding disorders, VWD, specific programs for men and women with a bleeding disorder, and a children's and teen track. Additionally, there will be social activities and lots of time to network.

As in past years, BDFNC will offer a hotel room for anyone who needs one on Saturday night, and all meals on Saturday and Sunday are included at no charge. More information will be available soon on the BDFNC website.



Ultra-Rare and von Willebrand Disease Education Day

June 3, 2023

Chapel Hill, NC

Save the date for the Ultra-Rare Bleeding Disorders and von Willebrand Disease Education Day! Following a successful inaugural event in 2022, the Bleeding Disorders Foundation of North Carolina is looking forward to growing the event for 2023. More information will be announced this spring.



Teens Grow Together: NC/SC Teen Retreat

August 10-13, 2023

Rock Hill, SC

The highly anticipated Teen Retreat will be returning to Camp Canaan in Rock Hill, SC August 10-13, 2023. This four-day event brings together teens from North Carolina and South Carolina for an amazing weekend of fun, learning, and connection! Open to ALL teens in the bleeding disorders community, including those diagnosed with a bleeding disorder, as well as siblings and children of someone with a bleeding disorder. More information will be available this spring.



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 next fall. The event will be aimed at families who have a child with a bleeding disorder. More information will be announced in the summer.



Community Conversations

November 15, 2022

Virtual

By: Alisha Curtiss, Community Conversations Volunteer Leader

I have been honored to be a part of this growing group where we focus on topics related to our strong and resilient community. The group shares ideas for topics related to our accomplishments and opportunities to share experiences to support each other through our continued growth.

In the November Community Conversation, we discussed the long-term effects of bleeds, including cranial bleeds and joint bleeds. Some of the long-term concerns could include, but are not limited to, memory loss, joint deterioration, limited mobility, and other comorbidities such as dementia. The group shared their experiences and concerns about this topic and steps taken to mitigate the long-term effects. Our consensus is thankfulness for the expansion of available options and continued focus on research and development.

Going Wild at Family Day

October 9, 2022

Asheboro, NC

Families went wild at the Bleeding Disorders Foundation of North Carolina's Family Day at the North Carolina Zoo! It was a perfect fall day to enjoy the outdoors and visit with the animals. Kids played games and made Halloween crafts while adults were able to chat and catch up with each other. After lunch, there was a special visit from the zookeepers who brought animals for the kids to learn about, including a turtle and snake. After the program was done, everyone went off to enjoy the zoo. It was so nice to see everyone together again after being apart for the past few years.



Blood Brotherhood & SOAR Weekend

September 17-18, 2022
Greensboro, NC

The Blood Brotherhood & SOAR Weekend was the perfect way to spend some time this fall. It was the first time the Bleeding Disorders Foundation of North Carolina (BDFNC) combined a men's and women's event into one weekend, which turned out to be very successful. Over two days, individuals with bleeding disorders learned and connected about their condition. Men heard from Jennifer Newman about the benefits of kinesio taping to support their joints. Jim Munn Zoomed in from Michigan to present Novel Therapies, discussing treatment options that are in development for bleeding disorders. Lora Joyner Zoomed in from Greenville to discuss aging and bleeding disorders. Women heard from Sarah O'Brien, who Zoomed in from Ohio about reproductive health and bleeding disorders. Shonda J. shared her story about her involvement with the bleeding disorders community, and how it led to her eventual diagnosis of hemophilia. Everyone came together for a program about financial wellness and how to become "financially well" in life. Finally, Gillian Schultz shared for the first time the results of BDFNC's Mental Health Survey and the next steps BDFNC will be taking to address mental health in the North Carolina bleeding disorders community. It wasn't all education. On Saturday night, many attendees worked together to escape at the Breakout Games! It was a lot of fun for everyone involved.



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Anita Smith Retires After 39 Years

continued from page 1



the NC Advisory Board for Bleeding Disorders. She's also the team captain of the Wake Walkers team, which has raised thousands of dollars for the bleeding disorders community.

Anita has watched as infants have become adults caring for their own families. She's been a part of the evolution of treatment options, seeing how progress has made longer and healthier lives possible for the bleeding disorders community. Simply put, Anita has been a rock for the NC bleeding disorders community. While she will be sorely missed, there is no doubt that Anita has made this community better through her love, dedication, and care.

Raleigh Family Festival & Walk for Bleeding Disorders

October 22, 2022
Morrisville, NC

It was a beautiful day for a walk at the 14th Raleigh Family Festival & Walk for Bleeding Disorders. The sun was shining over Lake Crabtree as the bleeding disorders community gathered for a day to celebrate the community, raise awareness, and walk to raise money for the Bleeding Disorders Foundation of North Carolina (BDFNC). Almost \$100,000 was raised to support people affected by bleeding disorders in North Carolina.

In addition to enjoying the beauty of Lake Crabtree Park, attendees had lots to entertain them, including an out-of-this-world jump rope performance by the Bouncing Bulldogs, face painting, an inflatable slide, cotton candy, music, basketball, games, crafts, ice cream from Marble Slab Creamery, caricature drawings, a photo booth, coffee from Caribou Coffee, and lunch from Sheetz.

Congratulations to the award winners:

- **Top Fundraising Team:** Clot Hoppers
- **Top Individual Fundraisers:** Charles & Kathy Register
- **Hospital Cup:** UNC Tarhealers
- **King Droplet:** Kevin Otey
- **Queen Droplet:** Cayton Elderdice
- **Junior Droplet:** Hayden Otey

Save the date for the 2023 Family Festival & Walks: April 22, 2023, in Charlotte and October 14, 2023, in Morrisville.



Latin Union at Pullen Park

October 29, 2022
Raleigh, NC

By: Guillermo Sanchez, Unión Latina Coordinator

Members of the Unión Latina held an interesting and emotional meeting at Pullen Park in Raleigh. Families had the opportunity to share their stories about how they gained knowledge about the bleeding disorder that has impacted their families. They talked about how the whole family has to learn about bleeding prevention and treatment management. Some of the bleeding disorders discussed were related to low or absent platelets and factor VIII. Although the event concluded on October 29, the conversation did not end that day. We will wait for the next meeting to continue learning from the stories that each family has to share.



SOAR Luncheon

October 16, 2022

Charlotte, NC and Virtual

Several women and teen girls got together for a hybrid SOAR Luncheon on October 16 to learn more about menstruation, presented by Chelsea Rivenbark from the ECU HTC. She shared causes of heavy bleeding as well as treatment options. The information presented was very comprehensive, with a lot of valuable information, and the women had a number of excellent questions.



Blood Brothers Enjoy a Night Out

November 5, 2022

Charlotte, NC



The Bleeding Disorders Foundation of North Carolina welcomed several men with a bleeding disorder for a Blood Brotherhood event at a Charlotte Checkers hockey game. While the Checkers ended up losing, it wasn't a losing night for the guys to get together and enjoy fellowship at a hockey game. The men are looking forward to more Blood Brotherhood events in 2023.



HTCs Meet with the Region

November 6-8, 2022

Atlanta, GA

North Carolina was well represented at the Southeast Region Hemophilia Network Training meeting for Hemophilia Treatment Centers (HTC). The photo doesn't even account for everyone who was there from North Carolina. North Carolina is fortunate to have fantastic hematology treatment centers across the state, and this conference is always an excellent opportunity to bring them together with other HTCs in the Southeast Region.

The Southeast Region Bleeding Disorders Program is a network of twenty-two federally funded HTCs that serve patients in Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee. In addition to the HTCs, nonprofits serving the bleeding disorders community, like the Bleeding Disorders Foundation of North Carolina (BDFNC), were also in attendance.

There was great information presented at the conference, from different types of bleeding disorders to current and future therapies. Four presentations were from North Carolinians, including a presentation led by Charlene Cowell, Executive Director of BDFNC. "Mental Health: Breaking Down Barriers" provided an overview of the results of the extensive mental health survey that BDFNC administered earlier in the year.



Unión Latina en Pullen Park

29 de octubre, 2022

Raleigh, NC

La Unión Latina realizó una reunión muy interesante y emotiva. Las familias tuvieron la oportunidad de compartir sus historias sobre cómo adquirieron los conocimientos sobre el trastorno hemorrágico que ha impactado a sus familias. Hablaron sobre cómo la familia completa tiene que aprender sobre la prevención de hemorragias y la administración del tratamiento. Algunos de los trastornos hemorrágicos sobre los que se hablaron están relacionados a la deficiencia o ausencia de plaquetas y el Factor VIII. La conversación no terminó ese día, así que esperamos la próxima reunión para seguir aprendiendo de las historias que cada familia tiene para compartir.



¿El español es su idioma principal? Reserve el próximo evento de la Unión Latina en su agenda

14 de enero de 2023

Morrisville, NC

Si su idioma principal es el español, esperamos que se una a la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) para el próximo evento de la Unión Latina el 14 de enero en la oficina de BDFNC en Morrisville. Conozca la importancia de estar preparado con el programa *Esperar lo inesperado: prepararse para todo*. Más información y el registro estarán disponibles en el sitio web de BDFNC.

Actualización del Programa Unión Latina

Es importante que las personas que viven con un trastorno hemorrágico se comuniquen con otras personas que también padecen de un trastorno hemorrágico. Cuando su idioma principal es el español, la importancia de este aumenta ya que es importante no solo encontrar personas que entiendan su condición de salud, sino también su cultura e idioma. El Programa Unión Latina de la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) brinda oportunidades para involucrarse y participar en actividades diferentes para que usted y su familia puedan informarse y aprender sobre los trastornos hemorrágicos, así como para brindar recursos para que puedan recibir tratamiento médico.

La Unión Latina está dirigida por el coordinador de voluntarios y miembro de la comunidad, Guillermo Sánchez, quien siempre está dispuesto a comunicarse con usted y hablar sobre sus experiencias. BDFNC espera que la Unión Latina crezca a lo largo de 2023. Si desea obtener más información o participar, comuníquese con Gillian Schultz, Directora de Programas en events@bleedingdisordersnc.org.

Vuelven las celebraciones navideñas

3 de diciembre de 2022

Greenville, NC

Después de posponer la Celebración Navideña presencial en Greenville dos veces debido al COVID-19, la Fundación de Trastornos Hemorrágicos de Carolina del Norte (BDFNC) finalmente pudo reunir a la comunidad para celebrar las fiestas. En asociación con el Centro de Tratamiento de Hemofilia ECU, cerca de 100 personas asistieron a la Celebración Navideña en el Hilton Greenville. Hubo almuerzo, juegos, manualidades con temas navideños, pintura facial, una presentación especial y un visitante del Polo Norte. La gente del Centro de Tratamiento de Hemofilia ECU preparó una presentación muy creativa: *Trastornos hemorrágicos: Pasado, Presente y Futuro*, se analizó cómo han evolucionado los tratamientos para los trastornos hemorrágicos a lo largo de los años y lo que se avecina. La presentación se hizo al estilo del clásico *Cuento de Navidad* de Charles Dickens, con el personal de ECU actuando como personajes de la historia, incluidos Ebenezer Scrooge, Jacob Marley y los Fantasmas de las Navidades Pasadas, Presentes y Futuras.

Después de la presentación y el almuerzo, Santa se tomó un tiempo de su apretada agenda navideña para visitar BDFNC y todos los niños se fueron con un regalo. A lo largo del día, la gente habló de lo maravilloso que era volver a estar juntos.



BDFNC Raises Awareness about Bleeding Disorders Across the State

September 30-October 1, 2022, Asheville, NC

November 3-4, 2022, Asheville, NC

December 8-9, 2022, Greensboro, NC

One way that the Bleeding Disorders Foundation of North Carolina (BDFNC) advocates for women and girls with bleeding disorders is by raising awareness about the signs and symptoms of bleeding disorders to medical providers across the state by exhibiting at various conferences. This fall, BDFNC exhibited at four conferences, each aimed at a different group of medical providers.

North Carolina Nurses Association

September 15-16, 2022

Raleigh, NC

Read all about BDFNC's time at the North Carolina Nurses Association in the Fall issue of *The Concentrate*.

North Carolina Dental Hygienists' Association

September 30-October 1, 2022

Asheville, NC

For the second time, BDFNC exhibited at the North Carolina Dental Hygienists Association (NCDHA) meeting in Asheville. Maintaining dental health is very important for individuals with bleeding disorders, but dental providers can be wary of taking care of these patients. By raising awareness with the dental hygienists, they can learn more about the signs and symptoms of bleeding disorders to look out for when treating their patients, as well as who the dentist should contact in order to coordinate care when they do treat patients with a bleeding disorder.



North Carolina Emergency Nurses Association

November 3-4, 2022

Asheville, NC

Have you ever experienced a visit to the emergency room where you knew more about your bleeding disorder than the medical providers there to help you? Emergency department providers have to know a little bit about everything, but that's really hard when dealing with rare conditions like bleeding disorders. Depending on when medical providers received their education about bleeding disorders, they also may be less likely to truly understand that women can have bleeding disorders, too, since this has only been becoming more understood in the past several years. BDFNC exhibits at the North Carolina Emergency Nurses Association (NCENA) conference to provide resources for emergency room nurses so they can better assist and care for you during those already stressful visits. Helping them to understand the importance of receiving treatment prior to any tests is especially important. Understanding the symptoms of bleeding disorders in women and the types

Continued next page

BDFNC Raises Awareness about Bleeding Disorders Across the State

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of bleeding disorders that women are likely to present can be the difference between a good ER visit and a bad ER visit. As a patient with a bleeding disorder, you are likely to know more than they do about the maintenance of your bleeding disorder. With the resources provided by BDFNC, the nurses will be able to work together with you so that you can receive the best care possible when having to make a trip to the emergency room.

North Carolina School Nurse Conference

December 8-9, 2022

Greensboro, NC

With over 800 school nurses in attendance, this was one of the largest nursing conferences that BDFNC has had the opportunity to raise awareness at. It only took 15 minutes of the first exhibit timeslot before April Lindsey-Evans, BDFNC community member, and Charlene were looking for a place to print additional informational packets for future exhibit breaks. School nurses were extremely grateful for the information. Dozens of nurses mentioned that they have children in their school with bleeding disorders. Many of them had at least one student with von Willebrand Disease (VWD) and that they weren't really familiar with that. Fortunately, April and Charlene had plenty of VWD materials to help educate them! It was fantastic to see how engaged school nurses were when talking about bleeding disorders, especially since they can often be one of the first to notice a girl who may have heavy menstrual bleeding. Thank you to all the school nurses who stopped by to learn about bleeding disorders!



To the Editor: Our dear friend David Howell (MD, PhD and Professor, Department of Pathology, Duke University Medical Center) wrote to us the following observations in response to a piece in The Concentrate (Summer 2022, pp. 12-13). We thought it most enlightening, and David has given us permission to publish it in this edition of the Concentrate. –Kathy and Charles Register (BDFNC members)

There is an interesting piece about a young woman who has one aberrant copy of the gene for factor VIII, located on the X chromosome. Though not overtly symptomatic initially, she had devastating bleeding when surgeons failed to take her underlying partial factor deficiency seriously and operated on her knee.

The biology of how a mutation of one of two X chromosomes causes functional abnormalities is fascinating. The received wisdom is that one copy of the X chromosome is just right for producing the correct amount of proteins encoded by genes on the chromosome (as opposed to the other 22 chromosomes, designated "autosomes," where the system is designed for two copies to yield the correct "dose"). Most males have one X and one Y (the latter of which has little in the way of conventional functional genes), so they make just the right amount of the encoded proteins unless one of the genes is faulty, in which case formidable problems often ensue (as you are well aware).

Females get around the XX double-dose problem by randomly inactivating one of their two X chromosomes early in embryonic development; this process is termed "lyonization" (nothing to do with feline carnivores – it was originally proposed by a celebrated English geneticist, Dr. Mary Lyon). If one of two gene copies is faulty (what traditionally is termed a "carrier" state), the "good" or "bad" gene copy in each embryonic cell gets inactivated, often with approximately equal frequency. (The patient in the article was described as having about 50% of the normal factor VIII level, compatible with this scenario.) This is usually (but not always) enough for the protein to do its job. Since lyonization is random, however, it's possible to have a majority of embryonic cells inactivate the chromosome carrying the "good" gene; in this case, the quantity of normal protein produced can be substantially less than 50%.

Things get even more complicated if the gene product is a structural protein rather than a circulating factor or enzyme. There is an X-linked renal disorder, Alport syndrome, where the mutation is in a gene encoding a special form of collagen that's crucial for the structure of specialized renal capillaries. Female individuals with one nonfunctional gene actually have patches of tissue in their kidneys that are totally lacking in the normal protein, in some cases leading to chronic structural damage and varying degrees of chronic renal failure.

Obviously, "carrier" is not a good way of describing individuals with symptomatic illness caused by a mutation on one of two X chromosomes. "Symptomatic carrier," as used in the article in *The Concentrate*, is a reasonable approach. Physicians often use the technical term "heterozygote" (e.g., "heterozygote for X-linked Alport syndrome") in such cases; it gets to the root cause of the problem, though I think that "symptomatic" probably resonates more with individuals living with the disorder.



Health Insurance: Finding the Right Fit

November 9, 2022

Virtual

As open enrollment for health insurance approached, the Bleeding Disorders Foundation of North Carolina (BDFNC) hosted a virtual event focused on tips on what someone with a bleeding disorder should look for when choosing insurance. BDFNC was grateful to have Michelle Rice from Michelle Rice & Associates as the presenter for this program. As the mother of two sons with severe hemophilia, Michelle has spent over 32 years advocating and leading change in various roles. Michelle is an experienced executive in healthcare policy and advocacy. She has worked across many areas of healthcare, including payer relations, federal and state policy, and pharmacy concerns.

Michelle has a wealth of knowledge and provided a lot of great information. BDFNC recorded the presentation and has the handouts provided, so anyone interested in the information can request these from Gillian at events@bleedingdisordersnc.org or (919) 319-0014.



Teens Enjoy Mini Golf

November 19, 2022

Charlotte, NC

The final Teen Empowerment event of 2022 didn't disappoint. Several teens gathered at Monster Mini Golf for a unique miniature golf experience. The teens made their way through a glow-in-the-dark course, encountering monsters and other "haunted" thrills. After they finished mini-golf, the teens had a conversation about how to start taking control of their bleeding disorder or other medical conditions, through self-infusing, ordering their factor or other medications, and knowing whom to call if they needed to speak to a doctor. The teens are looking forward to more events next year.



Festivities Return for the Holidays

December 3, 2022

Greenville, NC



After postponing the in-person Holiday Celebration in Greenville two times because of Covid-19, the Bleeding Disorders Foundation of North Carolina (BDFNC) finally was able to bring the community together for a celebration of the holidays. In partnership with the ECU Hemophilia Treatment Center, close to 100 people attended the Holiday Celebration at the Hilton Greenville. There was lunch, games, holiday themed crafts, a face painter, a special presentation, and a visitor from the North Pole. The folks from the ECU Hemophilia Treatment Center put together a very creative presentation: *Bleeding Disorders: Past, Present, and Future*, which took a look at how treatments for bleeding disorders have evolved over the years and what's on the horizon. The presentation was made in the style of Charles Dickens' classic holiday tale, *A Christmas Carol*, with ECU staff acting as characters from the story, including Ebenezer Scrooge, Jacob Marley, and the Ghosts of Christmas Past, Present, and Future.

After the presentation and lunch, Santa took time out of his very busy holiday schedule to visit with BDFNC, and all children left with a gift. Throughout the day, people talked about how wonderful it was to be back together again.





Blood Brotherhood Program Update

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

Over the past several months, BDFNC hosted two events for men with bleeding disorders, the Blood Brotherhood & SOAR Weekend and Blood Brotherhood Night at a Charlotte Checkers hockey game. In 2023, BDFNC seeks to offer more opportunities for men to connect. Whether you have been part of the North Carolina bleeding disorders community for years, are new to North Carolina, or



are a young adult, BDFNC hopes that you will participate in an event 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 toward families with children twelve and under.

In 2023, BDFNC looks 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, safe activities 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 will be sessions specifically for families at the Consumer Medical Symposium in March and the Summer Community Retreat in July. Family Day in November will be rebranded to the HOPE Family Day to provide connections and networks for families. Finally, two smaller programs are being planned for 2023, so be on the lookout for more information.

If you are the parent of a child with a bleeding disorder, you know the importance of connecting 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 want 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

By: Guillermo Sanchez, Unión Latina Coordinator

It is important that people who live with a bleeding disorder find a 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 who understand your health condition, but also your culture and language. The Bleeding Disorders Foundation of North Carolina (BDFNC) Unión Latina Program provides opportunities for getting involved and participate in different activities so that you and your family can become informed and educated about bleeding disorders, as well as providing resources so that you can receive appropriate medical treatment.

The Unión Latina is led by volunteer coordinator and 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

There has been so much happening associated with the SOAR Program in recent months. The Bleeding Disorders Foundation of North Carolina (BDFNC) held two events directly geared towards women with bleeding disorders, the Blood Brotherhood & SOAR Weekend and the SOAR Luncheon, which you can read about in this edition of *The Concentrate*. BDFNC has also been busy raising awareness about women with bleeding disorders at several medical conferences, including the North Carolina Nurses Association, North Carolina Dental Hygienists' Association, the North Carolina Emergency Nurses Association, and the School Nurse Association of North Carolina.

In 2023, BDFNC is looking forward to doing even more for women in the community. Look for information about updated resources and events for women across North Carolina. 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, 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.

SOAR is a program of BDFNC for women and girls with a bleeding disorder, including those diagnosed with von Willebrand disease, hemophilia A and B, rare factor deficiencies, platelet disorders, and carriers of any of these disorders (both symptomatic and nonsymptomatic). The mission is to improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential.

Please contact Gillian for more information about the SOAR Program at events@bleedingdisordersnc.org or by calling the BDFNC Office at (919) 319-0014.

Teen Empowerment Program

What a great inaugural year for the Teen Empowerment Program! The Bleeding Disorders Foundation of North Carolina (BDFNC) began the program in 2022 knowing there has been a lack of resources geared specifically towards teenagers. The hope was to build a program that allowed teens to get together with others who are growing up and dealing with similar health circumstances. In 2022, two events brought teens together for some education to learn about managing their bleeding disorder along with a fun activity to do together. This was in addition to the already scheduled teen tracks at the Winter Conference, Summer Community Retreat, and Teen Retreat.

BDFNC is looking forward to another great year in 2023, with multiple events and opportunities. Stay tuned for more information! To help create a sense of ownership for the program, BDFNC is looking to create a logo for the program and needs

Continued next page



Teen Empowerment Program

continued from previous page

**BLEEDING DISORDERS FOUNDATION
OF NORTH CAROLINA**

TEEN EMPOWERMENT PROGRAM

**LOGO
COMPETITION**

INFO

1 DESIGN
Your design should relate to TEENS and BLEEDING DISORDERS

2 ORIGINAL
Your design should be original and not based on other designs.

3 SUBMIT
Email your design by February 15 to the email below.

EMAIL YOUR LOGO TO:
G.SCHULTZ@BLEEDINGDISORDERSNC.ORG

**WINNERS WILL BE
ANNOUNCED ON:** **March 15, 2023**

YOUR help. If you are between the ages of 12-18, you can submit a design that will become the Teen Empowerment Program logo!

- The design should relate in some way to TEENS and BLEEDING DISORDERS.
- The design must be original.

Email your design by February 15.

- Between February 15-March 14, the community will vote on their favorite logo.

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

Attention: Spouses, Partners, and Caregivers



Are you a spouse, partner, or caregiver to someone with a bleeding disorder? While the Bleeding Disorders Foundation of North Carolina (BDFNC) hopes that you've always found benefit in BDFNC programs, a stronger network of support is being developed just for you! Nick Henry, who is the partner of someone with a bleeding disorder, is helping BDFNC to create a program specifically for spouses, partners, and caregivers in order to provide support and resources. Interested in learning more? Reach out to Gillian Schultz, Director of Programs, at events@bleedingdisordersnc.org or (919) 319-0014 and she can connect you with Nick.

Mental Health Initiative

Mental health conditions affect so many people across North Carolina. Living with a bleeding disorder can magnify many of the stresses of everyday life and contribute to increased mental health concerns. There is more and more support in the bleeding disorders community for those dealing with mental health conditions. The Bleeding Disorders Foundation of North Carolina (BDFNC) is in the process of publishing a Mental Health Resource Guide. Following the publication of results from the Mental Health survey in the fall edition of The Concentrate, BDFNC is looking at how to continue to research the mental health needs of the community and how to best support you.

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>.

Continued next page

Scan the QR Code to
SHARE YOUR STORY



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



Mental Health Initiative continued from previous page

BDFNC is committed to moving the conversation about mental health in the bleeding disorders community from talking about it to DOING something about it. The Mental Health Initiative brings that talk to action to support the bleeding disorders community.

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

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

2022 Friends of BDFNC

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

Employee Giving Programs (various)

Melissa Baldinger
Dan & Sarah Jane Cox
April Lindsey Evans
Brent White

Facebook Fundraisers

Jamie Batts Langley
Jade Bigelow
Jenn Eichorn
Shannon Elderdice
Lorin Fentress
Cindy Hargett

Financial Assistance Program

Linda & Allen Kurtz

In Honor of Robert Jeffrey Jones

Michael Jones

In Memory of Dale Brisson

Brisson Family & Friends

In Memory of Kasey Frye's Birthday & Christmas

Frye Family

George D. McCoy Scholarship Fund

Betty Hansen
Sylvia Herbert

General Donations

Boyd Furr
Nancy Huettel
Linda & Allen Kurtz
Brenda Plassman
Carrie Regler
Christina and Ron Roberts
David & Mary Valentino
Michelle Vanhook

Giving Tuesday Campaign

Charlene Cowell
Sue Cowell
Patricia DeSantis
Phil Poovey
Gillian Schultz

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

Are you on NC Medicaid?

If you're on Medicaid in North Carolina, make sure the Medicaid office has your current contact information. As part of a recent federal bill, the COVID-era Medicaid rules that stopped states from kicking people out of the health insurance program is ending. Starting April 1, state officials can re-examine a person's Medicaid eligibility and decide to remove them from the program. States will still be required to keep children enrolled in Medicaid for at least a year.



2022 Spotlight on Volunteers

The Bleeding Disorders Foundation of North Carolina (BDFNC) does a lot with a very small staff, so it's no wonder why BDFNC relies on the volunteerism of others. As 2022 comes to a close, BDFNC would like to give a very special thank you to some individuals who have dedicated countless hours over the last year to better the lives of others within the bleeding disorders community.



Alisha Curtiss

In addition to her volunteer role on multiple committees and as a mentor for new families within the community, Alisha agreed to lead BDFNC's monthly Community Conversations meetups. This online resource provides an opportunity for anyone from the NC bleeding disorders community to come together to gain support. Not only has Alisha been leading this important initiative, but she's also been creating excellent topics to spark conversation among the group. Her thoughtfulness is truly appreciated by those who join the meetups!

April Lindsey-Evans

April has been an active member of the community, especially the SOAR Program for women and girls with bleeding disorders. April and her daughter live with von Willebrand Disease (VWD) and have been offering their support in raising critical awareness of VWD. With approximately 1% of the population living with VWD, it's surprising how many people including medical providers have never heard of it. In an effort to change that, April exhibited at the NC School Nurse Conference in 2022, passing out materials and sharing her story to over 700 school nurses. April's efforts will no doubt have a positive ripple effect in the general population as nurses are able to better identify the signs and symptoms of possible bleeding disorders.



Cayton Elderdice

Those who follow us on social media have probably noticed that BDFNC's posts have been improving, and Cayton is to thank! Cayton has been working closely with BDFNC staff to increase social media presence and methods, like introducing stories for Facebook and Instagram. Interested in checking these out? Cayton has been able to save some of the highlights to the BDFNC Instagram page, including Thanksgiving quotes from community members about what they're grateful for. Cayton's work behind the scenes is helping BDFNC reach people where they are – and that's usually on their phones!

Cheri Clark

Along with being one of the friendliest faces at all BDFNC events, Cheri has been a fierce advocate for raising awareness that females can have bleeding disorders. Having lived for decades without a diagnosis, Cheri shares her story openly with others in hopes of helping others who are living with an undiagnosed bleeding disorder. And after many years of attending nursing conferences, there is no doubt Cheri has been doing just that. At each conference, there is at least one person who says they or someone they know received a diagnosis after meeting Cheri at the last conference. Cheri's longtime commitment to these exhibit opportunities is making a world of difference for women and girls who are living with undiagnosed bleeding disorders.

Continued next page



2022 Spotlight on Volunteers

continued from previous page



Guillermo Sanchez and Abi Landelius

Guillermo and Abi, along with their remarkable girls, are longtime community members. They have also been spearheading the BDFNC Unión Latina Program, dedicated to supporting people impacted by bleeding disorders whose primary language is Spanish. Guillermo and Abi's commitment to this program has been life-changing for the Spanish-speaking community, providing opportunities for these members to learn and network in a comfortable environment. Abi and Guillermo were driving forces in the creation of this program and BDFNC is extremely grateful for their dedication!

Kate Stotz

Despite a busy schedule, Kate spent the day raising awareness at the NC Emergency Nurses Association conference in November. Most people in the bleeding disorders community can attest to the challenges and frustrations that can occur when going to an ER. Kate, who has a son with hemophilia, was able to talk with nurses who work in emergency departments and help them understand more about bleeding disorders. Nurses in attendance were from all over the state, so there's a good chance that community members across NC will cross paths with one of these nurses.



Nick Henry

In early 2022, Nick came to BDFNC staff with a request: how can the organization provide a space for spouses and partners of people with bleeding disorders? As a partner to someone living with a bleeding disorder, Nick was really interested in getting tools, support, and knowledge from other spouses and partners. Having been a regular attendee at past events, Nick had been a great resource for others. Jumping at the challenge, Nick worked with BDFNC and his partner, Michelle Hodge, to create a program and dedicated space for partners, spouses, and caregivers.

Remembering Terry Crofts



The Bleeding Disorders Foundation of North Carolina (BDFNC) was sad to hear about the passing of Terry Crofts in October 2022. Terry's family became involved with BDFNC many years ago when his grandson was born with hemophilia. Terry was a kind and giving person who was always glad to help out in a very special way for our annual Holiday Celebration. For years, Terry came to the event as the jolly fella who brings joy (and presents) to all the kids. His wife, Becky, also played a special role. Together, they made this

event memorable for every child who attended the events. BDFNC is forever grateful for their dedication and passion for this community. Terry will be sorely missed!

Donations in Memory of Terry Crofts

Martha Canady Shaw

Cowell Family

Ann & Grady House

Samuel Jones

Peggy Lamoureaux

Piedmont Stone Center, PLLC

Teresa and Larry Seal

Taylor & Parsley CPAs, PLLC



New Document to Help Residential Substance Use Disorder Placement for Individuals with Bleeding Disorders

Reprinted from

NHF November 14, 2022



Historically, many residential substance use disorder (SUD) facilities have denied admittance to individuals with bleeding disorders – the basis of these denials are most often the use of self-administered, intravenous medications such as factor replacement therapies. The lack of access to residential addiction treatment facilities, can have very serious, even fatal outcomes for bleeding disorder (BD) patients in acute need of help with their addiction.

Results of a national survey of hemophilia treatment center (HTC) providers suggest that the majority of attempts to place patients at a residential addiction treatment facility or at mental health facilities have met with failure. However, interviews with HTC providers who have bucked this trend and secured residential placements have helped generate a document that provides best practices and resources for HTCs endeavoring to successfully refer a BD patient. It is a comprehensive resource that is meant to encompass the various referral stages, including things to consider prior to making a referral, during the referral process, and in the event of a denial.

Best Practices For Accessing Residential Substance Use Disorder Treatment For Individuals With Bleeding Disorders is a product of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), whose mission is to advocate for access to appropriate SUD and mental health (MH) treatment facilities for all individuals with BDs. The Coalition plans to develop a similar document centered on access to MH facilities.

Please note that the Coalition is very eager to collect as much information as possible relevant to denials for residential SUD treatment, so that they can continue to refine best practices and enhance support for individuals with BDs. Contact information for reporting these denials can be found in the document.

BD SUMHAC was formed via a partnership between the New England Hemophilia Association (NEHA), Hemophilia Federation of American (HFA), the National Hemophilia Foundation (NHF), HTC providers, and BD community members. Sponsoring organizations include NHF, NEHA, and the HTC at Rush University Medical Center.

The Best Practices For Accessing Residential Substance Use Disorder Treatment For Individuals With Bleeding Disorders guide can be found here: <https://tinyurl.com/ywk2yz97>



Make an Impact in DC: NHF Washington Days

March 8-10, 2023

Washington, DC

Each year, the National Hemophilia Foundation (NHF) hosts Washington Days, which is an opportunity for people affected by bleeding disorders to advocate for issues that are important to the community. The Bleeding Disorders Foundation of North Carolina (BDFNC) participates each year, providing a voice for NC's bleeding disorder community and a strong unified commitment to the national community.

You don't need to have any legislative advocacy experience to participate. Whether you're familiar with legislative advocacy or not, it is a great experience for everyone. Anyone interested in attending can contact Charlene (c.cowell@bleedingdisordersnc.org) for additional information on assistance with attending the NHF Washington Days.

While it has been a virtual event for the last few years, the 2023 Washington Days is planned to be an in-person experience March 8-10, 2023.



Advocacy Ambassadors and More!

By: Charlene Cowell, Executive Director



As we look to the future, we know that one of the Bleeding Disorders Foundation of North Carolina's (BDFNC) leading roles will be legislative advocacy on behalf of the bleeding disorders community. Advocacy has been the first pillar listed within our mission statement for a reason. Without a strong advocacy foundation, there is a real threat to access, care, and safety for people living with bleeding disorders. For example, the bleeding disorders community is largely responsible for the blood supply safety protocols in place today. Until recently, most people with hemophilia were denied access to skilled nursing facilities. Our community's advocacy efforts are the reason why that shouldn't be the case any longer. It is a prime example of why it's

imperative that our community advocates for itself, and BDFNC is proud to be able to train, educate, and offer opportunities to do that.

One of our newest initiatives is the Advocacy Ambassador Program. Officially rolling out in 2023, BDFNC is excited to debut this new initiative in detail in the first quarter of the year. The goal is to work with individuals from the bleeding disorders community who are interested in taking a leadership role when it comes to legislative advocacy. These individuals will have the opportunity to work together to spearhead BDFNC's advocacy efforts, attend national and local advocacy events, and act as spokespeople for this community. If interested in participating or learning more, please don't hesitate to reach out to me at c.cowell@bleedingdisordersnc.org or (919) 319-0014.

"When you stand and share your story in an empowering way, your story will heal you and your story will heal somebody else."

Iyanla Vanzant

Bleeding Disorders Foundation of North Carolina

2023 Calendar of Events Highlights



January 14, 2023

Unión Latina Event - Morrisville, NC

January 17, 2023

Community Conversations - Virtual

January 28, 2023

Volunteer Onboarding & Training - Virtual

February 21, 2023

Community Conversations - Virtual

February 25, 2023

Welcome to BDFNC! - Virtual

March 4-5, 2023

Consumer Medical Symposium - Raleigh, NC

April 22, 2023

Charlotte Festival & Walk -
Charlotte, NC

June 3, 2023

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

July 8-9, 2023

Summer Community Retreat - Morehead
City, NC

August 10-13, 2023

NC/SC Teen Retreat - Rock Hill, SC

September 22-24, 2023

Blood Brotherhood & SOAR Weekend -
Pine Knoll Shores, NC

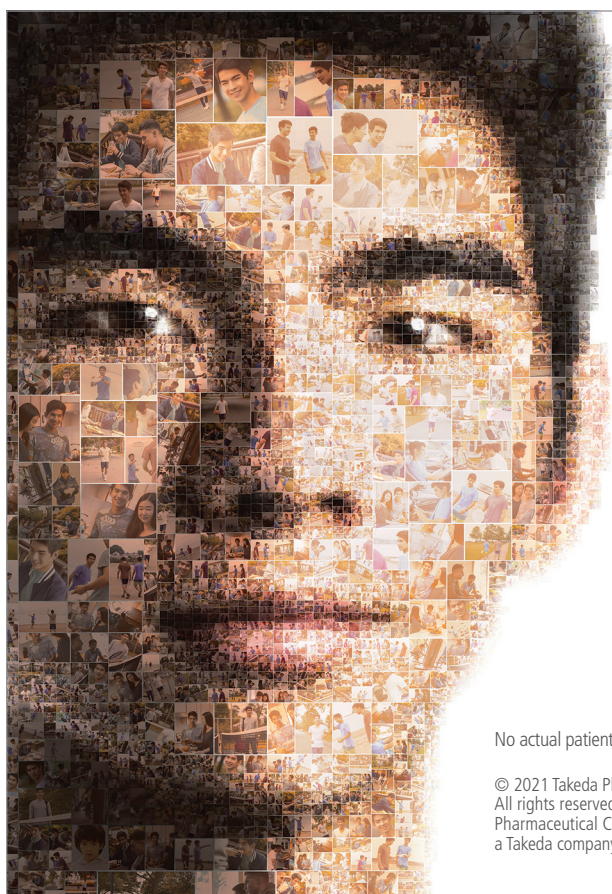
October 14, 2023

Raleigh Festival & Walk - Morrisville, NC

November 4, 2023

HOPE Family Day - Concord, NC

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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bleedingdisordersnc.org/festival



CHARLOTTE
Saturday, April 22, 2023

Mint Street at 3rd St. & MLK Blvd.
Uptown Charlotte, NC

RALEIGH
Saturday, October 12, 2023

Lake Crabtree County Park
Morrisville, NC



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

