

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

Winter 2021-22

New Name, Same Mission

By: Charlene Cowell, Executive Director

**BLEEDING
DISORDERS
FOUNDATION
OF NORTH CAROLINA**



I'm very excited to share some important news! In case you missed it in the summer edition of the newsletter, Hemophilia of North Carolina (HNC) will soon take a new name: the **Bleeding Disorders Foundation of North Carolina (BDFNC)**.

Many years ago, HNC staff and the board of directors started talking about the shift in our membership. We were not only serving the hemophilia community, but also a growing number of members with other bleeding disorders like factor VII deficiency and von Willebrand disease (VWD). It was around 2012 when our membership started to reflect a

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Back in Person – Save the Date for the Charlotte Family Festival & Walk for Bleeding Disorders

April 2, 2022
Charlotte, NC

Hemophilia of North Carolina (HNC) is so excited to be hosting the Charlotte Family Festival & Walk for Bleeding Disorders IN PERSON, after two years of being virtual due to the pandemic!

The Charlotte Festival & Walk is HNC's largest fundraiser in the Charlotte area. It raises critical funds to support HNC's many programs and services. Your help is needed to reach the fundraising goal! More information will be announced in January about how to register and start your walk team, as well as tips and tricks to make your FUNdraising easy. But it's not too early to start thinking about whom you can invite to join you. Encourage your family, friends, and coworkers to support your efforts! The more people who are involved, the more money that you can raise.

On April 2, plan to join us on Mint Street in front of Trust Street Field and Romare Bearden Park. There will be plenty of

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Save The Date

HNC Art Therapy
January 15, 2022
Virtual

HNC Community Conversations
January 18, 2022
Virtual

HNC Music Therapy
February 8, 2022
Charlotte + Virtual

HNC New Members Event
February 12, 2022
Virtual

HNC Community Conversations
February 15, 2022
Virtual

HNC Women's Event
February 19 & 20, 2022
Charlotte & Raleigh

NHF Washington Days
March 1-2, 2022
Virtual

Many more events coming up.
See page (27) for the complete list.



*Hemophilia of
North Carolina*

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

MISSION STATEMENT

Hemophilia 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

Hemophilia of North Carolina

(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 Hemophilia of North Carolina. 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 HNC website. If you would prefer not to receive a mailed copy of our newsletter, please contact the HNC office.

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

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

Hemophilia Treatment Centers

**East Carolina University
Brody School of Medicine**
600 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676

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

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

PEDIATRIC:

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

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

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

UNC Hemophilia and Thrombosis Center

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

Wake Forest University School of Medicine

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

Additional Medical Resources

Duke University Medical Center Hemostasis and Thrombosis Center

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

Mission Hospital Pediatric Hematology/ Oncology Program

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

Resource Information

National Hemophilia Foundation
www.hemophilia.org

Hemophilia Foundation of America
www.hemophiliafed.org

**American Society of Pediatric
Hematology/Oncology**
847-275-4716
www.aspho.org

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

Patient Services Incorporated (PSI)

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

World Federation of Hemophilia

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

VISION STATEMENT

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

Hemophilia 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.



2021 Volunteer of the Year: Karyn Davis



Many readers will recognize the name Karyn Davis, and for good reason. Not only was Karyn the Manager of Operations for Hemophilia of North Carolina (HNC) from 2015-2020, but she has remained an integral part of the organization's operations even after leaving her position. You can find Karyn (and her family) at every Family Festival & Walk, smiling and coordinating all of the 60+ volunteers that show up. Behind the scenes, she works to post the volunteer needs, communicate with interested volunteers, and develop clear instructions to make sure that the event goes as smoothly as possible. This is one of the many reasons that Karyn was the obvious choice for the 2021 HNC Volunteer of the Year award!

Karyn joined the organization without any family connection to the bleeding disorders community, although she did know two neighbors with hemophilia growing up. However, Karyn fell in love with this community, going above and beyond her job duties. When Karyn left her position in 2020 for personal reasons, she made it clear that she wanted to remain involved. While many people say this, it is unusual for someone to stay as involved as she has. Karyn's deep knowledge of this community and the operations of HNC have allowed her to transition into a volunteer role without any training.

Some of Karyn's many volunteer commitments include: sitting on multiple committees, coordinating volunteers, assisting with the transition of our donor and member database, preparing mailings, attending events where volunteer coordination is needed (most noteworthy are the two Festival & Walks), and being one of the most dedicated advocates on behalf of the bleeding disorders community.

One joke that people make is that once someone is involved in this community for a while, they're part of the family. It's hard not to fall in love with the bleeding disorders community. Karyn is proof of this. Her passion for people with bleeding disorders is evident by her commitment over this last year. For all of these reasons and more, we are so grateful for Karyn and proud to call her the 2021 Volunteer of the Year!



Want to congratulate Karyn?
Feel free to send her at email at
karyn.davis@hemophilia-nc.org.

New Name, Same Mission continued from page 1

majority of non-hemophilia bleeding disorders. Since that time, we have remained as "Hemophilia of North Carolina" while dedicated to serving a much larger bleeding disorder community.

The time has come for HNC's name to be updated to be more representative of the community we serve. Currently, the Public Relations Committee, as developed through our strategic plan process, is working on this project. Within the next few months, you will see not only a new and updated name but also an updated logo and a revamped website for our organization.

As this organization exists as a resource and "home" to those with bleeding disorders, we want to reassure the community that these changes do not impact our mission. We continue to dedicate ourselves to providing education, support, and resources, as well as advocacy and promotion of research for the NC bleeding disorders community.

HNC COVID-19 Event Statement and Policy

Hemophilia of North Carolina (HNC) continues to closely monitor changes in the COVID-19 pandemic. Safety metrics, CDC, and state guidelines will be used to determine whether events will be able to be held in person or virtually. HNC will notify the community as soon as it makes changes to any upcoming event.

HNC asks the community to abide by the following guidelines for all in-person events:

1. Masks will be required for everyone ages two and up.
2. If you or anyone in your family are feeling sick or have COVID-19 symptoms, please stay home.
3. Maintain physical distance from other families.

Return to In-Person Events

Hemophilia of North Carolina (HNC) continues to monitor the COVID-19 pandemic. With the ongoing pandemic and the continued needs of the bleeding disorders community, HNC is hoping to provide a mix of in-person, virtual, and hybrid events this upcoming winter and spring.

Upcoming events that HNC hopes to hold in person include:

- Music Therapy Programs
- Winter Conference & Medical Symposium in March
- Charlotte Family Festival & Walk for Bleeding Disorders in April
- Miscellaneous educational and support events to be scheduled

Events that will remain virtual include:

- Teen Event
- Community Conversations Groups
- Art Therapy Programs

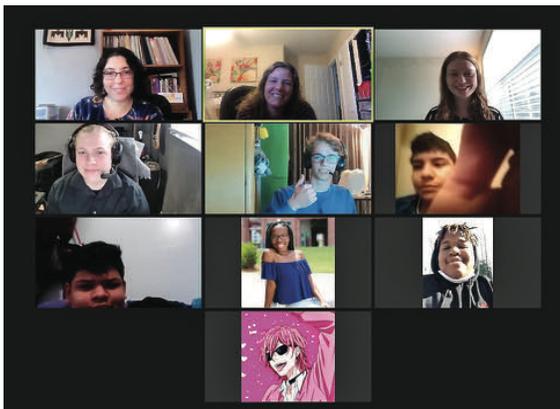
For some of the in-person events, HNC is looking into how to hold them as hybrid events, with some opportunities to attend either in person or virtually. In addition, for all in-person HNC events, attendees will be required to wear a mask and maintain social distancing if possible. HNC's event registration and attendance policy will also be followed. If you will need to cancel your registration for in person events for any reason, including illness, please make sure to contact HNC staff so they know that you will not be attending.

Stay tuned to HNC emails and additional communications about each event.



Teen Day

January 8, 2022



Hemophilia of North Carolina (HNC) really missed seeing our teens this past summer at the Teen Retreat. HNC is planning a fun Teen Day on January 8, to be held virtually! If you are between the ages of 13 and 18 – living with a bleeding disorder, a sibling of someone with a bleeding disorder, or a child of a parent with a bleeding disorder – this event is just for you. There will be fun activities and time to connect with other teens in the North Carolina bleeding disorders community.

Make sure to register for this fun event. Please check your email and the HNC website for more information and to register.

Art Therapy Program – LED Candles and Soul Collage

January 15, 2022 & February 26, 2022

As part of Hemophilia of North Carolina's (HNC) Mental Health Initiative, HNC is planning to present a variety of different modalities and alternative methods to teach you how to take care of your emotional wellness. The first of these alternative modalities is Art Therapy.

Art Therapy is an integrative mental health treatment that provides support through the creative process, active art-making, and human experience. It engages the mind, body, and spirit; gives voice to experience; and empowers individuals.



HNC will be partnering with the Art Therapy Institute of North Carolina to present two programs this winter. Both sessions will be led by Bridget Pemberton-Smith, a board certified art therapist and Executive Director of the Art Therapy Institute. The first session will take place virtually on January 15, 2022. Participants will be decorating an LED candle. Light is an important part of healing and something that is hard to get enough of during the winter time.

The second session will take place virtually on February 26, 2022. In this session, participants will be creating cards using Soul Collage. Soul Collage is a creative collage-making process that uses simple materials to create a personalized deck of cards with each card representing a part of their personality.

No art experience is required and the sessions will be open to anyone in the North Carolina bleeding disorders community. HNC will mail participants all materials that will be necessary to complete the projects. You may attend one or both sessions.

Stay tuned to your email and HNC website for more information and to register. If you have any questions, please contact Gillian Schultz at gillian.schultz@hemophilia-nc.org.

Music Therapy Program

February 8, 2022

Charlotte & Zoom



“One good thing about music, when it hits you, you feel no pain.” ~ Bob Marley

While Hemophilia of North Carolina (HNC) is not presenting a program that will rid you of your pain, HNC realizes that music can provide a therapeutic value. As part of HNC's Mental Health Initiative, two programs will be presented this year that focus on the benefit of music therapy as an alternative way to take care of your mental wellness. Music Therapy is a clinical and evidence-based use of music to accomplish individualized goals within a therapeutic relationship.

HNC is partnering with Piedmont Music Therapy to provide a two-part series focusing on music's effects on your health. There will be a context to explore stress management techniques using music. Attendees will learn more about themselves and hopefully feel more empowered to utilize coping skills through music or other available leisure activities.

The first session will take place on February 8, 2022 at 6:30pm as a hybrid event. Participants will be able to attend either in person in Charlotte or virtually on Zoom. All materials will be provided and no music experience is required. If you are attending virtually, HNC will send all materials ahead of time. The second session will take place in March, with a date to be announced soon. You may attend one or both sessions.

Stay tuned to your email and HNC website for more information and to register. If you have any questions, please contact Gillian Schultz at gillian.schultz@hemophilia-nc.org.

New Member Gathering

February 12, 2022

Are you new to Hemophilia of North Carolina (HNC) since the beginning of the COVID-19 pandemic? HNC is inviting anyone who became newly connected by receiving a medical ID or completing a new membership application to a New Member Event on February 12 at 11:00am on Zoom.

Learn about all the opportunities HNC offers to connect and get support in the bleeding disorders community in North Carolina. From educational events and support groups, to resources and other information, HNC has something to offer everyone.

More information will be coming out soon. Be sure to check the HNC website and stay tuned to your email for information about registering. If you have questions, please contact Gillian Schultz, Director of Programs, at events@hemophilia-nc.org.



Volunteer Onboarding and Refresher

January 22, 2022



Hemophilia of North Carolina (HNC) has been working all year to strengthen its volunteer program. Starting in 2022, HNC will be asking volunteers to participate in online volunteer training. These trainings will take place periodically throughout the year, to make sure that all HNC volunteers are familiar with the mission and vision of HNC as well as learn more about all HNC's needs. If you are already a registered volunteer, you will receive an email in early January with more details. If you would like to sign up to be a volunteer, please visit the HNC website and complete a Volunteer Registration Form: hemophilia-nc.org/volunteering. Volunteer opportunities include:

- Office help
- Mailing volunteers
- Community liaisons
- Spanish language translators
- Proofreading
- Online support
- Fundraising assistance
- Event volunteers
- Family Festival & Walk for Bleeding Disorders volunteers

If you have any questions, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org.

Community Conversations Support Groups

Virtual Events



Hemophilia of North Carolina (HNC) believes in the importance of connecting with others to share common experiences, triumphs, and challenges. The connections made with other people in the bleeding disorders community are essential in managing one's own health and well-being.

In 2021, HNC began a new initiative, called *Community Conversations*, so that people could connect with others in similar situations because of their bleeding disorders. *Community Conversations* are being held online, on Zoom, so that you can get to know other people with bleeding disorders from across North Carolina, no matter where you live. Distance no longer needs to be a barrier to finding support.

Community Conversations are held on the **third Tuesday of every month at 7:00pm** for all adults in the bleeding disorders community to join together, connect, and support one another. Events are informal, with conversation topics being determined by the needs of the community at the time.

For more information about *Community Conversations*, please contact Gillian Schultz, Director of Programs, at events@hemophilia-nc.org or by calling her directly at (919) 272-6000. You can also find out more by visiting the HNC website.

Winter Conference & Medical Symposium

March 13-14, 2022



Hemophilia of North Carolina (HNC) is looking forward to coming back together, in person, for the Winter Conference & Medical Symposium. This event is replacing the Annual Meeting that has traditionally been held every March.

Save the date for March 12-13, 2022, at the Marriott and Benton Convention Center in Winston-Salem. There will be sessions to provide education and support for men with bleeding disorders, women with bleeding disorders, parents, in Spanish, as well as medical and scientific focused sessions about bleeding disorders. As with past events, there will also be a children's and teen track. More details will be available in January.

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PK: Pharmacokinetics

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Save the Date for the Charlotte Family Festival & Walk for Bleeding Disorders *continued from page 1*



fun activities for the entire family. Of course, the morning wouldn't be complete without a walk on the streets around Bank of America Stadium.

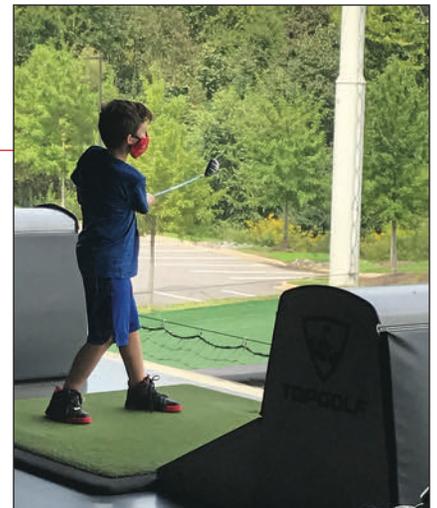
Team Captains: HNC will be contacting all past team captains with information to help you successfully fundraise in early 2022. If you were not a team captain in the past, but are interested in being one this year, please contact HNC at festival@hemophilia-nc.org.



Family Day at Topgolf

September 19, 2021
Charlotte, NC

Family Day was one of Hemophilia of North Carolina's (HNC) only in-person events this fall. Approximately 45 community members gathered at Topgolf in Charlotte for an afternoon of fun! Attendees had the opportunity to visit with the event sponsors and enjoy a buffet lunch, while Megan Rispoli, physical therapist at the St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital, led a short presentation and conversation about the benefits of physical activity for children with a bleeding disorder. Everyone was eager to head out to the golf bays at the conclusion of the presentation for an afternoon to practice their golf swings. It was a wonderful opportunity for the community to see each other again in person after so much time apart.



How to Talk to Your Child's School

September 29, 2021
Virtual



Something that all families who have a child with a bleeding disorder have to prepare for is when their child goes to school. What should the school know about bleeding disorders? How do they ensure that your child stays safe? What happens if there's a bleed?

On September 29, several families joined Hemophilia of North Carolina (HNC) on Zoom for the presentation *How to Communicate with Your Child's School*, offered by Michael Guerrero, MD and sponsored by Novo Nordisk. The presentation went over what to tell your child's teacher, the differences between an individualized health plan, 504 plan, and IEP, and which is best under what situation. It was a very informative evening with a lot of helpful information.

If you need more information or have questions about talking about your child's bleeding disorder with their school, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org.

Raleigh Family Festival & Walk for Bleeding Disorders

October 2, 2021
Morrisville, NC

It was a beautiful day to get back to the first in-person Festival & Walk since 2019! Hemophilia of North Carolina (HNC) was so excited to be able to host the event live this year. Though a smaller and somewhat scaled back version of the annual event, this year's Raleigh Family Festival & Walk for Bleeding Disorders was a huge success. You helped to raise \$105,702.80!

There were fun activities, including body painting, caricature drawing, and side-by-side basketball, a photo booth and inflatable slide added to the festivities. The music was great, and the entertainment



from the Bouncing Bulldogs jump-rope troupe was a sight to be seen. New this year: HNC held a raffle, which included a variety of prizes such as a trip to the beach, a night out in Raleigh, jewelry, and more.

Congratulations goes out to the following award winners:

- Top Fundraising Team: Clot Hoppers
- Top Individual Fundraiser: Charles & Kathy Register
- Hospital Cup Award: UNC Tarhealers
- King Droplet: Austin Caldwell
- Queen Droplet: Tracy Griles
- Junior Droplet: Gavin Bartlett
- Team T-shirt Contest: Team Gavin

Thank you to everyone who came out to make the day a success, including the amazing volunteers, sponsors, donors, fundraisers, and walkers.



Unión Latina Back at the Zoo

October 9, 2021
Asheboro, NC



Hemophilia of North Carolina's (HNC) Unión Latina Program returned to the NC Zoo on October 9 for an educational presentation about the mind-body connection followed by a visit to the zoo. While there were some concerns about the weather, the rain stopped in time for everyone to get together for a fun afternoon. The Unión Latina Program provides education and support for the Spanish speaking community.

Interested in learning more about the Unión Latina Program? Please reach out to Gillian by phone at (919) 272-6000 (call/text).

Fishing for Fun

November 7, 2021
Charlotte, NC

It was a perfect fall afternoon for Fishing for Fun at Freedom Park in Charlotte. Brandon Young, from Country Boy Fishing, helped all the kids to work on casting before they started fishing for the afternoon. While the fish weren't really biting, every child caught at least one fish. Thank you to the sponsors, Octapharma and HPC Specialty Infusion, and Country Boy Fishing, for coming out to Charlotte to teach kids with bleeding disorders about the joy of fishing!



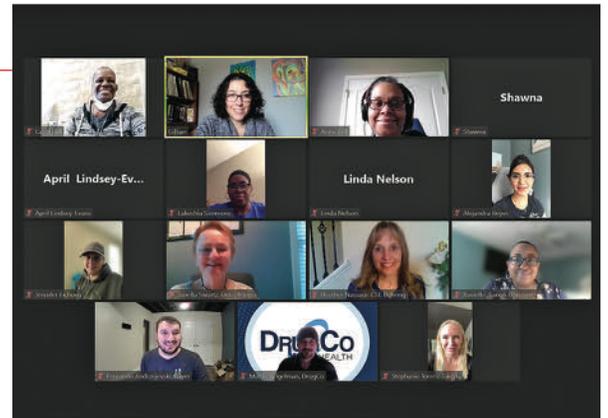
Blood Brotherhood and SOAR Weekend

Blood Brotherhood
November 20, 2021

SOAR
November 21, 2021

While it didn't work out to get together in person, it was great to be able to connect men with a bleeding disorder and women with a bleeding disorder. Hemophilia of North Carolina (HNC) decided to transition the weekend into a virtual program, with education and support programs on Saturday for Blood Brothers (men with a bleeding disorder) and on Sunday for the SOAR Program (women with a bleeding disorder).

On Saturday, men with a bleeding disorder got together on Zoom for a presentation from Dr. Steven Pipe about emerging therapies. He went over the history of prophylactic treatment and where the research is going, including research into new, longer-lasting factor products, products that provide a type of substitution for the typical factor product, and gene therapy. While these therapies are all in clinical trials, it is exciting to see where the research is going and to think of how far this community has come. Following the presentation, the men talked about ways to re-engage with the Blood Brotherhood Program as HNC hopes to get back to more in-person events soon.



On Sunday, women with a bleeding disorder got together on Zoom for a presentation about handling stress, presented by Anna Bell. She provided different strategies and resources to help deal with all the stresses that women face, from managing their bleeding disorder, taking care of their families, and balancing jobs. Following the presentation, there was a rap session where the women had the opportunity to connect with each other about their bleeding disorders.

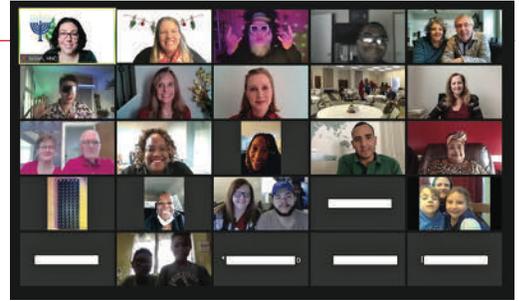
Thank you to the Blood Brotherhood & SOAR Weekend sponsors, and to the Hemophilia Federation of America for supporting this event.

HNC Brings in the Holidays with a Party

December 4, 2021

While this year's Holiday Celebration had to go virtual once again, Hemophilia of North Carolina (HNC) wanted to plan for a fun event for everyone to enjoy! With the help of GutMonkey, HNC brought the party to the Holiday Celebration. Some people may be familiar with GutMonkey as they provide fun and engaging programming for teens each year at the Teen Retreat. For the Holiday Celebration, they led Crazy Disco BINGO, with dance parties, high fives, and so much excitement. Following the games, Santa visited, read a story, and took pictures with the kids and dogs in attendance.

As is tradition, HNC also announced the winner of the Volunteer of the Year. This year's award went to Karyn Davis. Many may remember Karyn from when she was the Manager of Operations for HNC. Although she left HNC for personal reasons, she has continued to support the organization and is a regular and dedicated volunteer. Read more on page 3.



In the Spring Edition

Stay tuned to the spring edition of The Concentrate to read about winter events, including the art therapy and music therapy programs, Teen Day, New Member Gathering, and more.



Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at HemDifferently.com

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN

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Blood Brotherhood Program Update

The pandemic caused 2021 to be a quiet year for Blood Brotherhood programs for Hemophilia of North Carolina (HNC). But looking forward to 2022, HNC is hoping to provide more opportunities for men with a bleeding disorder to connect with each other.

During the Blood Brotherhood Weekend this past November, HNC had a great conversation about how to better engage with men with a bleeding disorder in the future. HNC would love to hear additional input, so if you have ideas or thoughts about the kind of events that you would like as part of the Blood Brotherhood Program, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org.



In 2022, HNC will continue offering Community Conversations groups to connect with others with a bleeding disorder. HNC is also planning on two, hopefully in-person, Blood Brotherhood Events, plus a Blood Brotherhood Weekend as well as Blood Brotherhood sessions at both the Winter Conference & Medical Symposium and Summer Retreat.

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@hemophilia-nc.org.



HOPE Program Update

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

You are not alone raising a child with a bleeding disorder! The Hemophilia of North Carolina (HNC) HOPE Program provides supportive programs, educational opportunities to help navigate raising a child with a bleeding disorder, and resources so that you can be an advocate for your child. Not only do you not need to feel alone as a parent, but your child can connect with other children who have a bleeding disorder, helping them to feel less

isolated. Whether you have an infant, toddler, preschooler, or school-aged child, find support with others at a HOPE Program event.

There are numerous opportunities throughout the year to connect with other families. HNC holds a monthly support group, called Community Conversations, so parents can share experiences and meet others in the bleeding disorders community. HNC also plans a variety of educational events throughout the year to provide you with resources and support. In addition, there is a Parent Mentoring Program to connect one-on-one with another parent who is raising or has raised a child with a bleeding disorder. The Winter Conference & Medical Symposium, Summer Retreat, and Family Day are additional opportunities to learn and connect with other families. New in 2022, HNC will be offering New Member Gatherings



to help provide additional support to those who are new in connecting with HNC.

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

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

Actualización del Programa de la Unión Latina

¡Si tu idioma principal es el Español, el Programa de la Unión Latina de la Asociación de Hemofilia de Carolina del Norte (HNC) es para ti! La Unión Latina proporciona educación y recursos a los miembros de la comunidad de habla hispana, totalmente en Español.

En el último año, el HNC ha ofrecido varias oportunidades virtuales para la comunidad de habla hispana, incluyendo presentaciones sobre mujeres y niñas con trastornos hemorrágicos, el cuidado de las articulaciones, cómo mantenerse activo con un trastorno hemorrágico y la conexión entre cuerpo y mente. Además, varias presentaciones que se dieron en inglés fueron interpretadas simultáneamente al Español, para que los detalles esenciales de las presentaciones pudieran estar disponibles para todos, incluyendo el BINGO de Crazy Disco en la celebración de las fiestas de este año.

En 2022, HNC espera conectarse más con los miembros de la Unión Latina para que puedan sentirse apoyados.

El Programa Unión Latina ofrece apoyo y educación a las personas y familias latinas de Carolina del Norte afectadas por trastornos hemorrágicos. La programación se ofrece en español y es posible gracias a un subsidio de Takeda. Para obtener más información, visite el sitio web del HNC.

Unión Latina Regresa al Zoológico

9 de octubre de 2021
Asheboro, NC



El Programa de la Unión Latina de la Asociación de Hemofilia de Carolina del Norte (HNC) regresa al zoológico de Carolina del Norte (NC) el 9 de octubre para una presentación educativa sobre la conexión entre cuerpo y mente, para posteriormente realizar una visita al zoológico. Aunque hubo algunas preocupaciones por el estado del tiempo, la lluvia cesó a tiempo para que todas las personas se reunieran para disfrutar de una tarde divertida.

La Celebración Festiva del HNC

4 de diciembre, 2021
Escrito por Guillermo Sanchez

La celebración virtual de pasado sábado 04 de diciembre resultó todo un éxito, y nos dio la oportunidad de reunirnos nuevamente. Las familias se divirtieron al jugar Disco Bingo, en donde hubo premios y baile de rock and roll. Durante el Bingo se puso a prueba el conocimiento de las y los participantes con la trivía sobre desordenes sanguíneos. El invitado especial llegó para finalizar la celebración: ¡Santa Claus!, quién nos leyó el cuento “La Noche Antes de Navidad”. Al final Santa Claus nos invitó a tomarnos fotos con él para nuestro álbum de navidad.



Se Solicita su Participación Importante Oportunidad para Realizar una Encuesta

Con la esperanza de prestar un mejor servicio a la comunidad de trastornos hemorrágicos, la Asociación de Hemofilia de Carolina del Norte (HNC) se ha asociado con el Centro de Impacto Social de la Universidad de Carolina del Norte Wilmington. **La HNC invita a los pacientes con un trastorno hemorrágico** a participar en una breve encuesta anónima para ayudarnos a comprender la relación entre los trastornos hemorrágicos y la salud mental (si el paciente es menor de 18 años, o no puede completar la encuesta, la HNC invita a uno de sus padres o a un cuidador a completar la encuesta en nombre del paciente).



Imagen de la Encuesta de Salud Mental

Esta es la primera encuesta de este tipo para la comunidad de trastornos hemorrágicos, y dado el pequeño tamaño de esta población, HNC realmente quiere saber de ti. Lo más importante es que esta encuesta es anónima y sólo le llevará unos 10 minutos completarla. Su participación, aunque voluntaria, contribuirá a los esfuerzos por mejorar la vida de los afectados por trastornos hemorrágicos. Para obtener información adicional y completar la encuesta, introduzca la siguiente URL o escanee el código QR con su dispositivo móvil para completar la encuesta en línea.

Gracias de antemano por su participación. (Si ya ha completado la encuesta en otro lugar, le pedimos que no la realice por segunda vez).

URL de la encuesta: https://uncw.az1.qualtrics.com/jfe/form/SV_cvZnI0pv02DViwC

De regreso en persona - ¡Reserve esta fecha! para el Festival de la Familia de Charlotte y la Caminata por los Trastornos Hemorrágicos

2 de Abril 2022
Charlotte, NC

¡La Asociación de Hemofilia de Carolina del Norte (HNC) está muy emocionada de albergar el Festival de la Familia de Charlotte y la Caminata por los Trastornos Hemorrágicos EN PERSONA, después de dos años de ser virtual debido a la pandemia!

El Festival de Charlotte y la Caminata es el mayor evento de recaudación de fondos de HNC en el área de Charlotte, que recauda fondos fundamentales para apoyar los numerosos programas y servicios de HNC. ¡Necesitamos que nos ayudes a alcanzar nuestra meta! En Enero se proporcionará mayor información sobre cómo registrarse y cómo iniciar tu equipo de caminata, así como consejos y trucos para facilitar tu recaudación de fondos. Pero no es demasiado pronto para empezar a pensar a quién puedes invitar a unirse a tu equipo. ¡Motiva a tus familiares, amigos y compañeros de trabajo para que te apoyen! Cuantas más personas participen, más dinero podrás recaudar.

El 2 de abril, haga planes para unirse a nosotros en Mint Street, frente a Truist Field y Romare Bearden Park. Habrá muchas actividades divertidas para toda la familia. Por supuesto, la mañana no estaría completa sin un paseo por las calles que rodean el Bank of America Stadium.

Capitanes de Equipo: HNC se pondrá en contacto con todos los capitanes de equipos anteriores con información para ayudarles a recaudar fondos con éxito a principios de 2022. Si no fuiste capitán de equipo en el pasado, pero estás interesado en serlo este año, por favor contacta con HNC en festival@hemophilia-nc.org.

HNC Raises Awareness about Bleeding Disorders



Raising awareness about bleeding disorders is part of Hemophilia of North Carolina's (HNC) mission. As part of the SOAR Program, HNC helps to raise awareness among medical professionals about what to expect if they have a patient with a bleeding disorder by exhibiting at conferences across the state.

In 2021, as organizations began to hold in-person events once again, HNC jumped on the opportunity to exhibit with familiar and some new organizations to raise awareness about bleeding disorders. In September, HNC exhibited at the North Carolina Dental Hygienists' Conference and at the North Carolina Nurses Association Conference. In November, HNC exhibited for the first time with the North Carolina Emergency Nurses Association. It was a wonderful opportunity to raise awareness and provide resources for emergency room nurses for when a patient with a bleeding disorder comes into

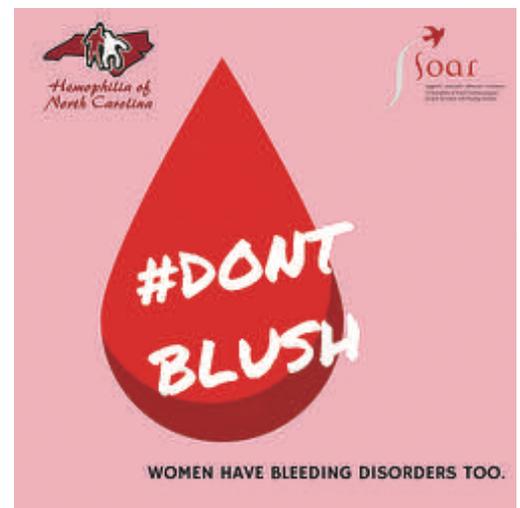
the emergency department. Through the three conferences, HNC made some great new connections and is looking forward to continuing the relationship with all three organizations in the future.

HNC would like to thank community members who helped at each of these events! Their participation helped to bring the realities of their experiences with bleeding disorders to the medical providers who may have very little first-hand experience.

HNC is hoping to be able to exhibit at more conferences in other specialty areas in the future, including OB/GYN and family medicine. If you are interested in helping HNC with any exhibits, please contact Gillian Schultz, Director of Programs, at events@hemophilia-nc.org or by calling (919) 319-0014.

Help Raise Awareness about Women with Bleeding Disorders

Would you like to help Hemophilia of North Carolina (HNC) raise awareness about women with bleeding disorders? HNC can provide printable flyers and other resources that you can share with your doctor, church group, or other organizations looking for more information. If you would like us to send you these resources, or are interested in having HNC present about women with bleeding disorders to your group, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org or by calling the HNC office at (919) 319-0014.



Unión Latina de Hemofilia

Unión Latina Program Update

If your primary language is Spanish, the Hemophilia of North Carolina (HNC) Unión Latina Program is for you! The Unión Latina provides education and resources to Spanish-speaking community members entirely in Spanish.

Over the past year, HNC has offered several virtual opportunities for the Spanish-speaking community, including presentations about women and girls with bleeding disorders, taking care of your joints, staying active with a bleeding disorder, and the mind-body connection. Additionally, several presentations that were given in English were simultaneously interpreted into Spanish so that the vital details of the presentations could be available for everyone, including the Crazy Disco BINGO at this year's Holiday Celebration.

In 2022, HNC hopes to connect more with members of the Unión Latina so that you can feel supported.

The Unión Latina Program provides support and education to Latino individuals and families in North Carolina who are affected by bleeding disorders. Programming is provided in Spanish and is possible thanks to a grant from Takeda. For more information, visit the HNC website.



SOAR Program Update

Women and girls with bleeding disorders face unique challenges. Hemophilia of North Carolina's (HNC) SOAR Program is dedicated to supporting women and girls to overcome those challenges. Specific events are planned to teach women how to advocate for themselves, to provide resources and education about bleeding disorders, and to provide a community that understands.

In 2022, HNC is looking forward to hosting several events for women with a bleeding disorder, including a program that is being planned for February, another one later in the year, the SOAR Weekend, and sessions at the Winter Conference & Medical Symposium and at the Summer Retreat. HNC also hosts a monthly Community Conversations group that provides the opportunity to connect with others who share similar experiences.

As part of the SOAR Program, HNC raises awareness about bleeding disorders in the general public and medical community. In 2021, HNC exhibited at the North Carolina Nurses Association Conference, the North Carolina Dental Hygienists' Conference, and the North Carolina Emergency Nurses Conference. HNC is looking forward to exhibiting at these as well as at additional conferences in 2022. These exhibit opportunities allow HNC to provide resources to medical providers who may not be aware of the signs and symptoms of bleeding disorders in women and girls.

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

Please contact Gillian Schultz, HNC's Director of Programs, for more information about the SOAR Program at gillian.schultz@hemophilia-nc.org or by calling the HNC Office at (919) 319-0014.



Teen Empowerment Program

The teenage years are the time when a young person begins to develop a true sense of self. While teens may at times be aloof, it is also when being with other people who share similar experiences is incredibly important. For years, Hemophilia of North Carolina (HNC) has recognized that teens in the bleeding disorders community have great needs, but not many opportunities. That is why developing a program just for teens has been incredibly important to HNC staff.



Starting in 2022, HNC is excited to be launching the Teen Empowerment Program! This program will provide multiple opportunities throughout the year for teens to connect with each other. While today's teens with a bleeding disorder are suffering fewer complications from their bleeding disorder than past generations, they still have unique needs. This program will provide an outlet just for them. And



HNC also knows that teens who are not diagnosed with a bleeding disorder but have a sibling or a parent with a bleeding disorder also need support. So this program is for them, too.

As part of the Teen Empowerment Program, there will be several events, fun giveaways, swag, and more. The first event is coming in January 2022, and HNC couldn't be more excited.

For more information about the Teen Empowerment Program, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org or by calling her directly at (919) 272-6000.

Mental Health Initiative

Hemophilia of North Carolina's (HNC) Mental Health Initiative is in full swing. Surveys have been sent to all HNC members in North Carolina to assess the mental health needs of persons with a bleeding disorder. The results of the survey will help HNC develop additional programming and determine where HNC's efforts need to focus. This winter HNC will be offering multiple programs using alternative modalities, including art therapy and music therapy, to take care of one's emotional wellness. A new financial assistance program will also be offered to help people with a bleeding disorder afford mental health treatment.

As with many chronic conditions, the stress of managing a bleeding disorder can lead to emotional distress and challenges. Additionally, navigating the COVID-19 pandemic has increased the mental health care needs of many in the community. HNC 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 HNC Mental Health Task Force which meets quarterly. You can also contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org or by calling the HNC office at (919) 319-0014.



Open the camera on your phone and hover over this QR code. It should give you an option to open the webpage with the survey.

Community Spotlight

Remembering Margaret Thomas Martin

By: Charlene Cowell, Executive Director

It's amazing how much you can learn from someone you have never met. A few months ago, I was introduced to Margaret Martin, who passed away at 100 years old on August 31, by her daughter Nancy. Nancy contacted Hemophilia of North Carolina (HNC) because her mom had passed away and in lieu of flowers, Nancy requested that people donate to HNC.

I had the honor of meeting Nancy in person in November and heard why Margaret asked for donations to be made to HNC upon her passing. Margaret's husband, William (Bill), lived with hemophilia and experienced the many physical challenges of someone who had hemophilia in the days before medical advances, prophylactic treatment, and at-home infusions. Despite those challenges, William worked hard and kept a positive outlook on life.

One of many interesting facts I learned while talking with Nancy: Margaret, William, and Nancy were invited to UNC Chapel Hill by Dr. Harold Roberts when Nancy was a kid. The purpose? Dr. Roberts was trying to figure out how many people with hemophilia lived in the state because UNC was considering starting a Hemophilia Treatment Center (HTC) to help patients. For those in the community, you know we now have five HTCs – but it all started from that meeting!

Below is a letter that Nancy wrote to her mom after she passed. We wanted to share this beautiful tribute and recognize those individuals who helped contribute over \$2,300 that will help HNC members.

Dear Mom,

You were my best friend. I will miss you so much.

Not everyone knows the life you lived. Or all the lives that you lived over the course of 100 years.

You were born on a farm, the youngest of eleven children. The world was very different in 1921 when you were born. Growing up on a farm during the Depression, you learned to be self-sufficient at an early age.

At 17 (you fibbed about your age to get into nursing school), you and your sister Ruth moved to Wilmington to attend the James Walker Memorial Nursing School. You fibbed about your age so you could attend. Right at the beginning of World War II you were a practicing nurse at the NC Ship Building Company. I remember well your stories of your time there, including that you were the only woman on a trial voyage of a new ship, representing the firm's medical department.

The ship building company was also an important part of your life, because there you met my father, Bill. A few years later, I was born. Ever self-sufficient, even after the War you continued to work as a nurse, initially at James Walker Memorial and later at New Hanover. After I was born, you worked nights, so that you could be with me during the day and Daddy could care for me at night. I was never alone.

Our great tragedy was Daddy's death of hemophilia at age 42 when I was a teenager. I know how you cared for Daddy during his illness.

Your work ethic taught and inspired me. I became a nurse because of you.

You weren't all work. I remember fondly our regular trips to Myrtle Beach to see variety shows. And you had such a rich social life in Wilmington, which you loved. It was so difficult to convince you to move to Cary to be near me.

But at age 85 you entered yet another phase of your life in Cary, and you blossomed. You made so many new friends. You were so sharp. Every time I walked into your room, you had a jigsaw puzzle going. Or you were working on a crossword puzzle.

You were also quite a card shark. With your friends, you played canasta. And at Thanksgiving, you would teach our young nieces and nephews other card games...and you played to win.

Mom, you had so many lives: farm child during the depression, nurse during World War II, loving wife, single mother – before your life was half over. You continued to see and experience many changes and you always adapted. Even to computers, which you discovered were a great way to play solitaire! But most importantly, you were an inspiration and a friend.

100 years of a life joyfully embraced and graciously lived.

I love you and I will miss you.

Nancy



Donations In Memory of Margaret Martin

- Glenn & Sally Adams
- Brian & Deborah Baillargeon
- Richard & Margaret Berry
- Dorothy Burchall
- Bobby & Carol Cockerham
- Charlene Cowell
- Shawn & Jacqueline Earle
- Susan Fisher
- Dr. and Mrs. Michael Fox
- Frank Genovese
- Leslie Harrison
- Nancy & Sigmon Hutchinson
- S. Allan & Fay Luihn
- Mike & Kaye Martin
- Richard & Yvonne Rayburn
- Tom & Karen Robinson
- Faye Senter
- Meredith & Susan Senter
- Michael & Nancy Senter
- Patricia Tilder
- Janet Williams

Lives that Touched Others

By: Charlene Cowell, Executive Director

This has been an especially hard few months as the bleeding disorders community experienced several losses. I want to take a moment to honor and remember these individuals.

Dale Brisson

A published writer and person living with severe hemophilia A, Dale had an amazing talent for articulating the struggles he went through as he grew up in the '50s with hemophilia. Dale's talents as a writer of short stories, poems, and articles earned him over a dozen writing awards throughout his career. Dale used wit and humor to brighten the day of those around him. His smile could light up a room and his laughter was infectious.



Dale and his wife, Kathy, at a past HNC Adult Retreat

John Sakakeeny

John was one of the most dedicated Blood Brothers you could meet. He was at almost every single Hemophilia of North Carolina (HNC) event and was always willing to help out with whatever he could. John loved shooting pool with the guys! John was an advocate for the bleeding disorders community, happy to talk to anyone who would listen. He would go around the events and thank sponsors for being there and share resources with fellow community members. John attended multiple national conferences and made a point to soak up as much education as possible from every meeting he participated in.

Rory Garrison

Along with his brother, Shory, you could find Rory at most of the Blood Brotherhood events. Rory enjoyed the fellowship that this community, and especially his fellow guys with bleeding disorders, provided. Rory's favorite HNC activities included shooting pool, fishing, and enjoying campfires with his fellow Blood Brothers. When he wasn't at an HNC event, you might have found him playing the bass guitar at his church.



Rory (middle) and John (right) with fellow Blood Brothers

On behalf of the community, we are going to miss you but appreciate the lasting legacy you leave behind.

Swimming for a Cause



Like a fish in the water, Hayden Otey swam 3,000 yds/120 lengths (his set goal) in 56 minutes. His personal goal for time was 60 minutes, so he blew that out of the water (literally)! Hayden, age 12, has been fundraising for Hemophilia of North Carolina (HNC) since he was a baby. Now that he's not crawling, he's swimming! And on November 6, Hayden was able to raise \$2,000 by hosting a swim-a-thon to support HNC! This fundraiser was possible because of Hayden's excellent swimming ability and the support of his coach, Tim Hillen. Thank you to all those who supported Hayden and the Otey family in their fundraising efforts. Go Team Wonderfully Made!



Hemophilia of North Carolina (HNC) wants to celebrate your important milestones!
Would you like to receive a card in the mail and celebrate your birthday, anniversary, or event with HNC?

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

If I could give one piece of advice to another parent who has a child just diagnosed with a bleeding disorder it would be...

“Take a deep breath, ask questions, and surround yourself with a great support team.”

~ Jaime Odom, hemophilia mom

“To know that you are not alone and that you have resources and support available. That a bleeding disorder is only part of who you are but does not define you, and that comprehensive treatment plans are available to support a healthy lifestyle.”

~ Alisha Curtiss, hemophilia mom

“Take things one day at a time. Thinking too far ahead will only make you anxious. Focus on the here and now and know that you and your child(ren) will be okay!”

~ Daniah Amir, hemophilia mom

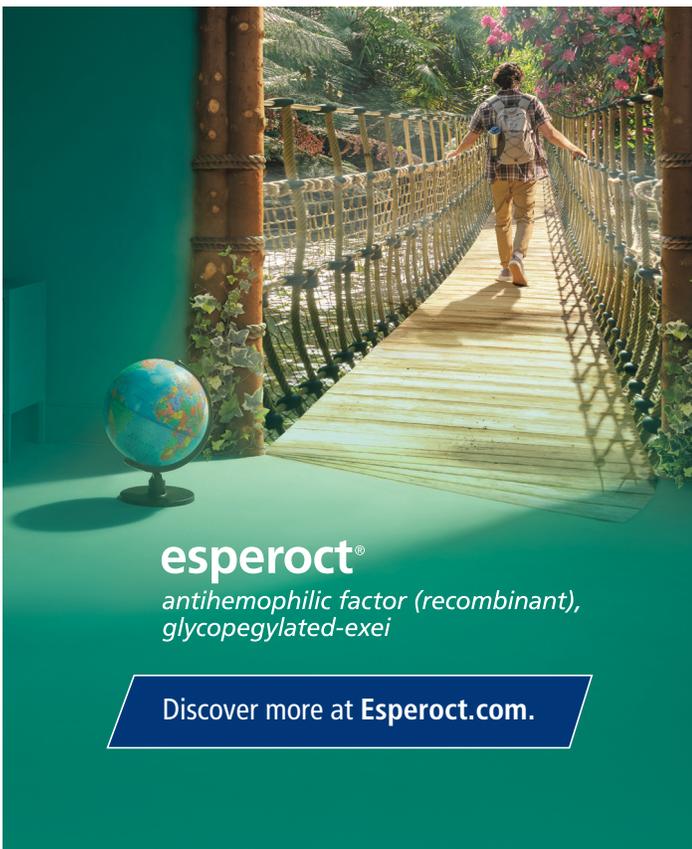
“Connect with other parents who have a child with a bleeding disorder so you can navigate parenting a child with a bleeding disorder together, and so your child doesn’t feel like the only one with a bleeding disorder.”

~anonymous

“That they don’t have to be wrapped in bubble wrap. With a good support system, including medical care, peer support, and resources, your child can grow up with few limitations.”

~Gillian Schultz, hemophilia mom,
HNC Director of Programs

We’d love to hear your advice! Email to gillian.schultz@hemophilia-nc.org or text (919) 272-6000.



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Dan Bull

Empowerment advocate

About Dan

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

Connect with Dan

DLBU@novonordisk.com
(240) 285-3948



**Hemophilia
Community Liaison**



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2021 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2021. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

Facebook Fundraisers

- Tammy Lee Chavis
- Blake Corbitt
- Charlene Cowell
- Eric Hall
- Carol Hill
- Emma Ingram
- Amy Keeler
- Julie Lamb

In Honor of Zack Hargett

- Tiffany Hargett
- Robin Swope

In Honor Charles & Kathy Register

- Ann & Sean O’Connell
- Joyce Walworth

In Honor Noah Schultz

- Amy & John Rynders

In Memory of Dale Brisson

- Nicole Brisson
- Semone Brisson
- Charles & Judith Byers
- Charlene Cowell
- Charles & Sue Cowell
- Amber Westbrook

In Memory of Kasey Frye

- Kevin & Melodee Frye

In Memory of Rory Garrison

- Charlene Cowell

In Memory of George McCoy

- Christy Spain

In Memory of

Dr. Campbell McMillan

- Mike & Vickie Strange

In Memory of John Sakakeeny

- Charlene Cowell
- Charles & Sue Cowell

In Memory of Paul Vess

- Carolyn Bailey

General Donations

- Asif Ansari
- Lynwood Best
- Irene Cowell
- Melissa Cruz
- Sue & Allen Heafner
- Jim Jarratt
- Diane Johnston
- Cathy Jones
- William Katz
- Linda & Allen Kurtz
- April Lindsey Evans
- Jacques Moody
- Phillip Poovey
- Carrie Regler
- David and Rebecca Sadi
- Andrew & Shirley Serrill
- Mary & David Valentino
- Brent White



**Your Participation Requested
Important Survey Opportunity**



In hopes of better serving the bleeding disorders community, Hemophilia of North Carolina (HNC) has partnered with the Center for Social Impact at the University of North Carolina Wilmington. **HNC is inviting patients with a bleeding disorder** to participate in a short, anonymous survey to help us understand the relationship between bleeding disorders and mental health *(if the patient is under the age of 18, or*

unable to complete the survey, HNC invites a parent or caregiver to complete the survey on behalf of the patient).

This is the first survey of its kind for the bleeding disorder community, and given the small size of this population, HNC really wants to hear from you. Importantly, this survey is anonymous, and it will take you only about 10 minutes to complete. Your participation, while voluntary, will contribute to efforts to improve the lives of those affected by bleeding disorders. For additional information and to complete the survey, enter the URL below or scan the QR code with your mobile device.

Thank you in advance for your participation. (If you have already completed the survey elsewhere, we ask that you not take it a second time.)

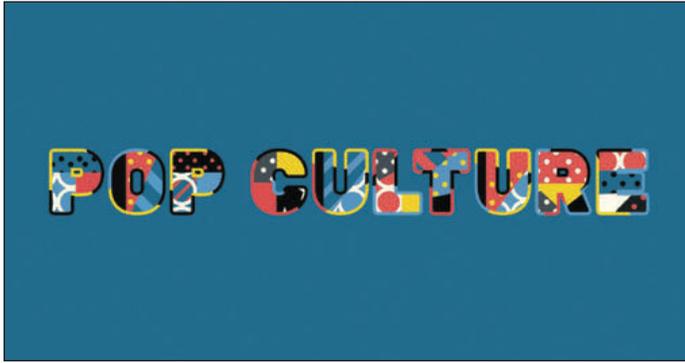
Survey URL: https://uncw.az1.qualtrics.com/jfe/form/SV_cvZnI0pv02DViwC

Bleeding Disorders in Pop Culture

A roundup of films, TV shows and plays that have featured hemophilia and other bleeding disorders.

By: Donna Behen

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Old (available to rent or buy on iTunes)

In this 2021 movie by director M. Night Shyamalan, based on the 2010 graphic novel *Sandcastle*, travelers on a tropical holiday discover that the beach they're visiting is causing them to age rapidly. Aaron Pierre plays an aspiring rapper named Mid-Sized Sedan who has hemophilia.

Roz and Ray

This two-person play, which features a pediatric hematologist and a single father whose twin sons have hemophilia, chronicles the early years of the HIV/AIDS epidemic, when thousands of people with hemophilia died after receiving contaminated factor infusions.

The play premiered in Seattle in 2016 and has since been performed in several other cities. Playwright Karen Hartman says she was inspired to write the play in part because her late father, Gary L. Hartman, MD, was a pediatric hematologist/ oncologist in San Diego during the early days of the AIDS crisis.

The Ryan White Story (available for streaming on Netflix)

This 1989 made-for-TV drama tells the true story of Ryan White, of Kokomo, Indiana, who was diagnosed with AIDS at age 13 due to contaminated factor infusions he received to treat his severe hemophilia. White and his family advocated for social justice and scientific research to improve the lives of those with HIV and AIDS. Both Ryan and his sister, Andrea, had cameos in the film, which aired a year before Ryan died.

Having a rare disease like hemophilia means you don't often get to see people who share your disease portrayed in movies, TV shows and other popular media. But over the years, the arts and entertainment industry has featured characters with hemophilia and other bleeding disorders—albeit not always accurately.

Here's a roundup of films, TV shows and plays that have featured hemophilia or another bleeding disorder in their storylines.

Royal Pains (available to stream on Peacock)

Royal Pains, a TV show that aired on the USA Network from 2009 to 2016, is set in the Hamptons on Long Island, New York, and features a concierge doctor who makes house calls to the rich and famous. Ezra Miller plays the recurring character Tucker Bryant, a teenager with hemophilia. Inspiration for the character came from Enrique Lenchewski, DDS, the father of *Royal Pains* creator and co-executive producer Andrew Lenchewski.

Grey's Anatomy (available for purchase on Amazon)

Season 1, episode 8, of *Grey's Anatomy*, entitled "Save Me," features an Orthodox Jewish patient named Devo Friedman who needs a heart valve replacement. She is ineligible for a mechanical heart valve because she has von Willebrand disease, and her religious beliefs prevent her from accepting a valve from a pig.

Nicholas and Alexandra (available for purchase on Amazon)

This 1971 Oscar-winning British movie is a partial account of the last ruling Russian monarch, Czar Nicholas II, and his wife, Alexandra. Their youngest child, Alexei, had hemophilia. The movie is based on a 1967 book of the same name written by historian Robert K. Massie, who was inspired to write it after doing research on hemophilia when his son, Bob, was diagnosed with the disease.

Continued next page

Bleeding Disorders in Pop Culture *continued from previous page*

Rasputin and the Empress (available for purchase on Amazon)

Released in 1932, this movie is a highly fictionalized account of the final years of Nicholas and Alexandra and is the only movie in which all three Barrymore siblings—John, Ethel and Lionel—appear.

Go Toward the Light (available for purchase on Amazon)

This 1988 made-for-TV movie is based on the true story of Ben Oyler, a boy with hemophilia who was 7 when he contracted AIDS through contaminated blood.

Law & Order: Criminal Intent (available for streaming on Peacock)

In season 3, episode 14, of Law and Order: Criminal Intent, entitled “Mis-Labeled,” the murder of a pharmaceutical sales rep uncovers a scandal involving clotting factor that’s been contaminated with HIV.

In the Soup (available for purchase on Amazon)

This 1992 independent film stars Steve Buscemi as a struggling screenwriter who hooks up with a gangster named Joe, who agrees to bankroll his movie. Will Patton plays Joe’s psychotic brother Skippy, who has hemophilia.

The Doe Boy (available for purchase on Amazon)

In this 2001 independent coming-of-age film, James Duval plays Hunter, a half-Cherokee, half-Caucasian boy who has hemophilia.

Senior Trip (available for purchase on Amazon)

In this 1981 made-for-TV movie, a group of Midwestern high school students travel to New York City to celebrate their impending graduation. Scott Baio plays Roger, an aspiring businessman who tries to hide his hemophilia from his classmates.

WHAT'S NEXT? YOU DECIDE.

At Genentech, we’re committed to creating programs for you, with you. From a web series focused on finding the *magic* in life, to a tournament for gamers, to workshops designed to help you think well, do well, and be well, we’re here to help you take on what comes next.

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TO SEE HOW WE’RE CREATING
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GENENTECH IN
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Ovarian Cysts: Normal or Not?

What women with bleeding disorders need to know about ovarian cysts.

By: Kathryn Anne Stewart

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Jillian Vilardo was a sophomore in high school when she first experienced a painful ovarian cyst, a fluid-filled sac that forms within or on the surface of the ovary. She was familiar with intense periods, as a result of having von Willebrand disease and factor V Leiden. But this pain was significantly worse.

“I couldn’t even lift my leg to get in my mom’s car,” she explains.

Doctors determined that the cyst was large and likely to rupture. She was rushed into surgery to remove it. Now 28 and a registered nurse in Snyder, New York, Vilardo hasn’t had any issues with cysts since. She and her husband welcomed a baby girl in May 2021.



What Causes Ovarian Cysts?

One of Vilardo’s physicians is Shaveta Malik, MD, an obstetrician/gynecologist and co-director of the Specialized Hematology Experts (S.H.E.) Clinic at Western New York BloodCare, in Buffalo, New York.

During the normal process of ovulation, she explains, each month the ovary releases a tiny follicle containing an egg. The follicle grows to about an inch wide, then releases the egg, along with a small amount of blood. Once in a while, the follicle continues to grow, becoming a larger cyst. Some cysts cause no symptoms, and others lead to tremendous pain or discomfort.

“Having a small cyst is very normal in reproductive-age women,” Malik says.

Some data suggests that they are more common in women with bleeding disorders. In one Centers for Disease Control and Prevention study, 52% of women with von Willebrand disease had a history of ovarian cysts, compared with just 22% of women without a bleeding disorder. However, this may be because women with bleeding disorders are more likely to have symptoms.

Diagnosis and Treatment

First, a doctor will feel the size of your ovaries and check for tenderness. Then, an ultrasound determines the size of the cyst and what kind it is.

Many cysts resolve on their own, according to Malik. Surgery is only necessary if there is significant bleeding and/or pain, or if the cyst is large (8 centimeters or more). To prevent new cysts from forming, oral contraceptives are often prescribed, Malik says.

Cysts related to ovulation don’t typically affect a woman’s fertility. Even if surgery is needed, it’s possible to remove the cyst, leaving the ovary intact. Vilardo and her husband were able to conceive after eight months of trying. “Of course, I was convinced that there was an issue,” she says. She spoke to Malik, who provided reassurance.

When to Contact Your Doctor About a Cyst

Nausea and abdominal pain, especially if they occur suddenly after strenuous activity, could be signs to see a doctor. Fortunately, Malik’s advice is simple: “Contact your ob/gyn if you don’t feel well,” she says.

HFA Hosts Virtual Fly-In



Due to ongoing concerns regarding public gatherings and the impact of COVID-19 on in-person legislative visits, Hemophilia Federation of America (HFA) held its annual Patient Fly-In and Congressional Reception experience as an online campaign. The event took place November 15-19, 2021. Gillian Schultz, HNC Director of Programs and community member, participated in the virtual advocacy event and represented NC.

On November 16th, grassroots bleeding disorders advocates participated in Congressional visits by video or conference

call. Participants asked Senators and Representatives to advance policies to make quality health care adequate, affordable, and accessible for all, including people with bleeding disorders. Participants called on lawmakers to permanently secure enhanced Advance Premium Tax Credits (APTCs) that were passed in the American Rescue Plan, and to provide coverage for millions of low-income adults living in non-expansion states who fall into the Medicaid coverage gap. In addition, HFA asked legislators to support legislation banning the use of copay accumulator adjuster programs in health plans. This harmful health plan strategy hurts people who rely on copay assistance programs to help them afford their essential medications.

A **ONCE-WEEKLY**
TREATMENT OPTION
FOR HEMOPHILIA B.

HOW DOES
THIS FACTOR IN?

To find out about a prescription option, talk to your doctor or visit
[OnceWeeklyForHemophiliaB.com](https://www.OnceWeeklyForHemophiliaB.com)

HFA Young Adult Advocacy Summit



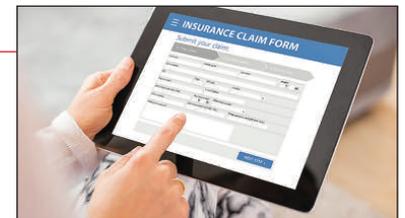
Every year, the Hemophilia Federation of America holds an inspiring and fun Young Adult Advocacy Summit (YAAS) to introduce young adults to legislative and personal advocacy in a safe and supportive manner with hands-on training and peer support. The outreach to legislative offices on Capitol Hill and federal agencies empowers participants to apply their knowledge and experience in their communities.

This year the event was held virtually September 19-20, 2021. North Carolina's very own Jeron Hill participated! Jeron can attest to HFA's Summit

goal that introducing young people to public service, especially in our nation's capital, deepens their understanding of society's needs and the various ways policymakers address these needs. YAAS is also a great way for young community members to enhance their educational, personal, and professional development.

Watch Your Insurance!

If you live in North Carolina and are on a Marketplace/ACA/Obamacare plan or on a state health plan, make sure that any copay assistance you are receiving is counting towards your out-of-pocket maximum. As of October 1, 2021, these NC insurance plans are required to accept any third-party payments (most often referred to as copay assistance and provided by pharmaceutical manufacturers) and count it towards your insurance. While this was how it had always been, in recent years the insurance companies had been implementing "Copay Accumulator Adjustment Programs" (CAAPs), which would disqualify any third-party assistance from counting.



If you think you may still be experiencing the CAAPs issue, please contact Charlene Cowell ASAP at advocacy@hemophilia-nc.org or (919) 319-0014.

A very special shout out to Linda Nelson, HNC community member, for testifying to the NC legislature about how CAAPs made her medicine unaffordable. Linda's testimony helped show how these insurance practices were hurting people's ability to stay healthy

First Meeting of HNC's Advocacy Champions

Hemophilia of North Carolina (HNC) continues to look for ways to increase its advocacy efforts on behalf of the bleeding disorders community. One of the most critical pieces: advocates! HNC staff cannot do it alone; advocacy depends on hearing from the many voices within the bleeding disorders community.

Therefore, HNC was excited to hold its first Advocate Gathering, which included community members, national organizations, and other stakeholders. The group celebrated recent successes within the bleeding disorders community, state and federal. HNC and the national organizations provided updates on current issues and potential challenges that may affect North Carolina based on trends in other states. Finally, the group brainstormed about how to grow the advocacy program to be sure that our voices are as amplified as possible.



Interested in hearing more about how to stay up-to-date on HNC advocacy issues? No advocacy experience or background needed – HNC breaks everything down so it's easy to understand! Contact Charlene Cowell for more information at charlene.cowell@hemophilia-nc.org or (919) 319-0014.

Hemophilia of North Carolina 2022 Calendar of Events Highlights

January 8, 2022	Teen Day - Virtual	July 19, 2022	Community Conversations - Virtual
January 15, 2022	Art Therapy - Virtual	July 30, 2022	New Members Event - Virtual
January 18, 2022	Community Conversations - Virtual	August 11-14, 2022	Teen Retreat - Rock Hill, SC
February 8, 2022	Music Therapy - Charlotte & Virtual Hybrid	August 16, 2022	Community Conversations - Virtual
February 12, 2022	New Members Event - Virtual	August 20, 2022	Women's Event - Location TBD
February 15, 2022	Community Conversations - Virtual	September 17-18, 2022	SOAR (women)/Blood Brotherhood (adult men) Weekend - Location TBD
February 19&20, 2022	Women's Event - Charlotte & Raleigh	September 20, 2022	Community Conversations - Virtual
February 26, 2022	Art Therapy - Virtual	October 8, 2022	Family Day & New Members Event - Location TBD
March 12-13, 2022	Winter Conference/Medical Symposium - Winston-Salem	October 18, 2022	Community Conversations - Virtual
March 15, 2022	Community Conversations - Virtual	October 22, 2022	Raleigh Festival & Walk - Morrisville, NC
March 26, 2022	Blood Brotherhood Event - Location TBD	October 29, 2022	Unión Latina Event - Location TBD
April 2, 2022	Charlotte Festival & Walk - Charlotte, NC	November 5, 2022	Blood Brotherhood Event - Location TBD
April 19, 2022	Community Conversations - Virtual	November 15, 2022	Community Conversations - Virtual
April 30, 2022	Unión Latina Event - Location TBD	November 19, 2022	Teen Event - Location TBD
May 17, 2022	Community Conversations - Virtual	December 3, 2022	Holiday Celebration/Unión Latina - Greenville, NC
June 21, 2022	Community Conversations - Virtual	December 13, 2022	Community Conversations - Virtual
June 26, 2022	VWD/Ultra-rare Bleeding Disorders Day - Location TBD		
July 8-10, 2022	Summer Retreat - Lake Junaluska, NC		

* We are providing the year's tentative calendar of events early this year so members can save the dates. Events will be added throughout the year and the dates/locations may change. All event details will be sent via email and text as soon as they are confirmed. Please make sure you are getting the information. Email HNC at events@hemophilia-nc.org or call (919) 319-0014 to be added to the email and/or text groups.





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save the dates

Fun for the entire family!
hemophilia-nc.org/festival



Charlotte **Saturday, April 2, 2022**

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

Raleigh **Saturday, October 22, 2022**

Lake Crabtree County Park
Morrisville, NC

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