

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2020

The Raleigh Family Festival & Walk Is Going Virtual

October 17, 2020

Virtual



With the ongoing COVID-19 pandemic, Hemophilia of North Carolina (HNC) has made the decision to transition the Raleigh Family Festival & Walk for Bleeding Disorders to a virtual event. Though it was a difficult decision to make, the health, safety, and well-being of the bleeding disorders community are HNC's greatest priority. The event will be live streamed on Facebook Live and Zoom on October 17, and it is still HNC's largest fundraising event. With a fundraising goal of \$120,000, HNC needs your help. One hundred percent of the proceeds go towards

HNC's mission to support the North Carolina bleeding disorders community,

Continued page 4

Board Member Spotlight

By: Ellen Kearney, MBA

I am originally from Norwalk, CT. I was raised by my mom, and I have one brother who has blessed me with two nephews. My husband Mitch and I have two kids, DJ – 23 and Sydnee – 15. I have been an HR professional for over 20 years. I started as a paralegal for General Electric in Connecticut in the Employee Benefits department and decided this HR stuff is interesting, and there it began! I am currently taking courses to complete my Ph.D. in Human Resource Management, and I am an adjunct professor at Southern New Hampshire College. What do I like to do in my free time? I don't have free time! Seriously, I enjoy reading and cooking. But my biggest love is traveling with my family and a small group of friends. We have had the pleasure of visiting the Great Wall of China and the Eiffel Tower, and we enjoyed a wonderful safari in South Africa, among other things. What is interesting about me is that I love to learn. I am always looking for ways to learn and share whatever knowledge and skills I have acquired with others, which is why I decided to become a board member. I wanted to find a way to give back and support my community and to help bring a voice to a cause that very few people know about.



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Save The Date

Let's Talk: Mental Health

October 3, 2020

Virtual

Evento de la Unión Latina

10 de octubre, 2020

Virtual

NHF Inhibitor Summit

October 16-18, 2020

Virtual

HNC Festival & Walk

October 17, 2020

Virtual

HNC Retiro de la Unión Latina

6-8 de noviembre, 2020

Virtual

NHF Inhibitor Summit

November 20-22, 2020

Virtual

HNC Holiday Celebration

December 5, 2020

Virtual

HNC Unión Latina

5 de diciembre, 2020

Virtual



*Hemophilia of
North Carolina*

260 Town Hall Dr., Suite A
Morrisville, NC 27560
(800) 990-5557
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

(800) 990-5557
(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 Moyer Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676

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

1021 Morehead Medical Drive, Suite 50100
Charlotte, NC 28204
Phone: (980) 442-4363
PEDIATRIC:
1001 Blythe Blvd., Suite 601
Charlotte, NC 28203
Phone: (704) 381-9900

St. Jude Affiliate Clinic at Novant Health

**Hemby Children's Hospital
Hematology & Oncology Clinic**
301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

UNC Hemophilia and Thrombosis Center

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

Wake Forest University School of Medicine

The Bowman Gray Campus
Department of Pediatrics
Medical Center Boulevard
Winston-Salem, NC 27157-1081
Phone: (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.unneedpsi.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.

MESSAGE FROM THE EXECUTIVE DIRECTOR

Responding to Changing Times

By: Charlene Cowell, HNC Executive Director

It's amazing how quickly things can change. At the beginning of the year, we were full speed ahead as we planned for all of the events we had scheduled for 2020. Then the pandemic hit. I am so proud of Hemophilia of North Carolina (HNC) staff and board, who made informed decisions early on to ensure the health and safety of our community by moving events to a virtual platform. I am especially in awe of Gillian, HNC's Program Manager, who immediately began acquiring the skills and technologies that would be needed to pull off such events. This was so new, and it still is. But like everyone else, HNC continues to adapt and find new ways to support the bleeding disorders community.

It's impossible to know what the future holds and when we'll return to in-person events, but we know for sure that HNC will continue providing education, resources, advocacy, social support, and assistance to those we serve. We are working with our hematology centers, national and local organizations, and pharma partners to

make sure that we can share useful information and resources. We are seeking out grant opportunities and continuing to fundraise for our financial assistance programs. We are communicating and partnering with fellow bleeding disorders organizations across the country to learn from them and share ideas about how to provide education and social support during this unique time. HNC's advocacy committee continues to monitor the national and state levels for anything that may impact our community.

In short, I want to assure the HNC community that we are here for you. If you have a need or a question, please do not hesitate to contact us. Even if we cannot provide the answers, we will try to supply you with resources to help. Stay strong and healthy!

We can't wait to see you again,

Charlene

COVID Assistance Available



Hemophilia of North Carolina (HNC) is proud to be able to extend its emergency financial assistance to include a special COVID Financial Assistance Fund. This fund is specifically geared towards helping people with bleeding disorders who live in North Carolina and have been financially impacted because of COVID-19. Any community members who would like to know more about this fund, whether as a potential donor or recipient, please contact the HNC office at (919) 319-0014 or email Rebecca Sadi, HNC Operations Specialist, at info@hemophilia-nc.org.

HNC Strategic Plan: Looking to Our Future

By: Amy Hadley, HNC Board Member



A key focus of Hemophilia of North Carolina (HNC) for the remainder of 2020 will be to create a 3-5 year strategic plan. This is an important effort to ensure the stability of the membership, as well as to keep a foot forward into tomorrow. Together we've been successfully involving advocacy groups; securing grants; engaging the HNC members in various programming opportunities; and most recently, transitioning into virtual events given COVID-19.

As we look to the future, we want to be grounded in a long-term strategy that ensures the stability of our mission; how we communicate and continue to engage our community; access to continued funding and endowment (moving towards becoming self-sustainable); continuing to deepen our relationships with members, caregivers, health care providers, and

volunteers; and building relationships with policy makers who can advocate on our behalf.

We have engaged the input of various stakeholders to gain insights into the HNC strategic plan, including board members, HNC staff, treatment centers, and community members. Over the months to come, we will be updating the membership on the details of the strategic plan via the newsletter, and aim to have the plan finalized prior to the end of December.

Your Voice Makes a Difference HNC Needs Assessment

The needs of the bleeding disorders community are always changing. As a member of Hemophilia of North Carolina (HNC), your voice matters. HNC needs to hear from its members to find out if your needs are being met, and how future programs and events can be tailored to the community and you.

If you have not already done so, please take the time to complete the HNC Needs Assessment. This survey will gather information about your current involvement in the community, your satisfaction with HNC programs and services, and what you would like to see from HNC in the future. Whether you are someone who participates in everything that you can, or if you are someone who has never been to an HNC event or utilized any of HNC's services, we want to hear from YOU!

The Needs Assessment is open to all adults in the bleeding disorders community, whether you have a bleeding disorder or care for someone with a bleeding disorder. If you have adult children outside of your home who may not be receiving HNC's communications, please ask them to provide their input as well. Your feedback is anonymous. HNC hopes to receive at least 100 responses to the Needs Assessment by December 1, 2020. As an appreciation for your time, everyone who completes the Needs Assessment will be entered into prize drawings held every three months throughout the year. The first two winners have already been chosen. The next prize drawing will be on September 30, 2020. Maybe you will be the winner!

You can access the Needs Assessment by going to the following website or by scanning the QR code on your phone: www.surveymonkey.com/r/HNCNeedsAssessment

Now, more than ever, your voice is needed!



Help Us to Reach You

Hemophilia of North Carolina (HNC) is currently updating its membership database. Please help by updating your membership information. If you have changed your phone number, email, or address, this is especially important. HNC sends out information at least once a week about educational opportunities and other relevant information from both the North Carolina bleeding disorders community and the national bleeding disorders community.

When updating your membership information, if possible, please include all members of your household. You can add details in the comment section of the online membership form.

An online membership form is available on the HNC website: www.hemophilia-nc.org/membership

The Raleigh Family Festival & Walk Is Going Virtual continued from page 1

including educational and supportive activities like retreats and one-day events, COVID relief, medical IDs, financial assistance, and more!

HNC learned a lot with the transition of the Charlotte Family Festival & Walk for Bleeding Disorders to a virtual event, and is planning for a fun event that you can participate in while at home. In the four weeks leading up to the walk, there will be weekly activities and fundraising challenges, leading up to a 2.5-5K walk on your own, and activities and announcements live streaming on

October 17. In addition, HNC plans on awarding great prizes: the Top Team and Top Individual Fundraising Awards; King, Queen, and Junior Droplet Awards for the man, woman, and child who go above and beyond in their efforts to support the Festival & Walk; and the Hospital Cup Award.

It's not too late to join in on the fun! You still have time to start a team and start fundraising. Please visit the HNC website for more information, and with your help, you can make a difference! www.hemophilia-nc.org/festival

Unión Latina Retreat Moving Virtual

November 6-8, 2020

Virtual

As with other events this year, the COVID-19 pandemic has forced Hemophilia of North Carolina (HNC) to rethink how it will be offering its educational and support opportunities. With the health and safety of its members of utmost importance, HNC has made the decision to transition the Unión Latina Retreat to a virtual event.

The Unión Latina Retreat provides the opportunity for those who speak Spanish to get together, learn, and find support from one another. All educational sessions are presented in Spanish so that language does not need to be a barrier to knowledge.

More details for the Unión Latina Retreat will be available on the HNC website. You may also text Gillian Schultz, HNC Program Manager, at (919) 272-6000 for more information.

Holiday Celebration Moves Virtual

December 5, 2020

Virtual

Hemophilia of North Carolina (HNC) is currently brainstorming ways to bring holiday cheer to the North Carolina bleeding disorders community for this year's Holiday Celebration. The difficult decision has been made to cancel the in-person event and transition to a virtual event on December 5. Stay tuned to your email and the HNC website for more details about how HNC plans to celebrate the holiday season with you.



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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Virtual Events... Zoom... and More!

By: Gillian Schultz, HNC Program Manager

We are all living through unprecedented times. Who would have thought back in March when COVID-19 first started to hit North Carolina that our lives would still be put on hold six months later! Many of us are still working from home, our children started a new school year with mostly remote or some hybrid remote/in-person instruction, and we are still limited as to the activities that we can do.

Hemophilia of North Carolina (HNC) has been working hard to continue providing opportunities for the community even during these virtual times. But we would like to know if what we are doing is working for you. Are virtual retreats as we have been doing something to continue? Would you like to see more informal coffee chats, happy hours, etc? Do you have other ideas to help keep the community connected during these times? Please let us know by sending your ideas to events@hemophilia-nc.org or by calling (919) 272-6000.

Save the Date!

Save the dates for the following Hemophilia of North Carolina (HNC) events planned for 2021.

HNC Annual Meeting – Spring 2021

Charlotte Family Festival & Walk for Bleeding Disorders – April 17, 2021

HNC Medical Symposium – May 1, 2021

HNC Adult & Family Retreat – July 9-11, 2021

HNC/HSC Teen Retreat – August 7-10, 2021

**** Please note all dates are subject to change. Decisions as to whether events will be held in person will depend on guidance from the Governor and conversations between HNC staff and the board of directors.**

Virtual Charlotte Family Festival & Walk

June 28, 2020

Virtual

On June 28, Hemophilia of North Carolina (HNC) held its first-ever virtual fundraiser, and it was a huge success! Because of the efforts of the bleeding disorders community, over \$65,838 was raised to support HNC's mission of improving the quality of life of persons affected by bleeding disorders.

After rescheduling the Charlotte Family Festival & Walk for Bleeding Disorders from April 18 to June 28, and then realizing that it would not be able to take place in person, HNC staff and volunteers worked hard to transition to a virtual event. They looked at other nonprofits around North Carolina and the country to determine best practices in the transition to a virtual event. Although people would not be able to get together in person, HNC wanted to create a fun event where people could still be "together" while apart. Throughout the month of June, leading up to June 28, HNC posted a weekly challenge to get everyone excited:

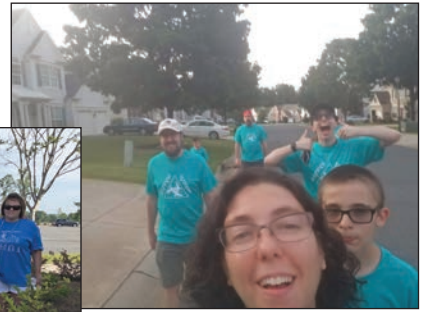
- June 1-7: take a picture or video of yourself getting ready to walk.
- June 8-14: post a funniest quarantine video.
- June 15-21: 18-rep challenge - do 18 reps of a physical activity like pushups and donate \$18 to your walk team.
- June 22-28: complete a 2.5K-5K walk. *Continued next page*



Virtual Charlotte Family Festival & Walk *continued from previous page*

On June 28, HNC held the festivities on Facebook Live and hosted a Zoom meeting for teams and individuals to safely get together online. There was Zumba led by Gee Smith, awards and prizes were announced, along with spotlights of all the teams involved. Congratulations to the award winners:

- Top Team: Team Diego
- Top Individual Fundraiser: Dylan Stephenson
- King Droplet: Jeron Hill
- Queen Droplet: Linda Kurtz
- Junior Droplet: Destiny Young
- Hospital Cup: Novant HTC



Of course, this event wouldn't have been possible without the support of the fundraisers, donors, volunteers, and sponsors who made it such a success!

Save the date for the 2021 Charlotte Family Festival & Walk for Bleeding Disorders: April 17, 2021, on World Hemophilia Day, back in Uptown Charlotte.

Hemophilia of North Carolina (HNC) would like to once again thank our kind and generous fundraisers for their commitment to the recent virtual Charlotte Family Festival & Walk. Below includes messages from some of these individuals.

Thank you to all who supported HNC by contributing to both of our teams! Good Luck at the Raleigh Virtual Walk!
~ Allen & Linda Kurtz

Supporting and caring for patients with bleeding disorders is not only my profession but my passion. HNC is a great advocate for the bleeding disorders community and I am proud to be associated with their endeavors. The team at HTC of LCI and LC hope to see you all next year in person for another successful Charlotte Festival & Walk!

"HTC and Me! Together We Stand!"
~ Dr. Mary Ann Knovich
Hemophilia Treatment Center of Levine Cancer Institute and Levine Children's

Thank you Hemophilia of North Carolina for all that you do to support the bleeding disorders community!
~ The Schultz Family

Huge thanks to my family and my twitch.tv/phyrus675 community for their amazing generosity.
~ Karl Schultz

In memory of George D. McCoy
~ Phil R. Poovey

Diego we all love you very much!
~ TEAM DIEGO

We are truly thankful for the support of our family, friends, and HNC
~ Team Wonderfully Made

Our family continues to be inspired by the bleeding disorders community's resilience and support of one another.
~ The Cowell & Conger family

April & Raine Lindsey-Evans

Linda & Herman Hodges

Steve & Debra Graziano

SOAR Education Days

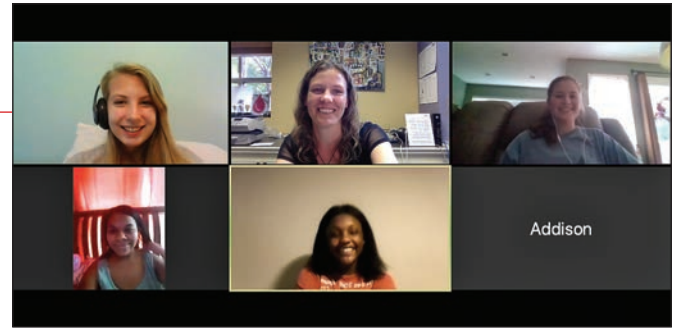
June 30-July 2

Virtual

COVID-19 may have prevented women with bleeding disorders from getting together in person, but it didn't prevent them from having the opportunity to connect and learn together. From June 30 to July 2, women and teenage girls participated in the SOAR Education Days, which provided education and emotional support for more than 30 women and teen girls who have a bleeding disorder.

On June 30, the women had the opportunity to participate in a roundtable conversation and art project sponsored by Diplomat Specialty Infusion Group. On July 1, the women chose between three breakout sessions: *Hemophilia in Women*, presented by Dr. Abajas from the HTC at UNC; *Rare Bleeding Disorders*, presented by Dr. Knovich from the HTC at Levine Cancer Institute; and *von Willebrand Disease*, presented by Virginia Kraus from Grifols. These sessions provided an opportunity to learn more about the bleeding disorder that they are affected by, how these disorders may affect them differently as women, and the importance of talking to their medical providers. Finally, on July 2, the women and teen girls participated in a "Rap Session" where they shared their experiences, challenges, and stories. In addition to the educational and supportive sessions over the three days, attendees had the opportunity to learn more about the sponsors and the products that they provide to the bleeding disorders community.

Although held virtually, new connections were made, and the women are looking forward to another opportunity to get together again at another SOAR event.



HNC/HSC Teen Retreat

August 7-8, 2020

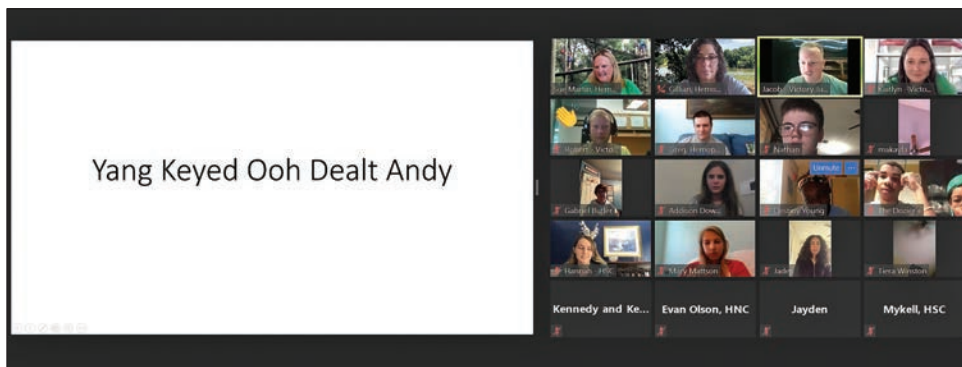
Virtual

This year's Teen Retreat looked a little different, but it still included lots of fun and education (don't tell the teens) with our neighbors from Hemophilia of South Carolina (HSC)! When Hemophilia of North Carolina (HNC) and HSC made the decision to hold the Teen Retreat virtually, the big question was, "What are we going to do?" Both HNC and HSC still wanted to provide an opportunity for teens to get together. HNC and HSC also knew that four days of virtual programming wouldn't work, so they decided to shorten the event to be held over two days. With the help of Victory Junction and the Hemophilia Federation of America (HFA), a plan was put in place.

On Friday night, Victory Junction helped to kick off the event with a fun campfire that included an ice-breaker and games. Greg Witul from HSC also emceed a Kahoot! game that was fun for everyone. On Saturday, Victory Junction started off the day with some games, a scavenger hunt (ask your teens if they know how people used to carry around their music), and a science experiment. The teens

also had the opportunity to take time to learn American Sign Language (ASL) or to learn how to write a resume. When everyone joined back together, the teens who learned sign language were able to introduce themselves using ASL, and the teens who went to the resume session were able to share what to include in a resume. After a

Continued next page



Playing "Guess the Gibberish"

HNC/HSC Teen Retreat *continued from previous page*

break, everyone came back for a session led by HFA that was fun and engaging. A variety of scenarios were presented and the teens had to talk about what to do if they were put in those situations. Some great conversation came from this session, and it was clear that these teens had strong heads on their shoulders. The evening ended with a closing campfire, led again by Victory Junction, where the teens reflected on the event and said their goodbyes.

Although not what anyone initially envisioned when planning for the Teen Retreat started in 2019, the event turned out to be a huge success. HNC is looking forward to hosting more activities for teens later in the year or early in 2021.

Hospital Cup Lunch

August 13, 2020

To thank the hematology center that raises the most money for the Family Festival & Walk fundraiser each year, Hemophilia of North Carolina (HNC) usually hosts a Hospital Cup lunch for the winning team. This year's lunch was held on August 13 to celebrate the first-place hematology center for the Charlotte Family Festival & Walk for Bleeding Disorders. Congratulations to the Hemophilia Treatment Center at St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital!



ECU and HNC: Bingo Fun!

August 22, 2020

Virtual

It was a fun Saturday, including Bleeding Disorders Bingo and time with friends from the East Carolina University (ECU) Hemophilia Treatment Center (HTC). Hemophilia of North Carolina (HNC) was excited to partner with ECU and provide some fun entertainment and time for support. Lora Joyner, ECU's Physical Therapist and HTC Coordinator, developed an online bingo game that was bleeding disorders themed. By the time one lucky player called out "BINGO," everyone had learned something new! It was an exciting way to expand one's knowledge. Thanks to ECU for partnering on this event and to the Hemophilia Alliance Foundation for making it possible through a grant.



UNC and HNC: Across the Disciplines

August 22, 2020

Virtual



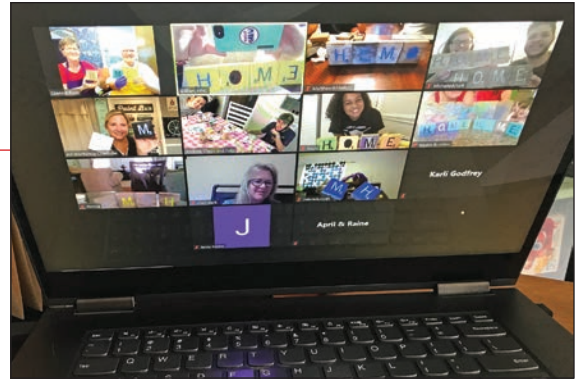
Hemophilia of North Carolina (HNC) members had a chance to learn from their University of North Carolina at Chapel Hill (UNC) Hemophilia Treatment Center (HTC) providers. Topics included dental health, gene therapy, other treatments and therapies, COVID, and more. One of the highlights from the program, aside from hearing from such a well-rounded group, was learning more about UNC's Women and Girls Clinic! The UNC HTC has developed a clinic specifically for women and girls with bleeding disorders, including access to an OB/GYN. This is an amazing opportunity as a lot of females struggle to find OB/GYNs who understand their bleeding disorder. Thanks to UNC for partnering on this event and to the Hemophilia Alliance Foundation for making it possible through a grant.

VWD Education Day

August 29, 2020
Virtual

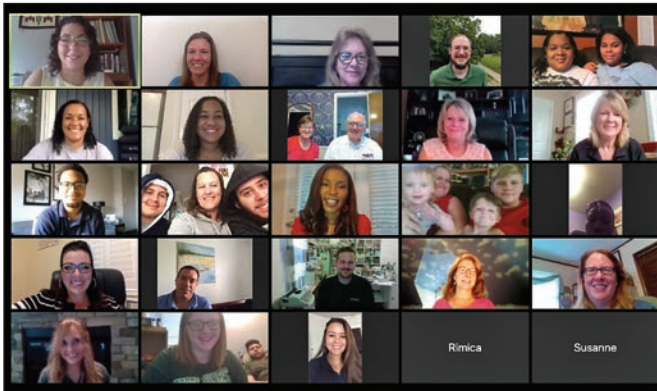
Hemophilia of North Carolina (HNC) held its first exclusively von Willebrand disease (VWD) event in many years on August 29. Nearly 40 people affected by VWD joined the virtual event to learn more about living with the most common bleeding disorder.

The event started with the session, *VWD: Not the Little Sister of Hemophilia*. Led by Kelly Lynn Gonzalez, the session focused on the importance of connecting with the community and not minimizing VWD as “no big deal.” After lunch, Dr. Hinson from the Hemophilia Treatment Center at Levine Children’s presented *Treatment Options for von Willebrand disease*. The presentation touched on topical treatments, the use of DDAVP



and Stiminate, and factor products, as well as where the research is going as far as future treatments and how von Willebrand factor may play a role in complications from COVID-19. The presentation also addressed the Stiminate recall and the importance of reaching out to your medical provider and pharmacy so you have a plan in place. Attendees had the opportunity to ask questions and share their feedback for future VWD events. Finally, everyone had the opportunity to participate in a wood-painting project led by AR Workshop Charlotte.

Thank you to the sponsors who helped to support this event. HNC is looking forward to providing more VWD-focused opportunities in the future.



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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Actualización del Programa Unión Latina

El Programa Unión Latina esta diseñado para proporcionar apoyo a los miembros de habla hispana, de la comunidad con problemas de desórdenes hemorrágicos. Aunque los programas no están siendo ofrecidos de manera presencial, el objetivo sigue siendo el mismo, proveer una comunidad y educación. Los eventos están siendo ofrecidos por ahora en línea, a través de la plataforma de Zoom. Los próximos eventos de la Unión Latina incluyen el Mes de la Herencia Hispánica, el 10 de Octubre, el Retiro de la Unión Latina, del 6 al 8 de Noviembre, y las festividades de fin de año, el 5 de Diciembre.

El Programa de la Unión Latina otorga soporte y educación a los individuales Latinos y sus familias en Carolina del Norte quienes sufren de desórdenes hemorrágicos. El programa es ofrecido en Español y es posible gracias al subsidio de Takeda. Para más información visite el sitio internet de HNC.

Evento de la Unión Latina – Mes de la Herencia Hispánica

10 de Octubre del 2020

Virtual

Hemofilia de Carolina del Norte (HNC por sus siglas en Ingles), les invita el 10 de Octubre a las 7 PM a una celebración especial del Mes de la Herencia Hispánica! El mes de la Herencia Hispánica celebra y reconoce las contribuciones de la comunidad Latina. El evento presentara actividades que reforzaran sus conocimientos de la cultura Latinoamericana. Adicionalmente a las actividades, se ofrecerá un programa educacional que brindará orientación en el manejo de sus problemas hemorrágicos, o de niños con estos desordenes. Están invitados a participar en este entretenido programa, con sus familiares y amigos. Mas información al respecto se encuentra disponible en el sitio internet de HNC, www.hemophilia-nc.org. También puede comunicarse con Gillian Schulz, Gerente del Programa, enviándole un texto al (919) 272-6000.

Retiro de la Unión Latina Versión Virtual

6 al 8 de Noviembre del 2020

Virtual

Así como ha ocurrido con otros eventos este ano, la pandemia del Covid-19 ha obligado a la Hemofilia de Carolina del Norte (HNC por sus siglas en Ingles) a reformar la manera como el programa seguirá ofreciendo su plan educacional y la oportunidad de apoyo. Teniendo en consideración que la salud y seguridad son lo mas importante, HNC ha tomado la decisión de realizar una transición y hacer el Retiro de la Unión Latina un evento virtual.

El Retiro de la Unión Latina proporciona a los individuos de habla Hispana la oportunidad de reunirse, aprender y apoyarse unos con otros. Todas las sesiones educacionales son presentadas en Español, de manera que el idioma no sea un inconveniente para adquirir conocimiento.

Mayores detalles acerca del Retiro de la Unión Latina estarán disponibles en el sitio internet del HNC. También puede enviarle un texto a Gillian Schultz, Gerente del Programa HNC al (919) 272-6000 para más información.

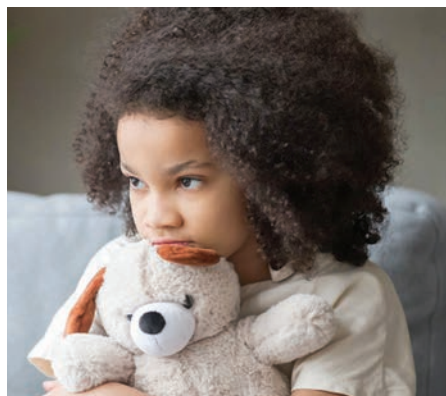


Cómo ayudar a su hijo(a) con un trastorno hemorrágico a sobrellevar la ansiedad y el estrés durante la pandemia

Consejos para familias en la comunidad con trastornos hemorrágicos durante la pandemia de COVID-19 y posteriormente

El autor: Donna Behen

La pandemia de COVID-19 tiene a muchas familias nerviosas en este momento. Se recortan los empleos, se interrumpen las rutinas y, con los requisitos de distanciamiento social establecidos en la mayor parte del país, los padres están haciendo malabares con las demandas de trabajar en casa para mantener a sus hijos saludables, felices y ocupados con actividades constructivas, incluido el aprendizaje en línea.



Por supuesto que las familias de la comunidad con trastornos hemorrágicos están lidiando con todos estos nuevos factores estresantes, pero eso se suma a las dificultades diarias únicas que conlleva el manejo de un trastorno hemorrágico.

“Vivir con un trastorno hemorrágico o criar a un(a) niño(a) con un trastorno hemorrágico puede ser muy estresante de todos modos, pero agregar una pandemia mundial solo aumenta este estrés”, dice Robert Loudén, MSW, LCSW, trabajador social del Centro de Hemofilia y Trombosis de Indiana en Indianápolis.

¿Qué puede hacer para ayudar a nutrir y proteger el bienestar emocional de su hijo(a) en tiempos de crisis? Esto es lo que Loudén y sus compañeros trabajadores sociales del Centro de Hemofilia y Trombosis de Indiana Gail Jordan, MSW, LCSW; DeAuntae Lawson, MSW, LSW; y Ashley Parmerlee, MSW, LCSW, recomiendan:

Mantenga sus rutinas regulares

Los niños prosperan bajo estructuras, por lo que, en la medida de lo posible, se adhieren a las rutinas normales de su hogar, incluidas las horas regulares de dormir, las comidas, las tareas domésticas, etc. Esa consistencia ayuda a los niños a sentirse tranquilos y seguros, especialmente a los más pequeños.

Sea honesto pero tranquilizador

Hable con sus hijos sobre lo que está sucediendo, pero de una manera que no induzca ni aumente su ansiedad. El objetivo es crear un entorno donde los niños se sientan cómodos expresando sus preocupaciones y haciendo preguntas, y donde pueda abordar cualquier idea errónea que puedan tener.

Consulte a sus hijos con frecuencia para evaluar su comprensión actual y el estrés que rodea la crisis. Esté atento a los signos de ansiedad y depresión, incluidos los cambios en el apetito, las interrupciones del sueño, la agresión, la irritabilidad y el miedo a estar solo(a) o retraído(a).

Cuide su propia salud física y mental

Como padres, deben modelar cómo hacer frente a situaciones estresantes de manera positiva manteniendo hábitos saludables,

incluido el ejercicio, un sueño adecuado y estableciendo un tiempo a solas siempre que sea posible.

Manténgase positivo

Recuérdale a sus hijos que estar confinados en su hogar es temporal y que, incluso en tiempos difíciles, siempre pueden encontrar razones para estar agradecido.

“Si bien este es un momento de incertidumbre, también es un momento para agradecer a quienes nos rodean”, dice Loudén. “Nos da la capacidad de apreciar lo valioso que es el tiempo y cómo podemos usar estos momentos adicionales de una manera productiva”.

A nivel práctico, el ritmo más lento en el hogar puede facilitar la programación del proceso de infusión en el hogar y que sea más tranquilo. “También puede permitir que los niños sean más prácticos en el proceso, y posiblemente les permita a los adolescentes asumir un papel más independiente”, dice Loudén.

Manténgase en contacto con su HTC

Si tiene alguna pregunta o inquietud, comuníquese con su centro local para el tratamiento de hemofilia (hemophilia treatment center, HTC). Los trabajadores sociales están aquí para ayudar.

Dice Loudén: “Todos se sienten muy inseguros acerca de todo lo que está sucediendo. Por eso, es que estamos tratando de estar lo más disponibles posible y bien versados en todos los recursos que podrían beneficiar a nuestros pacientes para que podamos orientarlos en la dirección correcta cuando lo necesiten”.

De HemAware. Reimpreso con permiso.

SOAR Program Update

Hemophilia of North Carolina's (HNC) SOAR Program is designed to provide support for women and girls diagnosed with a bleeding disorder.

From June 30 to July 2, HNC held the SOAR Education Days for women and teen girls with a bleeding disorder. Sessions provided education about the need to advocate for yourself with a bleeding disorder, education specific to hemophilia, von Willebrand disease, and rarer bleeding disorders, art therapy, and time to connect and chat.

In the coming months, HNC will be participating virtually in the North Carolina Nurses Association (NCNA) Conference. HNC exhibits at this conference annually to raise awareness about women and girls with bleeding disorders so that diagnosis can come more quickly and treatment can be administered for women and girls who are suffering from the symptoms of an undiagnosed bleeding disorder.

In addition to events and advocacy about women with bleeding disorders, HNC moderates a private SOAR Facebook group for women with bleeding disorders.

In the coming months, HNC staff will be looking at new ways to support women in the bleeding disorders community. If you are interested in sharing your thoughts and ideas, please contact Gillian Schultz, Program Manager, at gillian.schultz@hemophilia-nc.org or by calling or texting her at (919) 272-6000.

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 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 Schultz, HNC Program Manager, for more information about the SOAR Program at soar@hemophilia-nc.org or by calling the HNC Office at (919) 319-0014.

HNC Exhibits at the NCNA Conference

September 17-18, 2020

Hemophilia of North Carolina (HNC) is exhibiting virtually at the North Carolina Nurses Association (NCNA) Conference on September 17-18. At this annual event, HNC helps to raise awareness about the symptoms of bleeding disorders, especially among women and girls, so that those who are suffering from the symptoms of a bleeding disorder can be diagnosed and receive treatment to improve their quality of life.



In the Winter Edition

Hemophilia of North Carolina (HNC) was hosting the annual Family Retreat while this newsletter was in the process of being printed. Although the Family Retreat was originally scheduled to be at the Great Wolf Lodge, HNC still found ways to bring the fun to people's homes as the event switched to a virtual retreat! Read about the Family Retreat in the Winter Edition of *The Concentrate*.

NC Medicaid is Changing



North Carolina Medicaid is switching from a fee-for-service model to a managed care model. This Medicaid Transformation was originally scheduled to begin in 2020 but was delayed because of the state budget. The transition is now scheduled to take effect on July 1, 2021. What does this mean for those on Medicaid in NC? Details are still forthcoming, but it will be very important to pay attention to any information that comes from Medicaid about the changes. Information should be mailed to all Medicaid recipients, however Hemophilia of North Carolina will also continue to communicate information as Medicaid releases it. All patients will need to pick a primary health provider. The deadline to select a primary health provider has not been announced as of the date this article was written. More information can be found at www.medicaid.ncdhhs.gov/transformation



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Hemophilia of North Carolina (HNC), like so many other organizations and businesses, has been bracing for the inevitable financial impact of COVID-19. From event sponsorships to Walk fundraising, the impact has the potential to significantly reduce HNC's ability to serve the bleeding disorders community. Therefore, in addition to the individual donor recognitions listed on page 19, HNC wants to give a special note of appreciation to the companies that have continued supporting HNC's efforts during the last few months.

Legislative Day



Charlotte Family Festival & Walk

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Revamping of HNC Programs Coming Soon

Hemophilia of North Carolina (HNC) has a variety of programs to support people with different needs in the community including:

- Blood Brotherhood – for men with a bleeding disorder
- HOPE – for families who have a child with a bleeding disorder
- SOAR – for women and girls with a bleeding disorder
- Unión Latina – for Spanish speaking community members

Based on results from the Needs Assessment, feedback from community members, and changing demographics in the community, HNC is assessing its current programs and looking at ways to strengthen and make better the opportunities provided for people affected by bleeding disorders in North Carolina.

If you would like to share your thoughts, please email Gillian Schultz, HNC's Program Manager, at gillian.schultz@hemophilia-nc.org or call her at (919) 272-6000. In addition, if you have not already completed the Needs Assessment, please help HNC move the organization forward by completing the survey: www.surveymonkey.com/r/HNCNeedsAssessment



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

HOPE Program Update

Families who have a child with a bleeding disorder are encouraged to become part of Hemophilia of North Carolina's (HNC) HOPE Program. The HOPE Program provides support for families who have a child twelve and under diagnosed with a bleeding disorder through educational opportunities, peer and emotional support, and resources.

This year's Family Retreat, which was held virtually, is a HOPE Program event. The Family Retreat this year took place from September 11 – September 20, with sessions planned for parents and children, including a science experiment about clotting, tie-dying, a scavenger hunt, navigating back to school, maintaining connections during social distancing, and more. You will be able to read more about the Family Retreat in the winter edition of the newsletter.

If you are a parent of a newly diagnosed child with a bleeding disorder, HNC also offers a Parent Mentoring Program to help provide additional support. The mentors are all parents of a child with a bleeding disorder.

In addition to scheduled events, HNC moderates a private HOPE Facebook group.

In the coming months, HNC staff will be looking at new ways to support families in the bleeding disorders community. If you are interested in sharing your thoughts and ideas, are looking to be connected with another parent through the Mentoring Program, or need anything else to support raising a child with a bleeding disorder, please contact Gillian Schultz, Program Manager, at gillian.schultz@hemophilia-nc.org or by calling or texting her at (919) 272-6000.

You can also check the HNC webpage, your email, Facebook, Twitter, and Instagram pages for updates about upcoming programs and events.



Blood Brotherhood Program Update

HNC is looking to grow the Blood Brotherhood Program over the next year and encourages all men

with a bleeding disorder, no matter their age, to join scheduled programs. Is there something that you would like to see HNC offer? As the community continues to age, and younger guys are experiencing better outcomes than in past generations, HNC knows that your needs are changing. Please contact Gillian Schultz, HNC Program Manager, at gillian.schultz@hemophilia-nc.org or call (919) 272-6000 to speak with her directly about your ideas

for activities and events, or if you have any questions about the Blood Brotherhood Program.

HNC's Blood Brotherhood Program is an extension of the Hemophilia Federation of America's (HFA) Blood Brotherhood Program. It's designed to provide opportunities for men with bleeding disorders to get together both in person and online to discuss their issues with each other and with caring professionals. If you can't make an event, consider connecting with adult men with bleeding disorders from the comfort of your own home with the new and improved Blood Brotherhood private online forum! Go to www.hemophiliafed.org to register.

Unión Latina de Hemofilia

Unión Latina Program Update

The Unión Latina Program is aimed at providing support for Spanish-speaking members of the bleeding disorders community. Although events are not currently being held in person, the goals remain the same: to provide a sense of community and education. Events are currently being held online through the Zoom platform. Upcoming Unión Latina Events include a Hispanic Heritage Month celebration on October 10, the Unión Latina Retreat from November 6-8, and the Holiday Celebration on December 5.

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.

HNC Convenes Second Meeting of North Carolina Advisory Board for Bleeding Disorders

By: Steven Humes, HNC Board President



On Friday afternoon, July 31, a second Zoom meeting of the North Carolina Advisory Board for Bleeding Disorders (NCABBD) was convened by Hemophilia of North Carolina (HNC). The Board was initially started some years ago by HNC and the leadership of the Region IV-North Hemophilia Treatment Center (HTC) Network. For various reasons, attendance and membership gradually declined, and it became difficult to convene a consistent group of people. Thus, it was decided to shut down the group, at least temporarily. However, as new HTCs have entered the network in the past few years and HNC has expanded its reach, HNC staff and volunteers began to think about reviving the group in order to improve communication among HTCs, HNC, and consumers. This led to a relaunch of the group on April 24, 2020. *Continued next page*

The hemophilia treatments of today were once the dreams of yesterday. Proof that when

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HNC Convenes Second Meeting of North Carolina Advisory Board for Bleeding Disorders continued from previous page

The Board, which meets quarterly, is composed of staff members of HNC and HTC's in North Carolina, as well as consumers. It offers an opportunity for those involved to share information and provide feedback on HTC services and HNC programming. The Board is helpful in identifying unmet needs of the patient population from healthcare, educational, and emotional support perspectives. Steven Humes, who chaired the group before his retirement as the Region IV-North Regional Coordinator and who is now the Board President of HNC, leads the meetings.

During the July 31 meeting, there was a lengthy discussion of how HTC's and HNC are responding to the COVID-19 pandemic. Some centers are now encouraging in-person clinic visits, while others are doing as many telehealth appointments as possible. One center in Charlotte has had a few pediatric bleeding disorder patients who have contracted COVID-19. As bleeding disorders complicate the course of COVID-19, these patients have been very sick and have had issues with clotting.

HNC has moved all of its events online and will continue to do so for the foreseeable future. HNC has been very innovative in its approaches, and other chapters across the country have looked to HNC for technical assistance. With the move to virtual meetings, a different approach to industry has been required; no industry employees are allowed to participate in HNC events without invitation, including consumers who have dual roles. All industry employees in virtual meetings must clearly identify themselves.

The Board has been able to recruit three consumer members, but more would be welcome. If you are a consumer who would be interested in joining the NCABBD and can commit to attending a quarterly meeting, please contact Charlene Cowell at charlene.cowell@hemophilia-nc.org. HNC is particularly interested in having a diverse group of members (race, ethnicity, age, gender, type of bleeding disorder, and geographic location). The next meeting will take place on Friday, October 30, from 1:00 to 3:00 via Zoom.

Community Spotlight



**Bethany Mattson –
Teen Impact
Award Winner**

The Teen Impact Awards are presented to recognize teens in the bleeding disorders community who are making a positive impact at home, school, and their community. Presented by Believe Limited, the Teen Impact Awards were held during the first night of the National Hemophilia Foundation (NHF) Bleeding Disorders Conference and emceed by Patrick James Lynch, along with guest presenters, Super Bowl champion Josh Gordy, and CEO and mountaineer Chris Bombardier, along with other young adult leaders from NHF's National Youth Leadership Institute (NYLI).

One of this year's award recipients was Bethany Mattson from North Carolina!

Bethany received the nomination for the Teen Impact Award for Advocacy. She volunteers for several organizations across the Charlotte area including:

Overflow, which provides care for kids in foster homes across the greater Charlotte community. Bethany spent hours providing child care, assisting with parents' nights out, and offering support and encouragement to foster parents in the community.

Promising Pages, which helps to collect and distribute books to some of the poorest areas of Charlotte.

Samaritan's Feet, which distributes shoes and socks for kids in poverty.

Baptist Children's Home and the Harrisburg Public Library, making hundreds of cards for veterans, foster families, and nursing homes.

As a child, Bethany would introduce herself and say, "Hello. My name is Bethany and I like to help people!"

Congratulations, Bethany, for your hard work!

Hemophilia of North Carolina (HNC) wants to celebrate your important milestones!

Want to celebrate your birthday, anniversary, or event with HNC?

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

2020 Friends of HNC

*We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2020
We extend a sincere thank you to our supporters, some of who have contributed several times during this period.*

General Donations & Annual Giving Contributions

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Irene Cowell
Marlo Davis
Stan Efird
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William Katz
Phillip Poovey
Nancy Smoak
Daryl Steinbraker

COVID-19 Financial Assistance Fund

Linda & Allen Kurtz
Nicholas Register
Gillian & Karl Schultz

In Celebration of Phil Poovey

Sylvia Herbert
Carolyn Nusher

In Honor of The Registers

Carol Van Steenberg

Thank You 

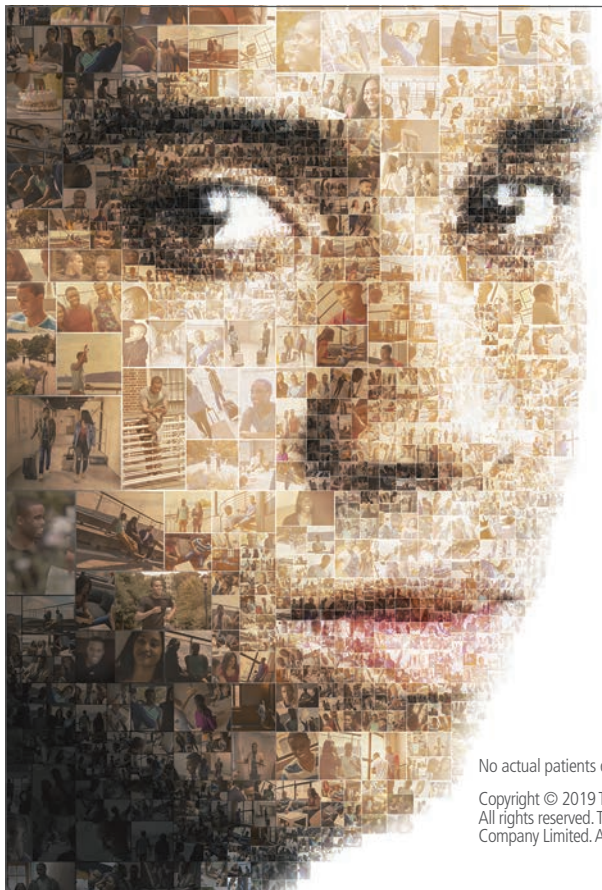
Going Back to School Amid COVID-19

By: Gillian Schultz, HNC Program Manager

The beginning of the school year is usually busy! Between shopping for school supplies, picking out lunchboxes and backpacks, or buying new clothes, there's a lot to do, even without a bleeding disorder. Throw in meetings with the new teacher and the school nurse to talk about managing bleeding disorders in school, and it gets even busier!

This year has been different, however. We live in Charlotte, and our school district is all remote for the time being. At the time I am writing this article, no decisions have been made about when in person learning will begin. Across North Carolina, school districts have a variety of learning plans, including all remote, hybrid models where schools are back partly in person and partly at home, and all in person, but with restrictions on activities and how the classroom is set up. Though we didn't have back-to-school shopping this year, we had several trips to my kids' schools to pick up Chromebooks, workbooks, musical instruments, and other materials that they need to make sure they are successful with their at-home learning.

Even with remote learning, it is important that your child's teacher is aware of their bleeding disorder. Though (s)he might not need extra time in the hallway to get from one class to another, it's important that plans are in place in case they need to miss *Continued next page*




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Going Back to School Amid COVID-19

continued from previous page

school due to a bleed, hospitalization, or other absence related to the bleeding disorder. There may also need to be accommodations for accessing the curriculum in case a bleed makes it difficult. My son slammed his finger in the door, which caused a bleed in his finger on his dominant hand, making it difficult for him to write. Although it had healed enough for him to write and submit assignments, if it was severe enough to prevent him from being able to type and write his assignments, accommodations would have been necessary, even though we're at home.

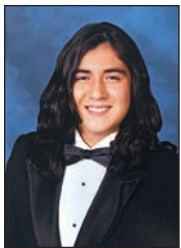
When I found out who Noah's teacher is this year and I introduced us to her over email, I made sure she had information about his hemophilia. Noah has an Emergency Health Plan which details what to do if he suffers an injury or a bleed at school, as well as a 504 plan which provides him with accommodations related to his hemophilia. Some of his accommodations include excused absences related to

hemophilia and access to the health room at all times. I sent the teacher resources about hemophilia and asked her to review his 504 plan and let me know if she had any questions. Noah also has a new school nurse this year, so I wanted to make sure she was aware of his hemophilia. Noah's 504 annual review isn't until January, so I didn't schedule a 504 meeting at this time, but if your child has a 504 plan that is supposed to be reviewed at the beginning of the year, it is important that you schedule that meeting now. Although we don't know when school will be returning in person, I have already spoken with the school nurse and teacher and we are planning for a meeting the week before school resumes in person, even if it isn't time for his 504 review.

COVID-19 has caused much in our lives to change. This is a temporary situation, and hopefully soon we will again begin to see some sense of normalcy. But for the time being, we will have to continue supporting our children through their new ways of schooling.

Congratulations to our scholarship winners!

Hemophilia of North Carolina (HNC) is proud to provide educational scholarships to community members through two scholarship funds: the Diplomat/HNC scholarship fund and the George D. McCoy scholarship fund, in honor of a founding member of HNC.



Johan Diaz
Sanata Ana, California



Ashley Holland
Hudsonville, Michigan



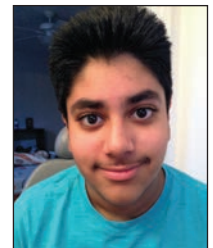
Mihir Joshi
San Francisco, California



Kendra Brewer
Virginia Beach, Virginia



Avery Amende
Bozeman, Montana



Anmol Saini
Engelwood, Ohio



Tori Robbins
Manahawkin,
New Jersey



Nathan Mermilliod
Riverside, California



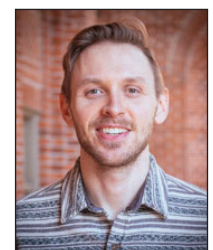
Matthew Bayer
Warminster, Pennsylvania



Timothy Wohl
Perrysburg, Ohio



Yan Ostanin
West Minster, Colorado



Corey Pierce
Portland, Oregon



Shane Secinaro
New Durham,
New Hampshire



Morgan Madison
Waterford, New York



Brian Duval
Golden Valley, Minnesota



Mykel Dolinski
Lincoln Park, Minnesota



Anonymous

COVID-19 and VWF

By: Leonard Valentino, MD, President and CEO, National Hemophilia Foundation

Recently, there has been considerable interest in the role von Willebrand Factor (VWF) may play in the complications of COVID-19, the infection caused by SARS-CoV-2, including in lay online media.

The SARS-CoV-2 virus attaches to the cells that line blood vessels and in some people causes a severe inflammatory response of those cells, a so-called endothelialitis. This story actually begins with the first cases described in Wuhan, China in late 2019 and early 2020. Preliminary reports initially from Wuhan and Shenzhen, China indicate that the patient's blood type may play a role in the susceptibility and severity of symptoms in patients with COVID-19; individuals with blood type O appear to more resistant while those with type A may be more susceptible and experience more severe symptoms. Normally, the levels of VWF in plasma vary considerably between individuals and within the same individual at different times, as VWF is influenced by several variables, such as age, pregnancy, smoking, hormones, and blood group. It is thought that blood group contributes to about 30% of the variability in VWF levels in plasma: Among people not considered to have von Willebrand disease (i.e., normal population) VWF levels are 25-35% lower in individuals with blood group O than in individuals with non-O blood group and those with blood type AB have the highest levels.


VWF has two functions in the body. First is carrying factor VIII, the protein that is deficient or absent in hemophilia A. Its second role is to facilitate binding of platelets to arteries and veins. It is a very sticky protein that therefore plays a significant role in preventing and controlling bleeding by facilitating platelet binding to sites of injury to the blood vessels. As such, low levels of VWF are associated with bleeding (von Willebrand disease) while high levels may be associated with blood clots in the arteries and possibly in the veins of the body. In fact, when there is a pathologically high level of the stickiest VWF molecules, a severe and often fatal blood clotting disorder results known as thrombotic thrombocytopenic purpura (TTP). TTP is due to the deficiency of an enzyme, ADAMTS-13, that cuts these stickiest VWF molecules into smaller sizes making them less adhesive and therefore less dangerous. Therefore, we have known for years that VWF plays a role in blood clotting (and in preventing bleeding).

While the blood group may play a role and be associated with higher levels of VWF, a more important effect is the inflammatory response in the blood vessel cells causing them to release proteins made in the cells including VWF. Very high levels of VWF in the blood of patients with severe COVID-19 disease have been observed since those early cases and additional research has confirmed this to be true. It is not surprising that someone, in this case Dr Aksenova at St Petersburg University in Russia, put forward a hypothesis that a more severe case of COVID-19 disease may be associated with the elevated levels of VWF. Of course, this is thought-provoking as any hypothesis should be and is designed to stimulate further investigation. However, it is neither unique nor is it novel. Scientists in Switzerland, Italy, The Netherlands, India and the United States have already tested this hypothesis by examining the blood of patients with COVID-19 to look at the role VWF might play in the

symptoms and death of some patients. It is thought that VWF plays a major role in the blood clots that develop in the lungs and other organs of patients with COVID-19 disease. Elevated levels of VWF due to the severe inflammation that occurs in the blood vessels is further worsened by a secondary deficiency of the ADAMTS-13 enzyme which is overwhelmed by the amount of VWF in the blood. This further contributes to very high VWF levels in the blood and a vicious cycle is created. Indeed, in the Italian study, these researchers showed that 5 out of 6 patients with dangerously low levels of ADAMTS-13 died.

How will the story end? We don't know quite yet. There is much to be learned about this new virus, SARS-CoV-2 and how to mitigate its effects once someone is infected but know that scientists are actively researching these important questions day and night. In regard to those in the bleeding disorders community, there may be a silver lining— might von Willebrand disease have protective influence against serious symptoms? This chapter remains to be written but I am certain the story will continue to unfold.

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NHF Bleeding Disorders Conference

August 1-8, 2020
Virtual

The National Hemophilia Foundation (NHF) Bleeding Disorders Conference was originally scheduled to take place in Atlanta, GA in early August. Due to the COVID-19 pandemic, it was transitioned into an online format and spread across a week. Despite the inability to be with friends in Atlanta and share hugs, this provided an opportunity for people to attend an NHF conference who otherwise may not have been able to travel. The conference included tracks for consumers, spouses/partners, teens, providers, chapters, and more. There were topics of interest no matter what your connection to the community may be!



HFA Symposium: Charting Our Future

August 24-29, 2020
Virtual

The Hemophilia Federation of America (HFA) Symposium was set to take place in beautiful Baltimore, MD. Once it was obvious that the event could not take place as planned, the HFA team shifted this important event to an online platform. The theme of the event, *Charting Our Future*, was a reminder to community members that they are responsible for creating the path for their future and their children's future. Sessions including those focused on telling your story and access to care reinforced the importance of advocacy. People from all over were able to gather virtually and learn from medical professionals and their peers. It was a great event!



Hemophilia Alliance Hill Days

July 27-29, 2020
Virtual



Each year, people from around the country head to Washington, DC for the Hemophilia Alliance Hill Days. This year, which happened to be Charlene and Gillian's first time participating in this event, looked a little different as the Alliance shifted to a virtual platform. More than 60 people participated, including Hemophilia Treatment Centers (HTCs), chapters, the National Hemophilia Foundation (NHF) and the Hemophilia Federation of America (HFA), and patient advocates. It was a busy couple of days as participants held over 80 meetings with Congressional offices. The talking points included education about bleeding disorders, the importance of the HTC network, and requests for co-sponsors for the Hemophilia SNF Access Act (S. 3233 / H.R. 5952).

Earlier in the year, the House (HR 5952) and Senate (S. 3233) introduced the Hemophilia SNF Access Act legislation, which has the potential to end a long-time issue that the bleeding disorders (BD) community has faced. Skilled Nursing Facilities (SNFs) provide care for people who require medically appropriate care, especially after surgery or being hospitalized. SNFs receive a daily rate (per diem) for each patient under Medicare Part A. As we know, BD medication can be very costly. Most SNFs will not take patients with BDs because the costs of medication far exceeds that of the per diem provided by Medicare. This legislation would allow BD medication to be billed separate from the per diem given to SNFs, eliminating this barrier so that patients can get the care they need in order to heal properly in an appropriate setting.

The SNF bills have already received additional co-signers since the Hill Day event, and advocates are continuing to reach out to remind their elected officials how important this legislation is to the community. Those interested in advocating can reach out to Hemophilia of North Carolina staff to learn more about how they can add their voice. This legislation is specifically for the bleeding disorders community, so it's up to this community to advocate and ensure access to proper care!

Hemophilia of North Carolina 2020-2021 Calendar of Events Highlights

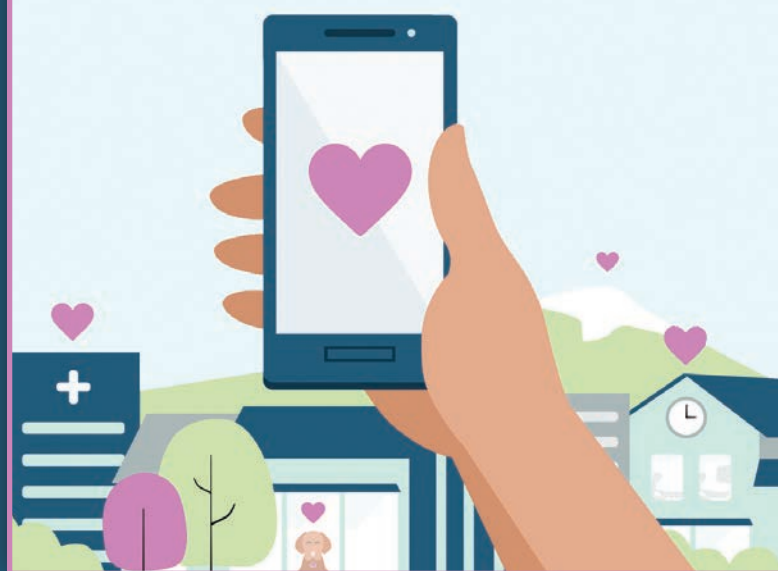


<u>October 3, 2020</u>	Let's Talk Mental Health - Virtual
<u>October 10, 2020</u>	Unión Latina - Virtual
<u>October 17, 2020</u>	Raleigh Festival & Walk – Virtual
<u>November 6-8, 2020</u>	Unión Latina Retreat – Virtual
<u>December 5, 2020</u>	Holiday Celebration - Virtual
<u>December 5, 2020</u>	Unión Latina (en la celebración navideña) – Virtual
<u>April 17, 2021</u>	Charlotte Festival & Walk - Charlotte, NC
<u>May 1, 2021</u>	Medical Symposium – Chapel Hill, NC
<u>August 7-10, 2021</u>	HNC/HSC Teen Retreat - Rock Hill, SC
<u>October 23, 2021</u>	Raleigh Festival & Walk - Morrisville, NC



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GOING VIRTUAL!

Hemophilia of North Carolina

**FAMILY '20
FESTIVAL**

& Walk for Bleeding Disorders



September 20-26 – “I Walk For” Challenge

September 27-October 3 – Fitness Challenge

October 4-10 – Costume Contest

October 11-17 – Walk for HNC

**– October 17 –
The Big Day: tune
in to Facebook Live**

MORE INFO: hemophilia-nc.org/festival