

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2021

HNC Awarded Large Grant



Hemophilia of North Carolina (HNC) was extremely honored to have been awarded the Hemophilia Alliance Foundation's Large Grant for 2021 to meet the mental health needs of the North Carolina bleeding disorders community.

This is a multifaceted project that will address a variety of areas and help HNC to plan for the future. In researching ways to support the mental health care needs specific to the bleeding disorders community, it was found that there are not many resources available. While HNC staff have heard about barriers to care, increased depression and anxiety, as well as other issues, there is only anecdotal evidence. In order to gather helpful information, HNC will be administering a survey this fall and winter. The survey is being developed in collaboration with the University of North Carolina Wilmington

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Meet Sujan – The Most Data Driven Intern In the World!

By: Fleming Samuels, Director of Philanthropy

Sujan Kumar has been working with Hemophilia of North Carolina (HNC) since March of this year and is transforming how we are working with our data and relationships with the community! He has been diligently inputting over 1,000 entries into our new database and communication system, that is more secure and searchable, according to how our members fill out their forms and the information that they would like to receive. This has not been a project where he gets to run errands for coffee or to the post office – he has sat two days a week, for two to four hours a day, carefully ensuring that each member has been entered correctly and their family is represented in our new system.



We have been so proud to work with an intern who has taken their work so seriously, and when we talked to Sujan about why he thought this work was special he mentioned several things. He said, "It's more than just data, it tells a story and makes me realize how important each person is to the organization.

I can see how important each story is, and why ensuring how the information is entered means information will get to the right person." After spending his spring semester working with us and also his summer break working in research, his goal after high

Continued page 5

Save The Date

HNC Educational Dinner
September 29, 2021
Virtual

HNC Festival & Walk
October 2, 2021
Morrisville, NC

Unión Latina
October 9, 2021
Asheville, NC

HFA Symposium
October 18-28, 2021
Virtual

Fishing for Fun!
November 7, 2021
Charlotte, NC

**Blood Brotherhood
& SOAR Weekend**
November 20-21, 2021
Greensboro, NC

HNC Holiday Celebration
December 4, 2021
Greenville, NC

HNC Festival & Walk
April 2, 2022
Charlotte, NC

HNC Teen Retreat
August 11-14, 2022
Rock Hill, SC

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SOAR SUPPLEMENT	Page 13



*Hemophilia of
North Carolina*

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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 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 (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.

MESSAGE FROM THE EXECUTIVE DIRECTOR

Your Time & Talents Are Needed

As Hemophilia of North Carolina (HNC), soon to be the Bleeding Disorders Foundation of North Carolina, continues to evolve, so do our needs. One need that hasn't changed is our reliance on volunteers to make the magic happen.

HNC has grown tremendously over the last decade, as have the needs of our diverse community. This would never have been possible without the dedicated efforts by individuals, whose contributions range from one-time volunteerism to decades of service.

We are constantly looking for individuals who can contribute their time and talents to sustain and improve the work HNC does. Currently, we are in need of committee members for specific tasks and for board members to govern the organization.

Committees include: Donor Cultivation; Community and Member Expansion; Programming and Offerings; Public Relations; Fiscal Oversight; and Staff, Board, and HQ.

HNC Board positions (two-year terms): currently seeking people with legal, accounting, and/or fundraising experience but all skillsets are welcome!

I would LOVE to talk with you about these opportunities. Please contact me at charlene.cowell@hemophilia-nc.org or (919) 319-0014.

~ Charlene, HNC Executive Director



HNC Awarded Large Grant *continued from page 1*

Center for Social Impact. From this survey, HNC hopes to assess the true needs of the community. Information collected will help HNC to develop new programs and supports that are specific to both bleeding disorders and mental health. HNC is also planning on using the information to help develop a resource guide, which will hopefully steer people towards the assistance that they need.

While HNC is not an organization that will be providing mental health services, plans are in the works to collaborate with organizations that provide music therapy, art therapy, therapeutic yoga, and mindfulness instruction, to learn about alternative and effective ways to manage emotional wellness. Although these programs will not be providing individual mental health services, HNC also recognizes that many mental health providers do not accept insurance and the cost of an appointment is out of reach for many. With that, HNC will be providing financial assistance to help community members access mental health services including therapy or psychiatry.

Some areas that will be supported by this grant have already been started. Support groups, called *Community Conversations*, have begun

with monthly meetings for various demographic groups. These groups are designed to provide connections with others who are in a similar place in life (such as parents, an adult man or woman with a bleeding disorder, etc.). HNC also started its mental health social media campaign in September in order to start collecting patient stories to help end the stigma of having mental health issues.

More details about the financial assistance, survey, resource guide, and programs will be coming out soon.

Since 2009, the Hemophilia Alliance Foundation has been providing grant funding to nonprofit organizations that support the inheritable blood disorders community. HNC has been awarded several of these grants that have supported the emergency financial assistance program, mentoring program, collaborations with North Carolina Hemophilia Treatment Centers, and more. Beginning in 2020, the Hemophilia Alliance Foundation was able to expand its grant opportunities to include a new, large grant for innovative projects. This competitive grant is only awarded to two organizations per year.

HNC COVID-19 Event Statement and Policy

Hemophilia of North Carolina (HNC) continues to closely monitor changes in the COVID-19 pandemic. While at this time HNC is planning on holding some in-person events this fall, safety metrics and CDC and state guidelines will be used to determine whether events will be able to continue as planned. If events do need to transition to virtual or be canceled, HNC will notify the community as soon as it has made the decision.

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.

Raleigh Family Festival & Walk for Bleeding Disorders

October 2, 2021
Morrisville, NC

Hemophilia of North Carolina (HNC) is excited to be holding the Family Festival & Walk for Bleeding Disorders in-person on October 2 at Lake Crabtree Park in Morrisville! With the spike in Delta variant cases of the COVID-19 virus, HNC was left grappling with the decision as to how to hold the event – should it be in person, virtual, or a hybrid version with both in person and virtual options? In the end, the decision was made to hold the event in person with numerous safety protocols, along with the understanding that some people would not be comfortable attending in person.

The Family Festival & Walk for Bleeding Disorders is HNC's largest fundraiser, with 100% of all proceeds supporting HNC's mission of advocacy, education, promotion of research, and delivery of supportive programs and services. This year's fundraising goal is \$100,000, with a goal of \$30,000 coming from individual and team fundraising.

Stay tuned for the winter edition of *The Concentrate* to find out the winners of the Top Team and Top Individual Fundraising Awards; King, Queen, and Junior Droplet Awards; and Hospital Cup Award winner.

You can learn more about the Family Festival & Walk for Bleeding Disorders by visiting the fundraising website: secure.qgiv.com/event/2021raleigh



Community Conversations

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.

This year, HNC began a new initiative, called *Community Conversations*, so that people could connect with others facing similar circumstances. *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.

Continued next page

Community Conversations *continued from previous page*

Community Conversations are being planned monthly, with each month geared towards a different subset of the community, including men with a bleeding disorder, women with a bleeding disorder, parents of children with a bleeding disorder, spouses/partners of someone with a bleeding disorder, individuals with rare bleeding disorders, and Spanish speaking individuals with a bleeding disorder. Stay tuned for the dates in October, November, and December. Meetings will be informal with icebreakers and other activities to get to know each other.

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.

Unión Latina Returning to the NC Zoo

October 9, 2021

Asheboro, NC

The Hemophilia of North Carolina (HNC) Unión Latina Program has traditionally held an event at the North Carolina Zoo in Asheboro each year. However, due to the COVID-19 pandemic, it has been a while since the Unión Latina has been there. HNC is very excited to be going back to the zoo this fall for a Unión Latina event!



The afternoon will include lunch, a presentation in Spanish about exploring the mind-body connection, and tickets to the zoo.

More information is available on the HNC website. Please make sure to register online for this event. You can also contact Gillian Schultz, Director of Programs, by **texting** (919) 272-6000, or by sending an email to events@hemophilia-nc.org.

Fishing with HNC

November 7, 2021

Charlotte, NC

Join Hemophilia of North Carolina (HNC) on November 7 at Freedom Park in Charlotte for an afternoon of fishing and fellowship. Brandon Young of Country Boy Fishing will lead the program to teach children with bleeding disorders about getting back to nature and the joy of fishing.

Thank you to Octapharma and HPC Specialty Infusion for sponsoring the event.

More information is available on the HNC website. If you have questions, please call the HNC office at (919) 319-0014 or email Gillian Schultz, Director of Programs, at events@hemophilia-nc.org.

Meet Sujan – The Most Data Driven Intern In the World!

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school is to pursue a degree in informatics. I can tell you after watching how carefully Sujan has worked with our systems that it will be a great fit for his future.

Sujan's internship is one of the longest internships HNC has ever had, with his work exceeding well over the 80 hours he was required to do for his program with Enloe High School in Raleigh. He is an AP Scholar with Distinction, a 2021 International Leadership Conference Finalist, and a member of the Medical Bioscience Academy at Enloe High School. With all of this, he is still coming back in his free time to finish his work with us and complete the last third of data entry in the new database. With that level of commitment, we were honored to have a long time HNC supporter award Sujan an honorarium towards his future career in recognition of his work with HNC. Please join us all in thanking Sujan! You can send him a note of gratitude by emailing info@hemophilia-nc.org.

Inviting Men & Women with Bleeding Disorders

November 20-21, 2021
Greensboro, NC

Blood Brotherhood & SOAR



Weekend



If you are a man or a woman with a bleeding disorder, you won't want to miss the SOAR and Blood Brotherhood Weekend this November. Make connections with other people from across North Carolina and catch up with old friends. Learn more about the Blood Brotherhood Program, for men with a bleeding disorder; and the SOAR Program, for women with a bleeding disorder. There will be separate tracks for men and women so that you can talk about and learn more about the issues that are important to you.

Hemophilia of North Carolina (HNC) is hoping that this event will be held in-person, with COVID-19 safety protocols in place. However, a contingency plan is also being developed in case the event has to change to a virtual format.

More information will be available on the HNC website. If you have questions, please call the HNC office at (919) 319-0014 or email Gillian Schultz, Director of Programs, at events@hemophilia-nc.org.



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.

VISIT [GENENTECHHEMOPHILIA.COM](https://www.genentechhemophilia.com)
TO SEE HOW WE'RE CREATING
WHAT'S NEXT, TOGETHER.



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**GENENTECH IN
HEMOPHILIA**

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A Member of the Roche Group

Holiday Cheer this December

December 4, 2021
Greenville, NC

Hemophilia of North Carolina (HNC) is looking forward to the Holiday Celebration this December, in-person, in Greenville, NC! The Holiday Celebration is one of HNC's most popular events celebrating the accomplishments of the past year, while bringing in some holiday cheer. There will be crafts, activities, lunch, and a special visitor from the North Pole. Stay tuned to your email and the HNC website for more information about the Holiday Celebration.



Teen Day

Winter 2021-22

Hemophilia of North Carolina (HNC) really missed seeing the teens this past summer at the Teen Retreat. Plans are in the works for a Teen Day of learning and fun activities this winter! If you are between the ages of 13-18 – 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. HNC knows how important it is for teens to connect with other teens who are facing similar circumstances and who can understand them. Parents and teens, stay tuned to your email, the HNC website, and HNC Facebook page for more information about this upcoming event.



Charlotte Family Festival & Walk for Bleeding Disorders

April 2, 2022
Charlotte, NC

Save the date for the Charlotte Family Festival & Walk for Bleeding Disorders, taking place April 2, 2022 in Uptown Charlotte. If you live in Charlotte and the surrounding areas, Hemophilia of North Carolina (HNC) hopes that you will plan to join this critical fundraising event. More information will be available in early 2022.



Summer Events around the State

July 10 and July 11, 2021
Asheville, Charlotte, Greenville, and Raleigh



Hemophilia of North Carolina (HNC) was excited to see everyone back in person at its summer events around the state. On July 10, HNC members in Charlotte and Raleigh enjoyed a picnic lunch and time to catch up with each other. On July 11, HNC members in Asheville and Greenville were able to get together for a picnic lunch and time for networking. While the weather was hot in Asheville, Charlotte, and Raleigh, HNC lucked out with beautiful days. If you talk to anyone who attended the Greenville event, they might share a different story, with intense storms coming through, soaking everyone and everything! Despite the heat and the rain, it was great to see so many community members again and share some laughs after being apart for so long. Thank you to the sponsors who helped to make this event possible!

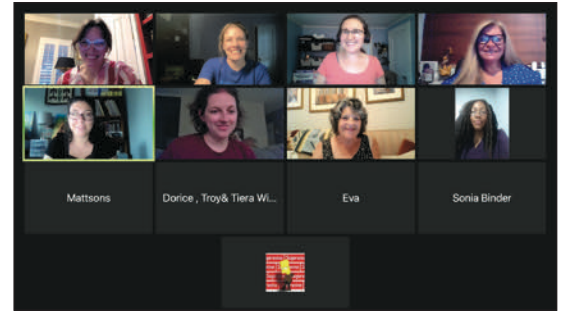


Spotlight on Siblings

June 16, 2021

Virtual

In the bleeding disorders community, the majority of the focus is on the person with a bleeding disorder. Without question, parents are likely to spend more time and focus more attention on their child with a bleeding disorder, especially as they are dealing with bleeds, learning how to treat the bleeding disorder, and trying to keep their child safe. But brothers and sisters who do not have a bleeding disorder are affected, too. For siblings of someone with a bleeding disorder, it can be difficult to navigate through life, as so much attention is placed on their brother or sister. Hemophilia of North Carolina realizes the importance of making sure everyone in the family, whether they have a bleeding disorder or not, receives support and resources. In June, Rachel Kroouze, CoRe Manager for Sanofi Genzyme, presented *Spotlight on Siblings*. This program addressed the challenges that siblings often face and provided tools for parents to help support their child who does not have a bleeding disorder. Everyone who attended left the evening with new resources so they could provide the needed attention and focus on their child without a bleeding disorder.



Unión Latina: Women and Bleeding Disorders

June 26, 2021

Virtual

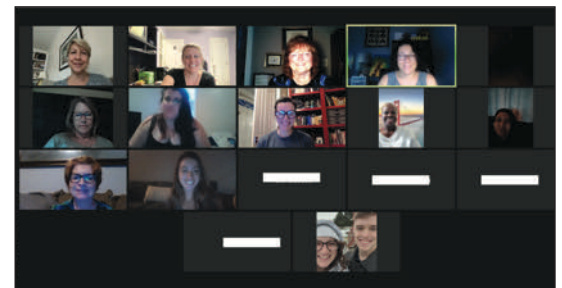
Several women learned more about managing a bleeding disorder as a woman and what they should know for their daughters with a bleeding disorder. Patricia Espinosa-Thomson presented, *La importancia de los trastornos sanguíneos en las mujeres*. The women had the chance to hear about how living with a bleeding disorder as a woman is different than for men and special challenges they may face. They also were able to ask questions about what to expect as a woman or girl with a bleeding disorder.

Women with Bleeding Disorders

June 28, 2021

Virtual

Women with bleeding disorders face unique and special challenges. Understanding how hemophilia and von Willebrand disease (VWD) affect women of all ages, but especially during the reproductive years, is critically important. This session, led by Virginia Kraus, RN, led participants through an overview of both hemophilia and VWD, emphasized reproductive issues that may occur, and closed with Q&A. It was an incredibly informative session.



In the Winter Edition

June 28, 2021

Virtual

Stay tuned for the winter edition of *The Concentrate* to read about Family Day, *Communicating with your Child's School* virtual presentation, Fishing for Fun, Raleigh Family Festival & Walk for Bleeding Disorders, Unión Latina at the Zoo, Blood Brotherhood and SOAR Weekend, and Holiday Celebration. In the meantime, enjoy some of the Family Day photos on page 17. It was a beautiful day for some golfing!



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 17, HNC wants to give a special note of appreciation to the companies that have continued to support HNC's efforts during the last few months.

Summer Events Around the State

PRESENTING SPONSORS

CSL Behring

Biotherapies for Life™



Genentech



EVENT SPONSORS



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antihemophilic factor (recombinant),
glycopegylated-exei

Discover more at Esperoct.com.

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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Blood Brotherhood Program Update

Hemophilia of North Carolina (HNC) would like to provide more support for men with bleeding disorders. There are several ideas in the works to bring more Blood Brotherhood programs to the North Carolina bleeding disorders community. Help to share your input about what you feel is important for the Blood Brotherhood by attending an upcoming *Community Conversations* online meetup.

The first (hopefully) in-person Blood Brotherhood event in more than 18 months is coming up November 20-21 in Greensboro. Join HNC for the Blood Brotherhood & SOAR Weekend. There will be sessions just for the guys on both Saturday and Sunday. In the event that the weekend will need to move to a virtual format, HNC will let you know.

Beyond North Carolina, there are also 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.

A blue flyer for the JIVI ADYNOVATE PK (Pharmacokinetics) Study Data. The top left features the 'JIVI' logo in white and 'ADYNOVATE' in white. The top right has a small logo for 'JIVI anti-hemophilic factor (recombinant) PPS (plasma-derived) LET'S GO'. The center text reads 'PK (Pharmacokinetics) Study Data' in white. Below this is a yellow box containing a white icon of a clipboard with a checklist and the text 'Talk to your doctor about the study.' in black. At the bottom left is a QR code with the text 'Scan the QR code to learn more about PK at UnderstandingPK.com' in white. The bottom left corner has small white text: 'PK: Pharmacokinetics © 2021 Bayer. All rights reserved. All trademarks are the property of their respective owners. Printed in USA. 05/21 PP-JIV-US-1437-1'. The bottom right corner features the Bayer logo, which is a white circle with a cross inside and the word 'BAYER' written vertically.





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

HOPE Program Update

Parenting a child with a bleeding disorder can be hard. But you are not alone! The Hemophilia of North Carolina (HNC) HOPE Program provides educational opportunities to help navigate raising a child with a bleeding disorder, supportive programs to help you feel connected and part of a community, and resources so that

you can be an advocate for your child. Whether you have an infant, toddler, preschooler, or school-aged child, find support with others at a HOPE Program event.

On September 29, HNC held a virtual educational session, *Communicating with your Child's School*, to provide tools and tips so that your child can be successful in school. HNC also has resources to help your child thrive in school or in daycare. Other opportunities available through the HOPE Program include *Community Conversations* meetup groups and the Parent Mentoring Program.

If you have questions or would like information about *Community Conversations* or the Parent Mentoring 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.



Unión Latina Program Update

If your primary language is Spanish, the Hemophilia of North Carolina (HNC) Unión Latina Program is meant 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, and staying active with a bleeding disorder. 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. This October, HNC is excited to be going back to an in-person event at the NC Zoo, so that you can once again connect and network with other Spanish-speaking members of the bleeding disorders community.

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. If you are a woman with a bleeding disorder, HNC hopes that you will join one of the upcoming SOAR events this fall, including the SOAR & Blood Brotherhood Weekend in November and an upcoming *Community Conversations* online meetup.

In addition to providing support for women and girls, HNC exhibits at multiple conferences throughout the state to raise awareness about the symptoms of bleeding disorders in women and girls. This fall, HNC will be exhibiting at the North Carolina Dental Hygienists Conference in Charlotte, the North Carolina Nurses' Association Conference in Concord, and the North Carolina Emergency Nurse Association Conference in Asheville. 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.

Actualización sobre el Programa Unión Latina

¡Si su idioma principal es el español, el Programa Unión Latina de Hemofilia de Carolina del Norte (HNC, por sus siglas en inglés) es para usted! Unión Latina brinda información y recursos completamente en español a los miembros hispanohablantes de la comunidad.

Durante el año pasado, HNC brindó diversas oportunidades virtuales a la comunidad hispanohablante, entre las que podemos mencionar presentaciones sobre mujeres y niñas con trastornos hemorrágicos, cómo proteger las articulaciones, y cómo mantenernos activos con un trastorno hemorrágico. Adicionalmente, varias de las presentaciones que se dieron en inglés contaron con interpretación simultánea al español para que los detalles de importancia vital de las mismas estén disponibles para todos. En octubre de este año, HNC se complace de regresar con un evento en persona en el Zoológico de Carolina del Norte para que pueda volver a estar en contacto y relacionarse con otros miembros hispanohablantes de la comunidad con trastornos hemorrágicos.

El Programa Unión Latina brinda apoyo e información a las personas y familias latinas de Carolina del Norte que sufren de trastornos hemorrágicos. La programación se ofrece en español, y la misma es posible gracias a un subsidio de Takeda. Para acceder a mayor información, visite el sitio web de HNC.

Evento de Unión Latina

26 de junio de 2021
Virtual

Muchas mujeres accedieron a mayor información sobre cómo gestionar un trastorno hemorrágico como una mujer y lo que deben saber para sus hijas con un trastorno hemorrágico. Patricia Espinosa-Thomson presentó La importancia de los trastornos hemorrágicos en las mujeres. Las asistentes tuvieron la oportunidad de escuchar por qué vivir con un trastorno hemorrágico es diferente para las mujeres en contraste con los hombres, los desafíos particulares a los que deben hacer frente, y pudieron hacer preguntas sobre lo que pueden esperar como una mujer o niña con un trastorno hemorrágico.

Unión Latina regresa al Zoológico de Carolina del Norte

9 de octubre de 2021
Asheboro, NC

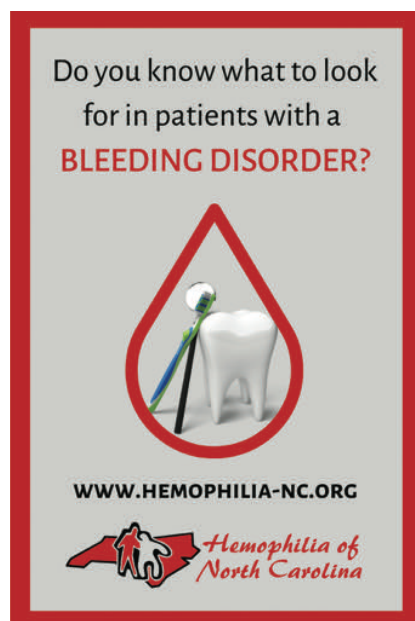
El Programa Unión Latina de Hemofilia de Carolina del Norte (HNC, por sus siglas en inglés) tradicionalmente organiza un evento en el Zoológico de Carolina del Norte en Asheboro todos los años. Sin embargo, debido a la pandemia de COVID-19, Unión Latina no está presente en el lugar desde hace un tiempo. HNC se complace de regresar al zoológico este otoño para un evento de Unión Latina.

La tarde incluirá el almuerzo, una presentación en español sobre cómo explorar la conexión entre la mente y el cuerpo, y entradas para el zoológico.

En el sitio web de HNC se encuentra disponible información adicional. No se olvide de inscribirse en línea para este evento. También puede comunicarse con Gillian Schultz, Directora de Programas, enviando un **mensaje de texto** a (919) 272-6000 o escribiendo a events@hemophilia-nc.org.



HNC Raising Awareness about Bleeding Disorders



As part of Hemophilia of North Carolina's (HNC) mission, raising awareness about bleeding disorders and advocating for improved diagnosis, treatment, and care is essential. Of great importance is especially to raise awareness about women and girls with bleeding disorders. One way that HNC meets this goal is by exhibiting at medical conferences across North Carolina. Although it's been a while since HNC has been able to exhibit in person, in September that is changing.

On September 17-18, HNC had the opportunity to exhibit at the North Carolina Dental Hygienists' Association Meeting in Charlotte. This was the first time that HNC had exhibited with an organization that focuses on dental health. Maintaining teeth and gums is essential for people with bleeding disorders. Poor gum health can lead to excess bleeding for anyone, but especially someone with a bleeding disorder. Helping dental hygienists to know about the signs and symptoms of bleeding disorders, along with how to help patients with bleeding disorders take care of their teeth, is important in maintaining good health.

On September 23-24, HNC exhibited once again at the North Carolina Nurses' Association Conference in Concord. HNC has been exhibiting at this conference for many years to raise awareness about women and girls with bleeding disorders,

and always looks forward to connecting with nurses that they have talked with in the past. At nearly every conference, a nurse comes to the booth thanking HNC for raising awareness because it has helped them to diagnose a woman with a bleeding disorder, or even learn that they have a bleeding disorder themselves!

Finally, on November 4-5, HNC will be exhibiting with the North Carolina Emergency Nurses' Annual Symposium. This will be another first for HNC. Visiting the emergency room can be an overwhelming and intimidating experience, but something that almost anyone with a bleeding disorder has or will experience. With so many different illnesses, disorders, and diseases that emergency room nurses come across, most are not likely to know about bleeding disorders. But helping them to be prepared for when someone with a bleeding disorder does come in is important in making sure that the patient has a good experience, rather than a bad one, in the emergency room.

HNC is hoping that it will 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.



Mental Health Initiative

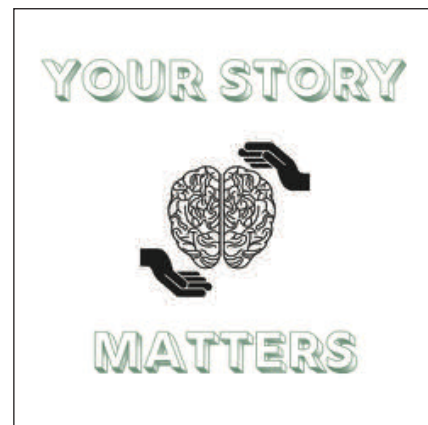


Hemophilia of North Carolina (HNC) was thrilled to have been awarded the Hemophilia Alliance Foundation Large Grant this fall to support the new mental health initiative (read more about the grant on page 1).

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. This September, HNC kicked off a social media campaign to help end the stigma of mental illness and mental health issues by asking community members to share their stories in order to help others know that they are not alone.

There will be additional activities in the coming months as HNC develops programs to support the emotional wellness of 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.



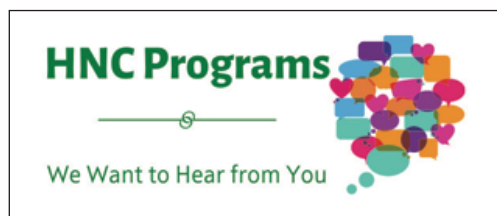
SHARE YOUR MENTAL HEALTH STORY!

Help normalize talking about mental health by sharing your story with HNC. Stories can be provided anonymously.

www.surveymonkey.com/r/WRB6GTH

Be a Part of Future HNC Programming

Do you want to have a bigger say in future Hemophilia of North Carolina (HNC) programming and events? HNC wants to hear from you with your thoughts. It's important to HNC that the programs and services offered meet the needs of the bleeding disorders community. Your thoughts and feedback help ensure that this happens. Contact Gillian Schultz, Director of Programs by email at gillian.schultz@hemophilia-nc.org or by calling 919-272-6000.



Hemophilia of North Carolina (HNC) is recruiting new mentors to provide individualized support to parents of a child with a bleeding disorder. If you're "been there - done that" and would like to support others, contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org or (919) 319-0014.

Community Spotlight

An Advocacy Rockstar!

Hemophilia of North Carolina wants to shout out an amazing advocate and North Carolina bleeding disorders community member: **Linda Nelson**. Over the past year, Linda has been getting more involved with legislative advocacy efforts on behalf of the community. When she was asked to testify in front of North Carolina legislators about an advocacy issue, Linda didn't hesitate to use her voice and share her story. Not only that, but she stayed committed even as the testimony date kept changing because of the legislative calendar. Linda is a rockstar advocate and voice for the community!



Linda Nelson

Community Spotlight

Kindergarten Here We Come!

By: Kate Stotz, HNC Community Member

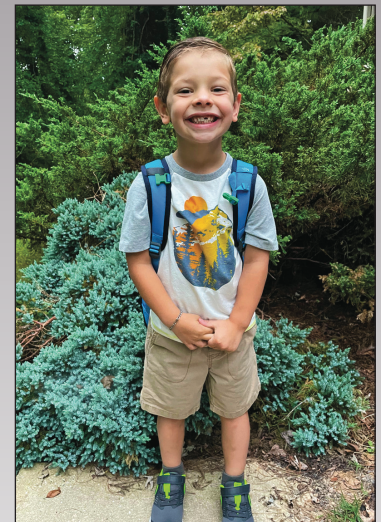
I can remember sitting in a session at the Hemophilia of North Carolina Family Retreat a few years ago, listening to other parents talk about what it was like when their child with a bleeding disorder started school for the first time. My son was only a toddler at the time, but I listened intently knowing that my time would be here before I knew it! Now, as I write this, my son Charlie has just finished his first week of kindergarten! I am so thankful for all those who shared their experiences at that retreat and on many other occasions over the last few years to help me prepare for this milestone!

I have two older children, so we are not new to the "back to school" routine. However, sending a child with severe hemophilia to school required a little different preparation! While I'm sure all schools have a slightly varied process of working with families, I'll share a quick timeline of my experience introducing hemophilia to our school. When I attended Kindergarten Registration in the spring, I met our school nurse. I gave her a letter from our Hemophilia Treatment Center (HTC) and spoke with her briefly about hemophilia. She gave me a "Hemophilia Action Plan" to complete and said we would be in touch later in the summer. She called a few weeks before

school was starting, and we went over some basic information about Charlie. She had made copies of the letter from my HTC and planned to distribute that to his teachers along with the Hemophilia Action Plan I had completed. I suggested we have a meeting before school started so I could provide some education about hemophilia and discuss some important information and concerns I had.

The week before school started, the nurse arranged a meeting with Charlie's kindergarten teacher, the school counselor, P.E. teacher, music teacher, art teacher, and media specialist. I was anxious as I prepared for this meeting because I felt the pressure of being able to present a simplified, yet thorough explanation of caring for a child with a severe bleeding disorder (and not be too boring!). I ended up putting together a short presentation to help me organize my thoughts. I printed out copies and made a booklet for each of the teachers (which they loved!). I wanted them to have something to

Continued next page



Community Spotlight continued...

take with them and review after our meeting. I pulled from a lot of the resources already available such as the "HFA Back to School Toolkit." My topics included the following: What is hemophilia, different types of bleeds, bleeds that Charlie has had, how Charlie is treated, Charlie's hemophilia timeline, and ways to help Charlie at school. I included lots of photos to make it personal and was sure to showcase all the active things he loves to do (riding his bike, playing soccer, swimming, hiking). I wanted them to know they didn't have to be afraid to let him be a kid! My goal was to help them understand enough about hemophilia and Charlie's treatment so they could understand how to support Charlie at school.

I left the meeting feeling grateful that I had this opportunity to advocate for my son. I can sometimes be guilty of thinking everything will be fine, and we won't have any problems, especially since Charlie has not had a bleed since beginning prophylactic treatment. I was reminded by my nephew, who broke his arm on the second day of school, that it is important to be prepared! Advocating for your child with a bleeding disorder is essential for helping the school be prepared to provide them with the care they need! All the teachers were extremely receptive to hearing about Charlie and asked lots of questions. We had some great discussion that may even end up benefiting other kids with medical needs at Charlie's school!

It's hard to believe my little guy is off to school, but I know he is ready! I'm thankful for all the support we've had from our HTC and the great education opportunities we've had through Hemophilia of North Carolina. We appreciate those in the bleeding disorders community who have gone before us and paved the way for Charlie. We made it through the first week of school without any problems, but I'm sure this will be a year full of learning for EVERYONE!



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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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.*

Mental Health Initiative Donors

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In honor of Brenda Nielsen
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Phillip Poovey
Jack and Margaret Prim
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Phillip Poovey
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Facebook Fundraisers

Gerald Battle
Tammy Lee Chavis
Eric Hall
Monica Masters

In Memory of Adah and Noah Lesslie

Dr. David Howell and Dr. Sara Miller

Thank You 



Donors Make Mental Health Programming Possible

By: Fleming Samuels, HNC Director of Philanthropy

We asked you for help and you answered. Thank you all for making our new Mental Health Initiative possible! With funds contributed by community members, along with a grant we received from the Hemophilia Foundation Alliance, we will be able to create new programming, conduct research, and initiate programs that will focus solely on mental health for the bleeding disorders community.

Individual donor funds are critical to the work that is being done right now to continue and enhance our Community Conversations groups, which are facilitated talks that give support to targeted groups within the bleeding disorders community. Each month, these programs provide a social network of support that is critical for people with bleeding disorders or their caregivers, to prevent isolation especially during this pandemic.

Thank you for your generosity! We are honored by all those who gave their support, allowing us to have a greater impact.



HNC Honors Phillip R. Poovey After Several Years of Board Service

By: Fleming Samuels, HNC Director of Philanthropy

This donor spotlight honors someone who has committed many years of service and love to Hemophilia of North Carolina (HNC) in partnership with his spouse George McCoy. We would like to honor **Phillip Poovey** as a leader in his own right for his many board achievements, as he just completed his last board term this past June.



Phil, left, with his late husband, George

Phil spent the last two years on the Board of Directors guiding HNC through strategic planning, staff searches, and now as we move forward, a new name of the organization his husband helped found.

Phil established the George D. McCoy Scholarship that has awarded three annual scholarships since its inception and been an avid supporter of staff education and growth.

President of the Board of Directors Steven Humes said, "During Phil's two-year tenure as Vice President of the HNC Board, he was a calm, steady presence, setting an example for other board members with his conscientiousness and willingness to tackle difficult projects. Most impressively, he led the process to overhaul and update the organization's bylaws, which had not been touched in many years. This was not an easy assignment, but Phil assembled a highly qualified group of volunteers and kept them on task. We can be very proud of what Phil and his committee accomplished."

We thank you for your leadership, Mr. Poovey; your shoes will be very hard to fill. I sincerely hope that your service will inspire others to board service.

Giving Tuesday Offers Multiple Ways to Support HNC

By: Fleming Samuels, HNC Director of Philanthropy



Do you like to post on social media about how great Hemophilia of North Carolina (HNC) is? Do you have an active group of friends on Facebook or Instagram? If so, you might be the perfect person to reach out and run a small campaign for HNC on Giving Tuesday.

Giving Tuesday is traditionally the Tuesday after Thanksgiving – **this year it's on November 30**. Giving Tuesday is a day where people give back and are grateful to their communities. Facebook and Instagram both help promote these events, and we also have graphics

and tools to help. Making HNC part of your Giving Tuesday can be done in two ways. You can simply make your annual Giving Tuesday donation through our page on Facebook and promote your contribution on your own Facebook Page. A second way to make a more significant impact is to run a Giving Tuesday Facebook fundraiser and ask for donations by promoting HNC's works for the bleeding disorders community. You can make a few posts throughout the day to let people know how close you are to reaching your goal.

Help be an elf for someone this year by supporting HNC's social service programs this holiday season. If you're interested in getting a jump on your holiday spirit, please let us know!

Please do not hesitate to call or email me for more information; I am always up for a fun chat – even on Facebook! Contact me at fleming.samuels@hemophilia-nc.org or by calling the HNC office at (919) 319-0014.

A **ONCE-WEEKLY**
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HOW DOES
THIS FACTOR IN?

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option, talk to your doctor or visit
OnceWeeklyForHemophiliaB.com

COVID-19 Vaccines and Bleeding Disorders: Frequently Asked Questions (FAQs)

The National Hemophilia Foundation (NHF) provided some great FAQs in an article on August 24, 2021. If you are interested in reading it, please go to the NHF website below or contact the Hemophilia of North Carolina office at (919) 319-0014 and we can send you a copy. Below is a snapshot of some of the information provided:

NHF recognizes that people with bleeding disorders may have questions and concerns related to the variant coronavirus' causing COVID-19 and the new COVID-19 vaccines, including any implications specific to their conditions. The following FAQs are therefore meant to address some of the most common questions from our community members. Please note that these answers were created for broad purposes and that affected individuals should engage closely with their healthcare provider to discuss the possibilities of disease signs and symptoms and vaccination, including potential contraindications (if any), and specific questions related to safety and efficacy. Given the nature of this virus, rapid developments in vaccines, and the ongoing transitions in our federal government, this continues to be a very fluid situation. If you have additional questions or need more information, please consult with your healthcare professional.

Have you or are you currently receiving any monoclonal antibody treatments?

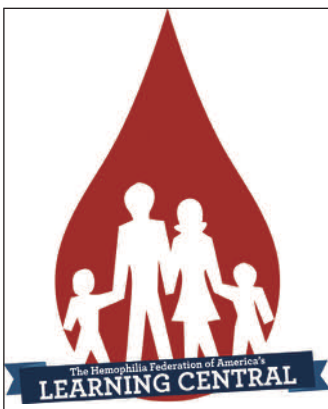
You may be asked this question before you receive the vaccine. Receiving emicizumab is not a reason not to receive a vaccine to prevent COVID-19 infection. Emicizumab is a monoclonal antibody that is used to prevent bleeding in people with hemophilia A. Other monoclonal antibodies have been and are being developed as treatments for COVID-19 infections. You can and should receive a vaccine even if you are taking emicizumab to prevent bleeding.

Are you taking any medications with one of the following ingredients.....one of those ingredients being a PEG?

Polyethylene glycol (PEG) is a stabilizer that is used in many medications including plasma derived and recombinant factor products. Factor products that use PEG to extend the half-life of the factor product or any factor products are not a reason to not take a vaccine unless you have had a reaction to PEG. If you have a question about this please talk with your hematologist or healthcare professional.

Article link: www.hemophilia.org/news/covid-19-vaccines-and-bleeding-disorders-frequently-asked-questions-faqs

HFA Learning Portal: Mental Health



The Hemophilia Federation of America (HFA) is now offering mental health and well-being courses through its Learning Central portal to support people with bleeding disorders, as well as their caregivers. With new families being diagnosed and many approved medications, emerging treatments, and gene therapies in clinical trials, HFA addresses the need for patient and caretaker education through Learning Central. Learning Central offers online learning modules, accessible via computer, tablet, and mobile device, using an integrated learning management system (LMS).

This LMS provides adult learners with knowledge in an easily accessible environment and measures learning success and other metrics. Learning is broken into small, but dense, learning pieces so users can learn a lot in just a few minutes. The instructional design is story-based and predictable to engage the learner in continued participation. It is also learner-decision-based: learners may choose what they wish to learn about and in what order. In some cases, they also have a choice regarding the complexity of the material (e.g., choosing basic or scientific information).

To get started, visit: www.hemophiliafed.org/the-institute

Hemophilia Federation of America Symposium

October 18-28, 2021

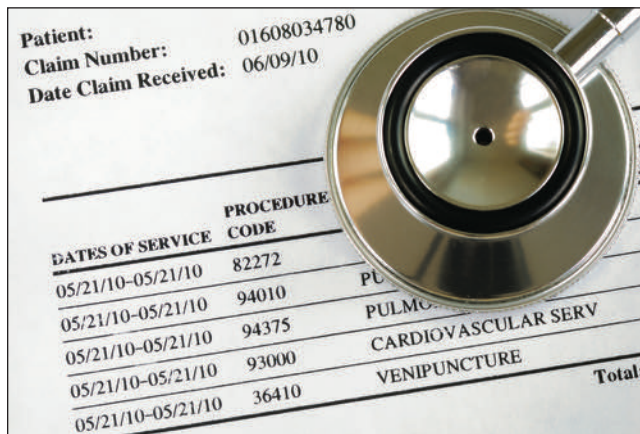
Virtual



Hemophilia Federation of America's annual Symposium will be online and offered to the community for **FREE**. Do not miss the chance to hear from experts in the bleeding disorders community, all while not having to change out of your pajamas! Live sessions are scheduled 5-8pm (ET) each weekday and will be easily accessible via computer, phone, or tablet with the click of a button. Children's and teen programming will take place on Saturday, October 23 from 12-6pm (ET). Register here: www.hfasymposium.org

Administration Issues First Rule on the No Surprises Act

Re-printed with permission from the Hemophilia Federation of America



On July 1, the Administration issued a first set of rules implementing the No Surprises Act. The statute and rules target the all-too-common problem of surprise or balance billing. Surprise billing can happen when a patient inadvertently gets services from an out-of-network (OON) health care provider. Maybe the patient was taken to an out-of-network (OON) hospital for emergency care – or maybe the patient sought treatment at an in-network hospital, but unwittingly received care from one or more OON providers. Either way, the patient ends up on the hook for outsize, unexpected charges. With millions of Americans affected by surprise medical billing, patient and consumer advocates waged a years' long effort to win passage of the No Surprises Act.

The new rule takes a first step toward implementing the Act's protections. Beginning in 2022, patients will be protected from charges over and above their regular in-network cost sharing when they receive emergency care at OON facilities, or when they receive non-emergency services from OON providers working at in-network facilities. The rule also establishes a framework for determining reimbursement rates from insurers to OON providers. And the rule spells out notice and consent requirements that OON providers must follow before treating or billing patients – as well as creating a complaint system for consumers who think they were wrongly billed.

The new rule doesn't resolve all aspects of the surprise billing problem. In coming months, federal agencies will undertake further rulemaking on how to resolve reimbursement disputes between insurers and OON health care providers. Agencies will also address air ambulance billing in separate rulemaking. Ground ambulance services (not covered by the No Surprises Act) will unfortunately continue to generate surprise medical bills for some patients. Even with these limitations, the surprise billing protections contained in the No Surprises Act will help millions and constitute a major consumer victory.



HNC Is North Carolina Leader in Health Advocacy

HNC Executive Director successfully leads the charge to ban Accumulator Adjustor Programs in NC

By: Kathy Register, HNC Board Member and Community Member



Charlene testifying to House Health Committee

We have great news about health insurance in North Carolina. Many people with bleeding disorders and other high-cost conditions rely on copay assistance, also called coupons or (in the case of bleeding disorders) factor assistance cards, to help afford their medicine. Unfortunately, insurance companies have implemented so-called Accumulator Adjustor Programs (AAPs) in their policies, in which the money being used to help pay for the medicine is accepted by the insurance company, but the insurer no longer counts that payment towards deductibles and out-of-pocket expenses. Consequently, if people receive the much-needed assistance, they still get stuck with the full cost



SB 257 passes 41-0 in Senate

because they are ultimately responsible for a pre-determined deductible and out-of-pocket total.

AAPs can cause major hardships for patients by making their medication unaffordable. While the problems associated with AAPs affect many in our bleeding disorders community, we are not alone. Therefore, HNC has been leading a coalition of over 30 patient organizations representing psoriasis, multiple sclerosis, and other health conditions. The goal of the coalition is to ban AAPs from NC Health Insurance Marketplace programs. As of 2021, five out of six NC Marketplace plans have AAPs in their policies.



Charlene educating legislators on AAPs

So far some 23 states have either passed legislation to ban the practice (Arizona, Georgia, Illinois, Virginia and West Virginia) or have bills under consideration.

In June, HNC Executive Director Charlene Cowell appeared before a large group of NC legislators to make them aware of the issue and ask their support for legislation that would ban this insurance practice. Shortly thereafter, HNC and the coalition provided input on language to be added to the Senate's Medication Cost Transparency Act (SB 257). In August, Charlene and HNC community member Linda Nelson testified at a meeting of the NC House Health Committee and



HNC member, Linda Nelson, testifying on the bill

urged them to support SB 257. On September 8, the Senate and House voted unanimously to pass the bill. The bill was signed into law by Governor Cooper on September 20, 2021.

This is a huge win for people who rely on copay assistance, including many of those with bleeding disorders. Our community can be proud of HNC for leading the effort with the support of other coalition members and stakeholders.

Hemophilia of North Carolina 2021 Calendar of Events Highlights



<u>September 21, 2021</u>	<u>Community Conversations - Virtual</u>
<u>September 29, 2021</u>	<u>Educational Dinner - Virtual</u>
<u>October 2, 2021</u>	<u>Raleigh Festival & Walk - Morrisville, NC</u>
<u>October 9, 2021</u>	<u>Unión Latina event - Asheboro, NC</u>
<u>November 7, 2021</u>	<u>Fishing for Fun - Charlotte, NC</u>
<u>November 20-21, 2021</u>	<u>Blood Brotherhood and SOAR Weekend Greensboro, NC</u>
<u>December 4, 2021</u>	<u>Holiday Celebration - Greenville, NC</u>
<u>April 2, 2022</u>	<u>Charlotte Festival & Walk - Charlotte, NC</u>
<u>August 11-14, 2022</u>	<u>Teen Retreat - Rock Hill, SC</u>



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