

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2021

The Return to In-Person Events



Since the pandemic began, Hemophilia of North Carolina (HNC) has developed new and innovative ways to connect with the community, so that people could feel a sense of togetherness while maintaining everyone's safety. While some of these opportunities will remain moving forward, HNC is also excited for what's to come. It appears that after almost one-and-a-half years, the COVID-19 pandemic is finally taking a turn for the better! More than 50% of adults in North

Carolina have received at least one dose of the COVID-19 vaccine, with more being vaccinated every day. All teenagers are now eligible to be vaccinated as well! With the percentage of positive cases going down, HNC is excited to be able to return to some in-person events!

The first events that will take place in-person will be the Summer Events on July 10 and July 11. The smaller, regional events will be taking the place of the HNC Summer Conference that was initially planned for July 9-11 at Lake Junaluska. Other summer and early fall events will

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First Look at HNC's Needs Assessment

The year 2020 was one for reflection. It had been a long time since Hemophilia of North Carolina (HNC) took a deep look at the needs of the community, but that changed in 2020 with the administration of the Community Needs Assessment. HNC sought input from community members including patients, family members, and caregivers, as well as medical providers, industry partners, and other key stakeholders. With a goal of having 100 responses, HNC is happy to announce that there were 118 people who participated. HNC is now evaluating the data that was collected to help improve the programs and services that are offered.

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Meet Arlette Whitaker, HNC's Newest Board Member

How long have you been involved with the bleeding disorders community?

I have been involved in the bleeding community for seven years. I have enjoyed all of them.

Why did you join Hemophilia of NC's board of directors?

I joined the board of directors to help advocate for bleeding disorders. Also to try and get more involvement from east of Raleigh.

When you aren't working or volunteering, what are you doing?

When I am not working you can catch me reading, cooking, or traveling.

What do you love most about the bleeding disorders community?

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Summer Gatherings

July 10, 2021

Charlotte & Raleigh, NC

Summer Gatherings

July 11, 2021

Asheville & Greenville, NC

NHF Conference

August 25-28, 2021

Virtual

Family Day

September 19, 2021

Charlotte, NC

HNC Festival & Walk

October 2, 2021

Morrisville, NC

HFA Symposium

October 18-28, 2021

Virtual

Unión Latina

October 29, 2021

TBA

Blood Brotherhood

& SOAR Weekend

November 20-21

Greensboro, NC

HNC Holiday Celebration

December 4, 2021

Greenville, NC



*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.

From the Executive Director A Time of Change

I'm very excited to share some important news! Hemophilia of North Carolina (HNC) will soon take a new name: the **Bleeding Disorders Foundation of North Carolina (BDFNC)**.

Many years ago, HNC staff and the board of directors started talking about the shift in our membership. We were not only serving the hemophilia community, but also a growing number of members with other bleeding disorders like factor VII deficiency and von Willebrand disease (VWD). It was around 2012 when our membership started to reflect a majority of non-hemophilia bleeding disorders. Since that time, we have remained as "Hemophilia of North Carolina" while dedicated to serving a much larger bleeding disorder community.

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

We remain dedicated to the bleeding disorders community and cannot wait to better reflect this publicly.

~ *Charlene*, HNC Executive Director



HNC Board of Directors Develop a Three-Year Strategic Plan

The Hemophilia of North Carolina (HNC) Board of Directors has begun a far-reaching project with the development of a strategic plan to guide HNC over the next three years: 2021-2023. The six areas to be addressed are:

1. Public Relations
2. Community and Member Expansion
3. Programming and Offerings
4. Donor Cultivation
5. Staff, Board, and HQ
6. Fiscal Oversight

Each area is being chaired by a staff or board member who has assembled committees to work on the development and implementation of each program area. The committees are meeting by Zoom and telephone to develop the objectives, action steps, and implementation procedures for each area.



The Return to In-Person Events continued from page one

include Family Day at Top Golf in Charlotte and the 2021 Raleigh Family Festival and Walk in Morrisville. HNC will be monitoring COVID trends across the state to determine if other events can be planned safely.

It will be necessary for anyone who attends in-person events to follow HNC guidelines. At this time, masks will be required for all attendees, ages two and up, whether vaccinated or not. In addition, you will need to follow posted social distancing guidelines and other safety measures put in place. If you or anyone in your family is feeling sick or under the weather, you will be asked not to attend an in-person event. Failure to abide by HNC's guidelines will limit your ability to attend future HNC events. As the year progresses, HNC board and staff will be revisiting these requirements.

If you have any questions about returning to in-person events, please do not hesitate to reach out to Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org. Your health and wellness is of utmost importance to HNC.

Meet Arlette Whitaker, HNC's Newest Board Member continued from page one

I love the bond that the community has. Everyone is so open to sharing information to enrich another person's life with bleeding disorders. The encouragement to one another warms my heart.

Who inspires you?

I am inspired daily. It's hard to say. Sometimes it's by strangers I see struggling but yet keep going and sometimes caregivers for I know the amount of sacrifice it takes to care for someone. A well-known person who inspires me would be Joseph Pilates.

What's something about you (a fun fact) that not many people know?

Lol, let's see, a fun fact? I love parasailing.

If you had to eat one meal every day for the rest of your life, what would it be?

One meal for the rest of my life? Geesh, it has to have bacon. BBQ chicken, collards, green beans with bacon, and mac and cheese. Lots of bacon on the green beans.

Summer Events Around North Carolina

July 10 & 11, 2021

Asheville, NC; Charlotte, NC; Greenville, NC; Raleigh, NC

Hemophilia of North Carolina (HNC) is looking forward to the first in-person events since March 2020. While the Summer Conference had to be canceled, HNC has transitioned from a large, 200-person event, to smaller, one-day events in locations across the state. On July 10, the events will take place in the Charlotte and Raleigh areas, and on July 11, the events will take place in the Asheville and Greenville areas.

All four events will follow a similar format. They will be outside, in picnic shelters at local area parks. Attendance will be limited to 50 people per event. There will be time to reconnect with HNC and find out what's new since the last time an event took place in person, an activity, lunch, and time to meet with bleeding disorders company representatives. While HNC will not be requiring anyone to be vaccinated, everyone will be required to wear a mask.

More information, including details and registration are available on the HNC website. For questions, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org.

Teen Retreat

It is with a very heavy heart that Hemophilia of North Carolina (HNC) is announcing that this year's Teen Retreat with Hemophilia of South Carolina has been canceled. While HNC was optimistic in hoping that procedures could be put in place to keep your teens safe for a four day event, there are too many variables in play, and rather than risking anyone's health, the difficult decision was made to cancel the event. HNC looks forward to being able to hold the event again in 2022. And be on the lookout for an announcement about an in-person Teen Event to be held later this year.

Family Day

September 19, 2021

Charlotte, NC

Get your family together and join Hemophilia of North Carolina (HNC) at Top Golf in Charlotte for an afternoon of fun! Following lunch, you will have two hours to practice your skills. A golf pro will be available to help you perfect your drive. More details will be announced soon on the HNC website.

HNC Can't Wait For The Raleigh Festival & Walk!

October 2, 2021
Morrisville, NC

Save the date for the Raleigh Family Festival & Walk for Bleeding Disorders, being planned as an in-person event on October 2 at Lake Crabtree County Park in Morrisville! Hemophilia of North Carolina (HNC) is planning for a fun and festive day at the lake where the community can get together and celebrate its fundraising accomplishments. The Family Festival & Walk for Bleeding Disorders is HNC's largest fundraiser of the year, with proceeds going toward supporting critical programs and services including emergency financial assistance, medical IDs, scholarships, programs and events to support and educate the community, and more. Your help is needed to make this event a success! More information will be announced this summer, with details available on the HNC website.



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Dan Bull

Empowerment advocate

About Dan

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

Connect with Dan

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(240) 285-3948

**Hemophilia
Community Liaison**



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Community Conversations

Hemophilia of North Carolina (HNC) believes in the importance of connecting with other people affected by bleeding disorders to share common experiences, triumphs, and challenges. Over the years, HNC has implemented a variety of experiences to allow the community to connect, including intimate educational dinners, Community Connections Groups, parent mentoring, one-day events, and larger retreats and meetings to connect with others facing similar situations.

The COVID pandemic has taken many opportunities away from the community to connect, but one opportunity over this hard time has been gained, and that is the opportunity to connect from home with people across the state! The barriers of traveling have been removed thanks to the implementation of Zoom.

Based on community input, HNC is starting virtual community support groups, called Community Conversations, so that you can connect more closely with others who share similar experiences, while at home. These group meetings will be held via Zoom so that you can connect wherever you are. To begin, there will be six groups with the opportunity to start more as needed:

- Men with bleeding disorders
- Parents of children with bleeding disorders
- Women with bleeding disorders
- Spouses/partners and caregivers of adults with bleeding disorders
- Rare bleeding disorders (factors 1, 2, 5, 7, 10, 12, 13, platelet disorders): Rare Conversations
- Spanish-speaking families

Each group will meet every three months. The first few meetings will be to connect and select group leaders. *Community Conversations* are expected to begin in July. For more information, please visit the HNC website.



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Save the Date: In-person Events

Save the date for upcoming events:

Small Summer Events: July 10, 2021 in Charlotte, NC and Raleigh, NC

Small Summer Events: July 11, 2021 in Asheville, NC and Greenville, NC

Family Day: September 19, 2021 in Charlotte, NC

Raleigh Family Festival & Walk for Bleeding Disorders: October 2, 2021 in Morrisville, NC

SOAR and Blood Brotherhood Weekend: November 20-21, 2021 in Greensboro, NC

Holiday Celebration: December 4, 2021 in Greenville, NC

2022 Charlotte Family Festival & Walk for Bleeding Disorders: April 2, 2022 in Charlotte, NC

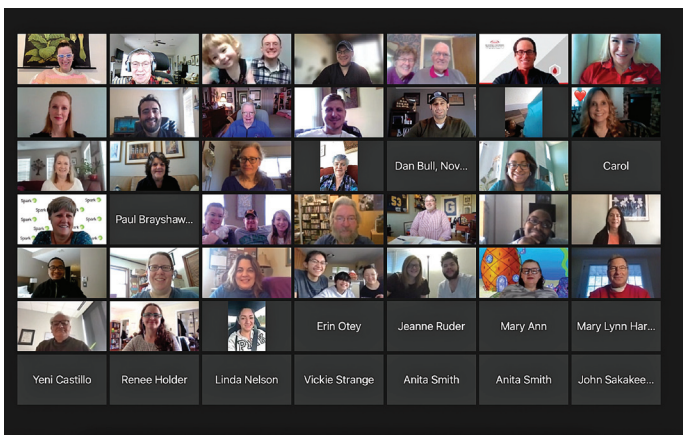
A Time of Change

March 6, 7, 13, 14, 20, 21

With Hemophilia of North Carolina (HNC) holding its Annual Meeting virtually, it provided an opportunity to spread out programming in order to allow people multiple opportunities to connect and learn. Over three weekends, there were numerous sessions to learn about the past, present, and future of living with a bleeding disorder. The theme of this year's Annual Meeting was *A Time of Change*, and throughout the three weekends, sessions touched on changes seen in the bleeding disorders community over the past several decades, from a focus on men and boys with hemophilia, to now including those affected by von Willebrand disease and more rare bleeding disorders, and women and girls with bleeding disorders.

As an opening, the Annual Meeting attendees heard from a panel of speakers, including medical providers and community members, about the changes seen in the bleeding disorders community over time. Attendees learned about the history of the bleeding disorders community and how resilience can help to move forward as well as the importance of taking care of yourself throughout this difficult year. There were sessions about hemophilia, von Willebrand disease, and rare bleeding disorders, as well as learning how to be an advocate for yourself with a bleeding disorder. There were sessions about insurance, Medicare, and HNC's advocacy initiatives for the year. Multiple sessions were presented for the different groups within HNC, including Blood Brotherhood sessions for men with a bleeding disorder, HOPE sessions for parents with children with a bleeding disorder, SOAR sessions to connect women with a bleeding disorder, a session for spouses and partners, and a session for Spanish-speaking community members.

Attendees learned about bias in healthcare and how it has affected women, the LGBTQ, and BIPOC communities. Finally, to conclude the meeting, a COVID-19 Town Hall session was presented, with questions from the community about COVID-19 *Continued next page*



A Time of Change *continued from previous page*

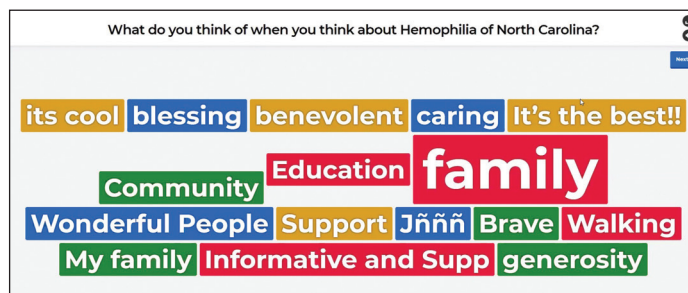
directed to several doctors. Though there wasn't an "exhibit hall" like that at an in-person event, attendees did have the opportunity to learn more about the different pharmaceutical companies and specialty pharmacies during the "Open House" breakout sessions throughout the three weekends. In addition to the educational sessions for adults, there was a Teen and Children's track, which includes sessions about becoming independent and taking responsibility for bleeding disorders care, games, a science demonstration about how blood clots, and fun presentation about frogs!

No Annual Meeting would be complete without some fun community bonding sessions. Attendees were able to participate in an online escape room, a fitness class, and a painting party.

While HNC hopes never to have to plan another virtual Annual Meeting again, the event was a huge success, with more than 150 community members signing in over the three weekends. Thank you to the sponsors who helped to make the event possible, our knowledgeable speakers, as well as the amazing HNC community members who showed up for the event.

Pre-Festival Game Night

April 12, 2021



In preparation for the Charlotte Family Festival & Walk for Bleeding Disorders, Hemophilia of North Carolina (HNC) held a fun game night for the community. The trivia game reminded participants about past HNC Festival & Walk events and provided opportunities to meet and learn about the sponsors of this year's Charlotte Festival & Walk. After trivia, there was a fun game of BINGO. Game Night was a great way to get excited for the virtual Festival & Walk, which took place the following weekend.

Bicycle Safety

March 20 and April 3, 2021



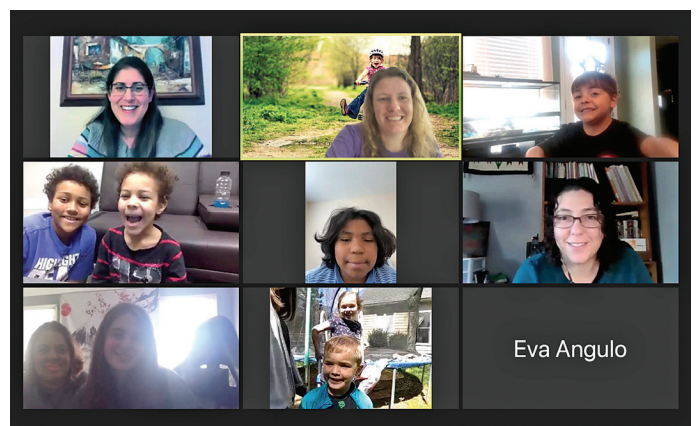
Riding a bike is a great way for children to have fun and stay healthy, and it can be a safe activity for children to participate in, even with a bleeding disorder!

This past winter, Hemophilia of North Carolina (HNC) was awarded a grant from the North Carolina Department of Transportation (NCDOT) to distribute bike helmets to community members in need. As part of the grant activities, HNC held two events to help teach about the rules of the road and the benefits of riding a bike.

On March 20, during the Annual Meeting, Jennifer Newman, physical therapist at the UNC Chapel Hill Hemophilia Treatment Center, and Lora Joyner, physical therapist from the ECU Hemophilia Treatment Center, presented *Health and Wellness for Children with Bleeding Disorders*. This session provided parents with an overview of safe activities to keep kids active and a more detailed dive into bicycle riding and the importance of wearing a helmet. Then, on April 3, Jen led a presentation for kids about how to stay safe while riding a bike, rules of the road, and the importance of wearing a helmet.

Attendees from both events were able to apply to receive free bicycle helmets. HNC has since opened the applications for bicycle helmets to all of its members and will distribute helmets until there are none left.

HNC wants to thank the NCDOT for the opportunity to receive this grant and distribute helmets.



Bleeding Disorders Awareness Month and World Hemophilia Day

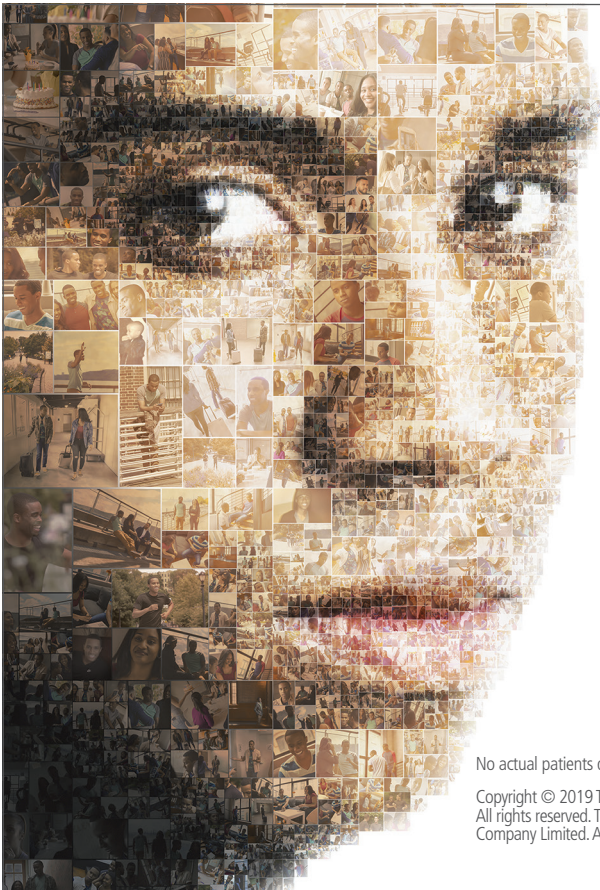


Wells Fargo Duke Energy Center

March was Bleeding Disorders Awareness Month and many Hemophilia of North Carolina (HNC) members used those 31 days to raise critical awareness of bleeding disorders. Some even made T-shirts for the occasion! Additionally, World Hemophilia Day took place on April 17, which also happened to be the date of HNC's virtual Charlotte Festival and Walk. See page 12 to learn more about how HNC celebrated the day and recognized the impact of bleeding disorders around the world. Buildings in Charlotte were lit up red in order to honor the day.



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Conversaciones Comunitarias

Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés) cree en la importancia de la conexión con otras personas afectadas por desordenes hemorrágicos con el fin de compartir experiencias, triunfos y retos. A través de los años, HNC ha implementado una variedad de experiencias que llevan a la comunidad a conectarse, incluyendo intimas cenas educativas, Grupos Comunitarios de Comunicación, tutorial y guía para padres, eventos de un día de duración, y retiros de mayor envergadura y reuniones con el objetivo de conectar con otras personas en situaciones similares.

La pandemia causada por el COVID nos ha robado muchas oportunidades de estar conectados con nuestra comunidad, pero si hay una oportunidad que hemos logrado y es la ventaja de poder comunicarnos desde nuestros hogares con gente de todo el país! Las barreras antes impuestas por la necesidad de viajar han sido superadas gracias a la implementación de ZOOM.

Basados en opiniones de la comunidad, HNC ha comenzado grupos de comunidad virtual, llamadas Conversaciones Comunitarias, de tal manera de poder comunicarse mas estrechamente con otras personas con experiencias

similares, sin moverse de su hogar. Las reuniones de estos grupos se realizarán vía ZOOM, así es podrán comunicar desde el lugar donde se encuentren en ese momento. Para comenzar, habrá seis grupos con la posibilidad de agregar otros según necesidad:

- Hombres con desordenes hemorrágicos
- Padres de hijos con desordenes hemorrágicos
- Mujeres con desordenes hemorrágicos
- Conyugues/parejas y cuidadores de adultos con desordenes hemorrágicos
- Desordenes hemorrágicos inusuales (factores 1, 2, 5, 7, 10, 12, 13, desordenes de plaquetas): Conversaciones Inusuales
- Familias de Habla Hispana

Cada grupo se reunirá cada tres meses. El propósito de la primera reunión será para conocerse y seleccionar los líderes del grupo. Esperamos que el grupo *Conversaciones Inusuales* comience en Julio. Para más información, por favor visiten el sitio de internet del HNC.

Iniciativa de Salud Mental

Cuando se piensa en como se vive y como se maneja un desorden hemorrágico, al paciente se le trata como una condición medica, porque es de verdad una condición medica. El paciente asiste a sus visitas medicas anuales, para verificar que el tratamiento recibido esta siendo efectivo y que tiene las herramientas para cuidar de su organismo. Al paciente se le enseñan maneras de como manejar, tratar y prevenir problemas a las articulaciones. El paciente contacta a su doctor primario y lo visita cuando tiene una necesidad severa. No pensaría en ignorar la preocupación por un sangramiento o simplemente esperar que el problema se supere por si mismo si no lo menciona. Pero cuando se habla de salud mental, se le asocia un estigma negativo al momento de buscar ayuda para el bienestar emocional. Los individuos que sufren o son afectados por desordenes hemorrágicos pueden sufrir de desafíos adicionales relacionados con su bienestar emocional y salud mental, incluyendo dolor, aislamiento, depresión, ansiedad, culpa, y trauma.

Por muchos años, usted puede haber observado sesiones ocasionales relacionadas con como atender y lograr un bienestar emocional, incorporadas dentro de eventos de Hemofilia de Carolina del Norte (HNC por sus siglas en

Inglés). Desafortunadamente, no ha habido consistencia con este tema, mas allá de saber que era bueno introducirlo a la comunidad. Durante el pasado año, y enfrentando la pandemia del COVID-19, los empleados del HNC han conversado con miembros de la comunidad quienes sufren de problemas de salud mental incluyendo aislamiento, depresión, y problemas para el cuidado de desordenes hemorrágicos. Después de mucho dialogo sostenido entre el personal de HNC y de otros relacionados con desordenes hemorrágicos a través de todo el país, HNC ha tomado las riendas para ir mas allá de sesiones ocasionales y hablar de bienestar emocional y tomar acciones concretas.

HNC ha organizado un grupo de trabajo de miembros de la comunidad y personal del centro de tratamientos para analizar las necesidades y retos que enfrentan la comunidad con desordenes hemorrágicos. HNC se ha puesto en contacto con organizaciones de salud mental y otras similares para colaborar en programas futuros. HNC no es exactamente una organización de ayuda, pero puede proporcionar recursos y educación para ayudar a la gente a conseguir acceso a la salud mental que necesiten, y esta aunando esfuerzos para desarrollar una encuesta que será *continúa página siguiente*

Actualización del Programa Unión Latina

El Programa de la Unión Latina está dirigido a prestar apoyo a los miembros de habla hispana de la comunidad con desordenes hemorrágicos. Por medio de presentaciones educativas y de un retiro anual, este soporte es proporcionado a individuos y familias que hablan Español, enteramente en su idioma.

Durante la primavera recién pasada, Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés) sostuvo varios eventos de la Unión Latina, incluyendo una sesión en la Reunión Anual así como también disponibilidad de traducción para los días de inauguración y cierre de la Reunión Anual, y dos

programas educativos, uno en Mayo acerca de salud de las articulaciones y uno en Junio acerca de mujeres con problemas hemorrágicos. HNC espera con mucho entusiasmo ofrecer más programas para la Unión Latina los próximos verano y otoño así como también el retorno de los eventos en persona.

El Programa Unión Latina ofrece soporte y educación a los individuos de origen Latino y sus familias en Carolina del Norte, quienes sufren de desordenes hemorrágicos. Este programa es ofrecido en Español y es posible gracias a una beca de Takeda. Para más información, visite el sitio de internet de HNC.

Un Esfuerzo en Conjunto

15 de Mayo, 2021

El Segundo evento del año de la Unión Latina fue realizado virtualmente el 15 de Mayo. Patricia Espinosa-Thomson, Educadora Clínica Bilingüe de Takeda, nos presentó *Un Esfuerzo en Conjunto: Unidos Para Proteger las Articulaciones*.

Los participantes se informaron de cómo mantener articulaciones saludables y prevenir el daño de estas. A continuación de la presentación, los participantes jugaron un divertido BINGO! El siguiente evento de la Unión Latina se realizó de manera virtual el 26 de Junio, así es que leerán más acerca de este evento en la próxima edición de The Concentrate. Agradecemos a Takeda por el apoyo con el Programa Unión Latina.



NUEVO Serie de Videos de Salud Mental en Español

La Federación de Hemofilia de América ha lanzado una serie nueva de videos de salud mental para los miembros de la comunidad de habla hispana. Los trabajadores sociales de HFA comparten información, recursos y consejos sobre salud mental y bienestar. Puede encontrar los videos en el canal de YouTube de HFA en www.youtube.com/HemophiliaFederationofAmerica.



Iniciativa de Salud Mental viene de la página anterior

distribuida a fin de conocer más cuáles puedan ser sus necesidades. Adicionalmente, HNC estará trabajando en una campaña para ayudar a romper el estigma que rodea la salud mental.

Si usted estuviese interesado en unirse al Grupo de Trabajo de Salud Mental, o tiene alguna idea o sugerencia que compartir, por favor contactarse con Gillian Schultz, Director de Programas en gillian.schultz@hemophilia-nc.org o bien llamando a la oficina de HNC al (919) 319-0014.

Charlotte Festival & Walk – Virtual Again!

April 17, 2021



Who would have guessed over a year ago that not one, but two Charlotte Festival & Walk for Bleeding Disorders fundraisers would need to be virtual? But when the COVID-19 pandemic was getting worse rather than improving this past winter, Hemophilia of North Carolina (HNC) knew that the safest option would be to transition the Charlotte Festival & Walk to a virtual event once again!

Held on World Hemophilia Day, the 7th Annual Charlotte Family Festival & Walk for Bleeding Disorders turned out to be another big success. Starting at 10:00 am on April 17,

HNC began live streaming activities, announcements, and prize winners! There were two emcees for the event, North Carolina community member Jacob Hoernlein and bleeding disorders community member Max Feinstein. Max is also a musician who uses his platform to raise awareness about bleeding disorders and mental health, and he performed a few of his songs during the event. Since the event took place on World Hemophilia Day, HNC shared facts about bleeding disorders around the world.



This year's fundraising efforts were focused differently than in the past, since many of HNC's corporate and industry sponsors

were not able to support the Festival & Walk as they previously had due to the pandemic. So instead of focusing on the total fundraising amount, HNC decided to encourage everyone to raise **\$20,000**, the individual and team fundraising goal! You blew that out of the water, raising more than **\$26,240**. That amount, plus HNC's corporate and industry sponsors, helped to raise more than \$56,504 that all goes to support HNC's programs and services.

Congratulations to the award winners:

Top Team Fundraiser: SHARPSHARKS

Top Individual Fundraiser: Andrea Mayle

King Droplet: Spike Myers

Queen Droplet: Julie Mayle

Junior Droplets: Riley & Noah Schultz

Hospital Cup: Novant HTC

Thank you to Jacob Hoernlein and Max Feinstein for being the emcees, Karl Schultz for putting together the video montage, supporters, individual fundraisers, team members, and sponsors. If you missed it, you can still view the event on HNC's Facebook page: www.facebook.com/HemophiliaNC. Save the date for the 8th Annual Charlotte Family Festival & Walk for Bleeding Disorders – on April 2, 2022 in uptown Charlotte. And join us in-person for the 14th Annual Raleigh Family Festival & Walk for Bleeding Disorders – on October 2, 2021 at Lake Crabtree Park in Morrisville.

Continued next page

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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.

We are proud to support HNC and the bleeding disorders community!

~ Charlene Cowell and John Prim

~ The Hill Family

Congratulations SharpSharks! And thank you HNC for making this year's Virtual Family Festival successful & fun!

~ Linda and Allen Kurtz

~ TEAM DIEGO

We are incredibly thankful for the love and support from our family and friends year after year in our efforts to raise money for the bleeding disorders community. We are also very grateful for the many ways HNC uses this money to assist and promote the welfare of every member in the community.

~ The Otey Family

In Memory of George D. McCoy

~ Phil Poovey

Congratulations HNC for meeting your goal!

~ The Schultz Family

Courtney Carr

Jenny Fowles

Ryan Griffith

Mary Ann Knovich

Ethan Kurtz

Eric and Melanie Lanier

Genise Lee

Don & Elizabeth Lineberger

DeEtte Mann

Spike Myers

Rebecca Odom

Tommy Odom

Shellie Peters

Diana Smith

Kate Stotz

Deb and Jim Thomas

Heidi Traficanti

Julie Vibbert

Erika, Luke, & Vivi Wilson

Dorice Winston

Consumer Medical Symposium

May 1, 2021



For some time now, Hemophilia of North Carolina (HNC) has been hoping to provide an event that brings the science and medicine of bleeding disorders to the patient and consumer level. Initially, HNC was planning to hold the first Consumer Medical Symposium in the spring of 2020; however, COVID-19 put a damper on that idea. Being early in the pandemic, HNC and the community weren't used to using Zoom as they are now. When it was clear that events would need to stay virtual through at least mid-2021, HNC decided to jump in and hold the first Consumer Medical Symposium virtually.

HNC received a grant from the Hemophilia Alliance Foundation to hold the event. Speakers were recruited from North Carolina's hemophilia treatment centers (HTCs) to present all the sessions. Presentation topics included the importance of comprehensive care for bleeding disorders, sessions about the different types of bleeding disorders, physical therapy, nutrition for care of bleeding disorders, novel therapies, aging with a bleeding disorder, women with bleeding disorders, and genetic testing for bleeding disorders. At the conclusion of the event, participants had the opportunity to paint a special painting, designed exclusively for this event! Wine & Design, Cary, created a special painting of a "DNA Tree" to symbolize how bleeding disorders community members are connected.

HNC would like to especially thank the staff at the ECU HTC for taking such a pivotal role in helping to plan the event, along with the other North Carolina HTCs for helping to support this event, and the Hemophilia Alliance Foundation for the grant that made this event possible.

First Look at HNC's Needs Assessment *continued from page 1*

Bleeding Disorders

From those who have attended events, HNC knows that the community is diverse. However, in many cases, unless someone discloses their bleeding disorder, it is not always known. The results of the Needs Assessment show the great diversity of bleeding disorders that HNC serves.

Community Involvement

Reasons for getting involved with HNC vary from person to person. The majority of people became involved because they were looking for patient education about bleeding disorders and were looking to connect with other people who are affected by bleeding disorders.

While 82% of respondents attend at least one HNC event each year, there are significant barriers to being able to attend events including the distance to events and people's schedules.

Needs of the Community

The needs of the bleeding disorders community varied substantially. Of significant note, 75% indicated that they need help raising awareness about their bleeding disorder and 71% want more information about research into novel therapies and treatments for bleeding disorders.

Communications

With changing times, HNC wanted to know how people prefer to get their information. Ninety-six percent of people prefer email communications and 45% of people still like to get their information from the newsletter, *The Concentrate*. While HNC has been looking at other ways of communicating, including social media, only 24% of respondents prefer Facebook, and 2% and 1% of respondents prefer Instagram and Twitter respectively. Mail still seems to be a valuable resource, with the HNC website and text messages closely behind.

How Do People Ultimately Feel about HNC

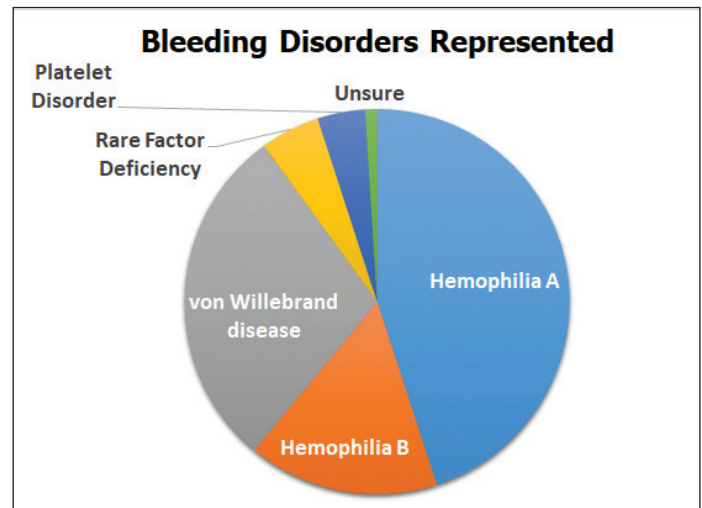
The overall results of the Needs Assessment were positive. Ninety-four percent of respondents agree that HNC is an advocacy leader, 92% agree that HNC acts in the best interests of the community, and 88% of respondents agree that HNC puts members first.

Moving Forward

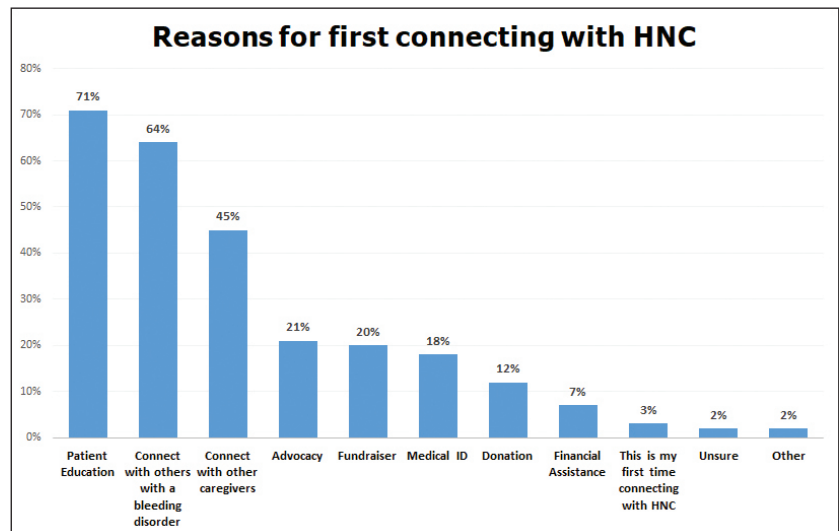
So where does HNC go from here? Over the next couple of months, HNC is going to continue reviewing the data from the Needs Assessment to see what areas need improvement. The staff and volunteers on some of the strategic planning committees have been talking about ways to meet the community where they are so the distance to events becomes less of a barrier to receiving education and support. Some ideas that have been discussed so far include:

- Determining how to utilize Zoom and other virtual opportunities as we come out of the pandemic. While questions regarding virtual opportunities were not part of the Needs Assessment as it was developed prior to COVID-19, HNC has noticed a significant increase in attendance from people who would not otherwise be able to make it to events due to distance and schedules. HNC is planning to continue its use of Zoom even as many events go back to taking place in-person.

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Needs Assessment Graph: Bleeding Disorders Represented

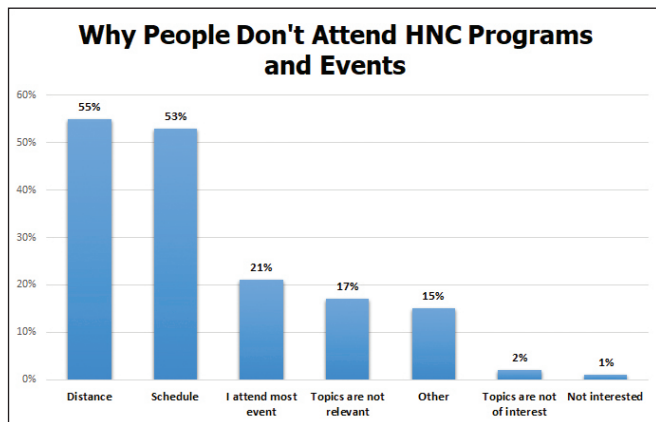


Needs Assessment Graph: Reasons for Connecting

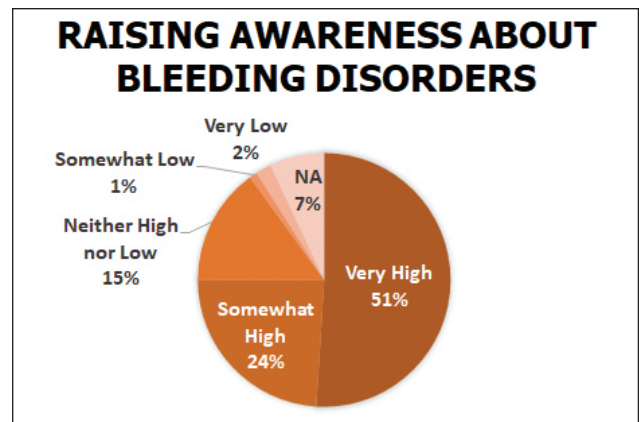
First Look at HNC's Needs Assessment *continued from previous page*

- Determining how to bring more local events to different corners of the state. With such a large state and a small staff, HNC is looking at ways to utilize volunteers to help make this possible.
- Increasing HNC's educational opportunities for individuals with von Willebrand disease and rarer bleeding disorders.

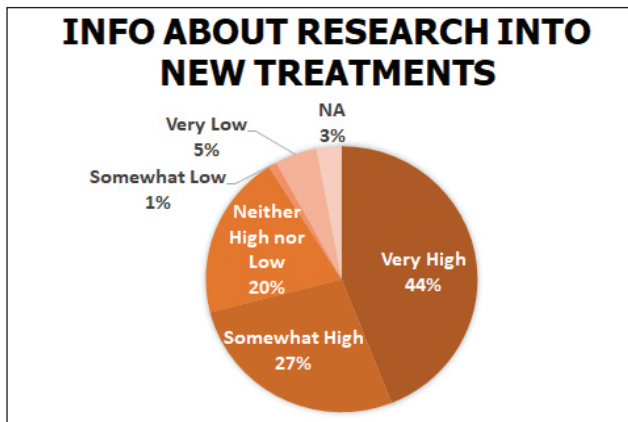
How can you help? If you're interested in sharing your thoughts or assisting with any future plans, please reach out Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org or by contacting the HNC office at (919) 319-0014.



Needs Assessment Graph: Barriers to Attending



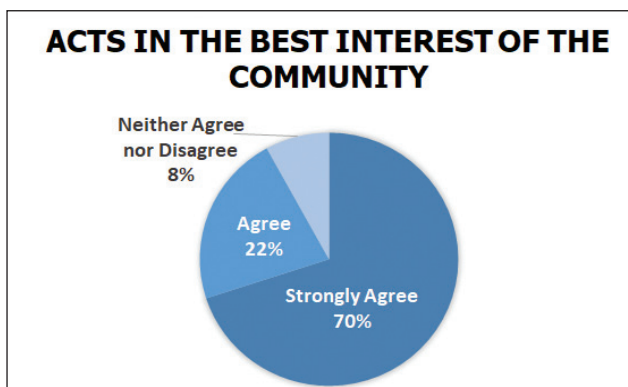
Needs Assessment Graph: Raising Awareness



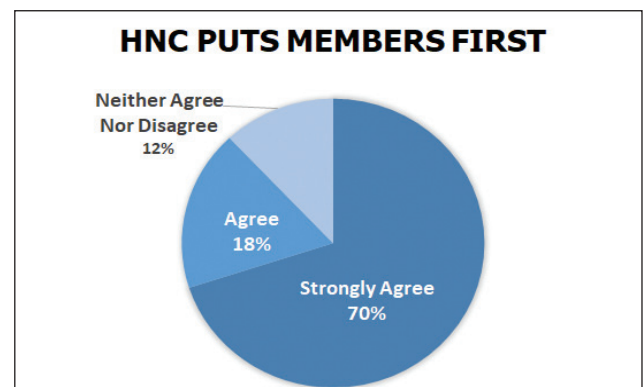
Needs Assessment Graph: Info About Research



Needs Assessment Graph: A Leader in Advocacy



Needs Assessment Graph: Community's Best Interest



Needs Assessment Graph: Puts Members First

A Joint Effort

May 15, 2021

The second Unión Latina event of the year was held virtually on May 15. Patricia Espinosa-Thomson, Bilingual Clinical Educator from Takeda, presented *A Joint Effort: Teaming Up for Joint Protection*. Participants learned about how to maintain healthy joints and prevent joint damage. Following the presentation, everyone played a fun game of BINGO! The next Unión Latina event was held virtually on June 26, so read about it in the next edition of *The Concentrate*. Thank you to Takeda for supporting the Unión Latina Program.

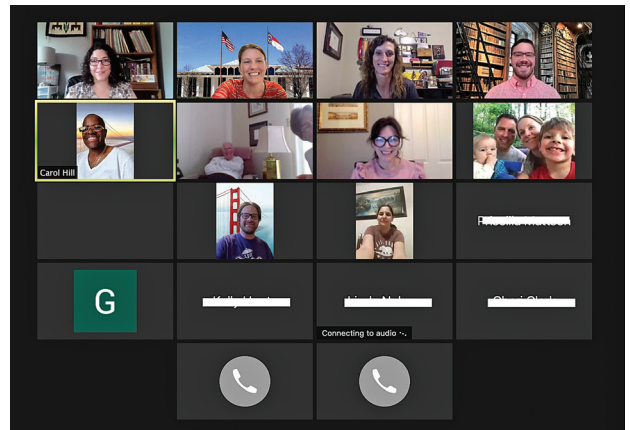
A Busy Time for Advocacy

Over the last few months, Hemophilia of North Carolina (HNC) has held three virtual events dedicated to legislative advocacy. These events were a part of a series of Pre-Legislative Day informational sessions to help educate and prepare HNC's advocates for the annual Legislative Day event.

Hear From Your Peers - April 28, 2021

Attendees had a chance to hear from Randi Clites, a bleeding disorders community member and former Member of the Ohio House of Representatives. Randi shared about her experiences within the bleeding disorders community, what inspired and motivated her to begin advocating, and how sharing her story led to a passion of inspiring big

Continued next page







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A Busy Time for Advocacy continued from previous page

changes, which included running for public office! Attendees also heard from Nathan Schaefer, Vice President of Public Policy at the National Hemophilia Foundation (NHF). Nathan shared his experiences in working with the bleeding disorders community across the country -- from those with advocacy backgrounds to those who have never stepped foot in a legislative office before. The event closed with a great Q&A session, which allowed attendees to ask Randi and Nathan deeper questions about advocacy involvement and its importance.

Copay Assistance and Accumulator Adjusters - May 10, 2021

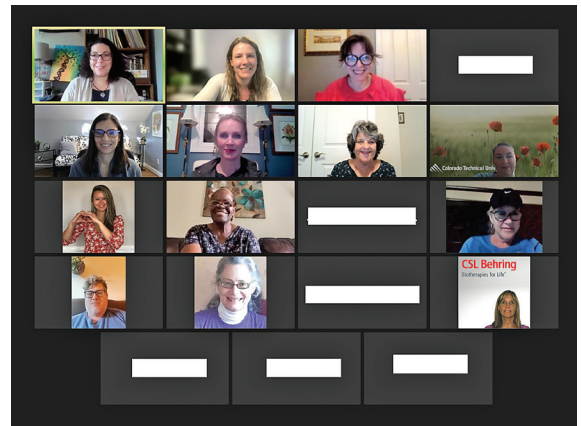
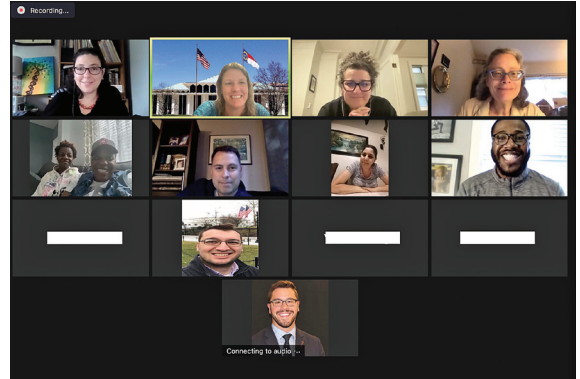
Marla Feinstein, Senior Policy and Healthcare Analyst for NHF, presented to NC community members about a scary, complicated topic involving copay assistance. Many patients on high-cost drugs have had to use copay assistance (also called coupons or factor assistance cards) to help afford their medicine. Unfortunately, insurance companies have implemented Accumulator Adjuster Programs (AAPs) in which the coupon or assistance fund being used to help pay for the medicine is accepted by the insurance company, but the insurance does not count it towards the patient's out-of-pocket expenses as they used to. So even though a company is providing assistance, the patient still gets stuck with the full cost. Marla and Charlene, HNC Executive Director, talked about what states are doing to try and ban this practice.

Medicaid Expansion - May 13, 2021

Julia Lerche, Chief Strategy Officer and Chief Actuary for the North Carolina Department of Health and Human Services, Division of Health Benefits, gave an excellent presentation on Medicaid in NC. The presentation covered Medicaid 101, who currently benefits, who would benefit if NC expanded Medicaid, financial implications of Medicaid expansion, the impact of not having expanded Medicaid, and more. Participants had a lot of great questions. Thank you to Julia and NC Medicaid for helping to educate the bleeding disorders community.

The Copay Assistance and Medicaid Expansion sessions were recorded and PowerPoint slides are available. If anyone would like a copy, please contact Charlene at info@hemophilia-nc.org or (919) 319-0014.

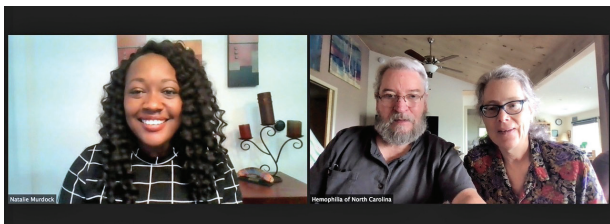
All of these advocacy sessions were made possible through a grant by NHF. HNC really appreciates NHF's support in strengthening our advocacy efforts!



Legislative Day: A Voice for the Community

May 25, 2021

Every year, Hemophilia of North Carolina (HNC) advocates gather to advocate for issues that are important to the bleeding disorders community. This year, the gathering required access to Zoom or the phone. No travel required! There were 14 legislative meetings scheduled, in addition to some that were planned for other days. Additionally, HNC set up an advocacy alert using Phone2Action, a tool that allows individuals to quickly and easily send an email and/or Tweet to their senator and representative. Through this effort, there



Sen. Murdock & HNC advocates

were 140 connections made, including 120 emails sent and 20 Tweets! Advocates talked to their legislators about two important topics:

1. Ban Copay Accumulator Adjuster Programs (AAPS): As patients with rare, chronic conditions, people with bleeding disorders need high-cost specialty medications. Copays and coinsurance have increased, as have deductibles, over the years. This has made it harder for people with conditions such as hemophilia to afford

Continued next page

Legislative Day: A Voice for the Community continued from previous page

their medication year after year. In order to remain compliant on their medication, many patients rely on financial assistance from charities and drug manufacturers in order to afford the medicine. One of the greatest resources has been copay assistance programs, which serve as a lifeline to those in need. Under the AAPs, insurance companies are not counting the amount of money covered by manufacturer copay assistance programs toward enrollees' annual deductibles and out-of-pocket limits, but they keep the copay assistance funds used.

2. Expand Health Care Access: Provide health care options for people who do not currently qualify for Medicaid but also do not qualify for subsidies on the Marketplace. Medicaid expansion will protect these individuals so that they can be proactive with their care instead of having to resort to hospitals. In turn, hospitals, especially those in rural areas, will not have to bear such a financial burden.

HNC is grateful to all of the participants, who used their voices to better the lives of people living with bleeding disorders.



Rep. Potts & HNC advocates

In the Fall Edition

Read about educational dinners including *Spotlight on Siblings* and *Women with Bleeding Disorders*, as well as the June Unión Latina event, and the Summer Events in the fall edition of *The Concentrate*.



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.

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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 23, 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.

Programa Unión Latina



Annual Meeting

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Blood Brotherhood Program Update

Hemophilia of North Carolina (HNC) is looking to build its Blood Brotherhood Program in the upcoming months. After more than a year of separation, HNC is looking forward to providing new opportunities for men who have a bleeding disorder. Would you like a chance to get together and have fun with the guys? Do you want to learn more about something related to your bleeding disorder, or even just “adulting”? Let HNC know what you want to see from the Blood Brotherhood Program. And save the date for the Blood Brotherhood Weekend on November 20-21, 2021 in Greensboro. More details will be announced in the coming months.

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.hemophiliated.org.



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

HOPE Program Update

As the COVID-19 pandemic dragged on, Hemophilia of North Carolina (HNC) continued to provide opportunities for families who have a child with a bleeding disorder. At the Annual Meeting and other educational events over the past year, the community joined HNC to learn about managing their child's bleeding disorder, going to school with a bleeding disorder, and education about bleeding disorders themselves. Children (and parents) participated in science demonstrations to learn how blood clots and play games on Zoom. And parents and children learned about the importance of staying active and riding a bike with a bleeding disorder. As HNC starts opening back up with more in-person events, there will be more opportunities to reconnect or start connecting with other families affected by bleeding disorders. If you are a mother, father, guardian, or caregiver of a child who is diagnosed with a bleeding disorder, the HOPE Program is for you!

Join HNC and connect with other families at one of the Summer Events in Asheville, Charlotte, Garner, or Greenville. Come to Charlotte for Family Day at Top Golf. Or sign on to Zoom for Parenting Community Conversations, and for even more support, ask to be connected with a Parent Mentor.

The HOPE Program provides educational opportunities to help you navigate raising a child with a bleeding disorder, support programs to help you feel connected and part of a community, and additional resources so that you can become empowered to advocate for your child's needs. HNC aims to support the entire family, as having a bleeding disorder affects everyone.

If you have questions or would like more information, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org or by calling the HNC office at (919) 319-0014. You may also check the HNC webpage, your email, Facebook, Twitter, and Instagram pages for updates about upcoming programs and events.

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

The Unión Latina Program is aimed at providing support for Spanish-speaking members of the bleeding disorders community. Through educational presentations and an annual retreat, support is provided to Spanish-speaking individuals and families entirely in Spanish.

This past spring, Hemophilia of North Carolina (HNC) held several Unión Latina events. These events included a session at the Annual Meeting with interpretation available for the opening and closing days of the Annual Meeting, and two educational programs, one in May about joint health and one in June about women with bleeding disorders. HNC is looking forward to more Unión Latina programs this summer and fall as in-person events resume.

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





Soar Program Update

If you are a woman or a mother of a girl with a bleeding disorder, then Hemophilia of North Carolina (HNC) hopes you will connect with the **SOAR Program**. Over the past year and a half, HNC has held multiple events to support women and to provide valuable connections. Unfortunately, women with bleeding disorders have a big job of advocating for their needs, as there are still medical providers who don't know enough about bleeding disorders in women. Through many events throughout the year, HNC helps to educate and empower women to advocate for their own care. There will be more opportunities to connect and learn with other women in the coming months. Join one of the new online Women's Community Conversations Groups and save the date for the SOAR Weekend on November 20-21, 2021 in Greensboro.

In addition to providing support for women with bleeding disorders, the SOAR Program exhibits at multiple conferences throughout the year to raise awareness about women with bleeding disorders. Although events in the past year were virtual, HNC had the opportunity to virtually exhibit with the North Carolina Nurses Association. In the coming months, there will be in-person exhibits at the North Carolina Nurses Association Conference, Emergency Nurses Conference, and Dental Hygienists Conference.

SOAR is an HNC program for women and girls with a bleeding disorder, including those diagnosed with von Willebrand disease, hemophilia A and B, rare factor deficiencies, and platelet disorders, and also 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 they can SOAR to their full potential.

Please contact Gillian Schultz, HNC 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.

Mental Health Initiative



When you think about living with and managing a bleeding disorder, you treat it as the medical condition it is. You go to annual comprehensive care visits to make sure your treatments are effective and that you have the tools to take care of your body. You learn ways to manage, treat, and prevent joint problems. You contact your medical provider and visit them when you have an acute need. You wouldn't think to ignore the feeling of a bleed and just hope that it will go away on its own if you don't talk about it. But when it comes to mental health, a stigma may be associated with seeking help for your emotional wellness. Individuals living with or affected by a bleeding disorder may have additional challenges related to their emotional wellness and mental health, including pain, isolation, depression, anxiety, guilt, and trauma.

For many years, you may have noticed occasional sessions built into Hemophilia of North Carolina (HNC) events that deal with taking care of your emotional self. But there has not been a consistency with these sessions, other than that they are good to present to the community. Over the past year, in dealing with COVID-19 pandemic, HNC staff have spoken with members of the community who are suffering from mental health issues including isolation, depression, and barriers to care related to having a bleeding disorder. After many discussions held between HNC staff and other bleeding disorders staff members from across the country, HNC has taken the reins of moving beyond occasional sessions and talk of emotional wellness and is moving toward actionable things that can be done.

HNC put together a task force of community members and treatment center staff to brainstorm the needs and challenges faced in the bleeding disorders community. HNC has spoken with mental health organizations and others to collaborate on future programs. HNC is not a mental health organization, but it can provide resources and education to help guide the community toward the help that someone may need. Currently, HNC is developing resources to help people access the mental healthcare that they need and is working on developing a survey that will be distributed to find out more about what your mental needs may be. Additionally, HNC will be working on a campaign to help break down the stigma surrounding mental health.

If you are interested in joining the Mental Health Task Force, or you have an idea that you would like to share, please contact Gillian Schultz, Director of Programs, at gillian.schultz@hemophilia-nc.org or by calling the HNC office at (919) 319-0014.

North Carolina Advisory Board for Bleeding Disorders

By: Kathy Register

On Friday, April 30, the North Carolina Advisory Board for Bleeding Disorders (NCABBD) convened its second quarterly meeting of 2021. The NCABBD brings together consumers and Hemophilia Treatment Centers to review the state of the bleeding disorders community. The boards were a part of the equation when treatment centers received federal funds. The purpose is to keep open the lines of communication between the bleeding disorders community and providers. While no longer mandated, members consider the board extremely valuable. The NCABBD looks at issues past, present, and future that could affect our lives—politics, money, healthcare, family, lifestyles, opportunities, employment, and more. We exchange important information to help carry out our respective missions. The NCABBD has met using Zoom technology since early in the pandemic.

HNC President Steve Humes is chair. Representing HNC were Steve, Charlene Cowell, Gillian Schultz, Kathy Register, Phil Poovey, and Fleming Samuels. Consumers who attended were Charles Register and Mark Cleary. Institutions represented were Atrium Health's Levine Children's Hospital, University of NC's Harold R. Roberts Hemophilia and Thrombosis Center, Wake Forest Baptist Hospital Hemophilia Treatment Center, The St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital, and the East Carolina University Hemophilia Treatment Center.

Much of the agenda centered around the COVID pandemic and patient vaccine hesitancy, testing, and clinic protocols. In-person clinic visits are starting up again, but cautiously and slowly. Insurance

reimbursements vary for virtual visits (some reimbursement)

and telephone visits (very little reimbursement if any). During the pandemic, the centers have been asked to do more with fewer resources and less staff availability. With vaccines becoming available, and based on the number of Medical ID applications it received in the past year, HNC has been aware of increased numbers of clinic visits.

Nationally, the bleeding disorders community is seeing a spike in mental health crises. This has always been a concern, but COVID and isolation have deepened the issues. HNC put together a Mental Health Task Force that has brainstormed about the issues and is focusing on what is actionable. HNC will be asking for treatment center support. Charlene and Gillian presented updates to the advisory board about HNC's programs & services, its strategic planning, and advocacy efforts.

All treatment centers are working on QI --quality improvement-- in an effort mandated by federal grant objectives. Efforts include transitions to alternative management, website improvements, patient flow at clinics, and patient satisfaction.

The next NCABBD meeting will be July 30. Anyone interested in becoming a member of this advisory board, please contact Steve Humes at steven.humes@hemophilia-nc.org



Community Spotlight

Hemophilia of North Carolina (HNC) would like to give a very special shout-out to all of the 2021 Virtual Legislative Day attendees who agreed to meet with their legislators. While HNC knows how empowering and vital these meetings are, it can be overwhelming and scary for people who are less familiar with legislative advocacy. These individuals took time out of their schedule to learn about issues affecting the bleeding disorders community. They participated in pre-event sessions and practiced sharing their stories. They stepped up to be an advocate for the greater community, and HNC is so grateful. A heartfelt thank you to:

**Carol
Charlene**

**Dorice
Erin**

**Gillian
Jeanne**

**Kathy
Charles**

**Linda K.
Linda N.**

Matt



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.

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.

General Donations

William and Patricia Andrews
Sonya Atkins
Jill Baker
BreAnna Branch
Daisy Bratton
Mark and Jo Anne Buckley
Irene Cowell

Sue and Charles Cowell
Fran Davis
Marlo Davis
Leonard and Naomi Duffy
Jama Fleming
Jann Haynes
Sue and Allen Heafner
Jim and Doris Lucia

Melissa Poole
Phillip Poovey
Charlene Cowell and John Prim
Oscar Gonzalez and Jessica Prim
Michelle Vanhook
Brent White

Facebook Fundraisers

Katlin Marie
Blake Corbitt
Phillip Poovey
Linda Ann
Tamara Brayboy
Tara Burgess

Julie Lamb
Charlene Morriane-Osgood
Elizabeth Parks
LaQuenta Caldwell-Moody
Mark Diorio
Troy Schoolcraft

In memory of Blanche Olive Goldston

Teresa Clark
Valinda Dudley
Verna Fields
Bryan and Margaret Goldston
Marquerite Moore
Howard and Rita Willett

In memory of George D. McCoy

Sue and Charles Cowell
Amy Hadley
Lucy Kucmierz
Phillip Poovey
Charlene Cowell and John Prim
Charles and Katherine Register
Steven Humes and Mark Waters
Bryant Windham

Bleeding Disorder Awareness Month 2021

Andrew and Tina Bullard
Sarah Campbell
Clark Harris
Clyde Harris
CP Harris
Linda and Allen Kurtz
Charlene Cowell and John Prim
Charles and Katherine Register
Kirk and Fleming Samuels
Karl and Gillian Schultz

In honor of Charles & Katherine Register

Geoffrey Register

In memory of Christopher McNeil

Betty Judd

In honor of Jamie McNeil

Gary Cox

In honor of Jimmy Griffin

Ned and Nancy Combs
Judy Benfield

COVID-19 Financial Assistance Fund

Karyn and Kyle Davis
John and Teresa Sakakeeny

Member Spotlight... Why We Give

Donor Profile: Mr. and Mrs. W. Allen and Sue Heafner

By: Fleming Samuels, HNC Director of Philanthropy



Meet Sue and Allen Heafner! They joined me to discuss why Hemophilia of North Carolina (HNC) matters to them and how the organization has grown and helped the bleeding disorders community through the years. When I asked Mr. and Mrs. Heafner how HNC has made a difference in their life, they didn't hesitate to answer that the education and community relationships made HNC so special.

The Heafners said, "Imagine if a mother or a father with a son who has severe hemophilia is out there and they don't have a clue what is ahead — they need somewhere to go with hope — a place where people are living and thriving and everything is OK." This place to land is one of the primary reasons that they want to make sure that HNC is here for the long term with their support. "As long as we can do this, we want HNC to be here for people."

When I asked them what they wished more people knew about HNC, they said, "We wish people knew more about women who suffer from bleeding disorders and how badly hemophilia can affect people if left untreated. There is a whole community out here for you, and people need to know more. We've been to walks and annual meetings, and the community is bigger than we realize, and seeing these faces over and over makes a huge difference."

Talking to the Heafners made my day, and when I asked them about something that they wished more people considered, they wanted to talk to more people about how they give monthly. "It is about sustaining something that we feel should be here for everyone — especially education. It's not about how much you give; it's that you keep giving because it's the dollars together that make a difference!" They mentioned how much they have seen HNC grow over the years. They are proud to have been part of this growth.

How the American Rescue Plan Can Affect Your Healthcare Coverage

Reprinted from the National Hemophilia Foundation



The American Rescue Plan (ARP), signed into law on March 11, 2021, provides new opportunities to get health insurance coverage, and/or to reduce the cost of your premiums. Review your coverage now to make sure you are maximizing your benefits under the new law.

WHO SHOULD REVIEW THEIR COVERAGE?

- Anyone who buys their own insurance, is currently uninsured, or recently lost employer coverage.
- Anyone who buys their own health insurance (on- or off-marketplace.)
- Anyone who has non-ACA-compliant, off-marketplace coverage (e.g., short term plan, healthcare sharing ministry plan, Farm Bureau plan, etc.) that is not working for them.
- Anyone who received or is expected to receive unemployment insurance (UI) in 2021.
- Special considerations:
 - If you are a parent who is currently uninsured, but your child(ren) are covered through Medicaid or CHIP, you now may have affordable options to get your own coverage.
 - If you are over 50 and buy your own marketplace coverage, it is extremely likely that you will be eligible for more financial assistance with your premiums.
 - **Remember that enrollment in Medicaid, for those eligible, is open year-round.**

WHY ACT NOW?

- There are **new opportunities to enroll in marketplace coverage.**
 - All federal marketplaces are currently open for a special enrollment period (SEP) until August 15th. Similarly, all state-based marketplaces are also open (though they may have adopted different deadlines).
 - In addition to getting new coverage, people with off-marketplace coverage as well as current enrollees in federal and some state-based marketplaces also have the opportunity to switch coverage during the SEP.
 - For people with state-based marketplace coverage, you will need to check with your marketplace to see if switching is allowed.
 - Be aware that if you are thinking about switching plans during the SEP, you should consider where you are in meeting your deductible. If you switch plans, you may have to start over with a new deductible. Check the rules of your marketplace and talk to the company that issues your health plan.
- If you are eligible* for ACA subsidies, **you will receive more help paying for marketplace coverage.**
 - Individuals and families earning between 100-150% of the Federal Poverty Level (FPL)** are eligible for a silver tier health insurance plan with \$0 premiums and a significantly lower deductible.
 - Individuals and families earning between 150-400% of FPL will see substantial savings; they will get a big boost to the premium subsidies that they currently receive/would receive.
 - Individuals and families earning above 400% of FPL (previously ineligible for subsidies due to income) are now eligible for help with their premiums. People in this category who buy a marketplace plan will now be eligible for tax credits and will pay no more than 8.5% of their annual income in premiums for a benchmark silver plan.
 - The enhanced subsidies are available for the entire 2021 plan year to anyone who qualifies and enrolls in marketplace coverage – whether you enrolled during the regular 2021 open enrollment, or enrolled during the SEP (before or after enactment of the ARP). These enhanced subsidies will also be available for 2022.
- If you receive or are expected to receive **unemployment insurance (UI) benefits** during any point in 2021 you may be eligible for enhanced marketplace subsidies.
 - Many people in this category will be entitled to a benchmark silver plan with \$0 premium and additional cost sharing subsidies to help with deductibles and copays.
 - There are several things to note here:
 - You will have to meet additional eligibility criteria for marketplace subsidies.
 - These special rules will only be in effect during 2021.
 - Due to implementation complexity, enhanced subsidies may not be available until summer of 2021.
 - Notably, the provision of enhanced marketplace subsidies for UI beneficiaries **closes the “coverage gap” in non-Medicaid-expansion states**, creating new options for individuals who earned too little to qualify for subsidies previously.
- As an alternative to marketplace coverage, new subsidies may make **COBRA a good deal for you** if you recently lost your job or saw an involuntary reduction in hours.
 - If you are entitled to extension of your former coverage under COBRA, **your COBRA premium payments may be 100% subsidized** for up to six months, ending September 2021.
 - Note that this provision **does not create or extend eligibility for COBRA**. You need to meet the criteria for COBRA eligibility, and still be within your period of eligibility for COBRA benefits. And after September 2021, you will be responsible for the costs of your COBRA premium.

Continued next page

How the American Rescue Plan Can Affect Your Healthcare Coverage *continued from previous page*

YOUR TO-DO LIST

- If you don't have insurance coverage, explore your options on www.healthcare.gov. The site will tell you if you are eligible for Medicaid coverage or for subsidized Marketplace coverage.
 - Don't be put off by the list prices you see! These are estimates based on the information you provided. Most purchasers will be eligible for subsidies that bring down the cost of the premiums (as explained above). Once the Marketplace has all the required documentation, they will update your premium.
- If you are eligible for COBRA, consider that option, recognizing that you may be able to continue your existing coverage at no cost to you through September 30, 2021.
- If you have individual coverage, on- or off-marketplace, go to www.healthcare.gov to see if you qualify for new or enhanced subsidies and/or to make sure that your premiums have been updated. The new, more generous premium subsidies are retroactive to January 2021.
 - Some marketplaces may automatically adjust your premiums without requiring action on your part.
 - If you don't take action to reset your premiums, and your marketplace doesn't automatically update them, you will eventually receive a refund when you file your 2021 federal taxes next year.
 - For now, continue paying premiums. Don't risk having your insurance cut off!

Your national organizations -- NHF and HFA -- are here to help. Please contact us if you have questions about how to navigate coverage issues.
 Advocate@hemophilia.org
 Advocacy@hemophiliafed.org

*In order to receive enhanced subsidies, you must meet underlying eligibility criteria for subsidies (i.e., you do not have an offer of affordable coverage from your employer).

**The Federal Poverty Level for 2021 is \$12,880 for a single individual and \$26,500 for a family of four.

Article can be found here: www.hemophilia.org/news/how-the-american-rescue-plan-can-affect-your-healthcare-coverage

ON THE NATIONAL & LEGISLATIVE FRONT

National Hemophilia Foundation Bleeding Disorders Conference

August 25-28, 2021
 Virtual



The National Hemophilia Foundation's (NHF) annual Bleeding Disorders Conference is virtual -- so put on some comfortable clothes and join in! Leading community members and experts on hemophilia and other bleeding disorders come together every year to present the most recent advances in treatment, exchange information about the latest scientific developments, and discuss the newest clinical applications designed to improve patient care. Through an extensive lineup of educational sessions for patients, medical providers, and chapters, poster and oral communications, state-of-the-art lectures, and exhibits and professional networking opportunities, the Conference promotes important advancement for the community.

Register today: www.hemophilia.org/events/bleeding-disorders-conference

Hemophilia Federation of America Symposium

October 18-28, 2021
 Virtual



Hemophilia Federation of America's annual Symposium will be online at www.hemophiliafed.org. 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, Oct. 23 from 12 to 6pm (ET). The Symposium is offered to community members free of charge. Registration is required and opens in June.

Hemophilia Alliance Hill Day

Reprinted with permission

By: Johanna Gray

The Hemophilia Alliance held another successful virtual Hill Day in early May. We had 17 teams of advocates – including HTC staff members, patient advocates, representatives from NHF and HFA, and Alliance contractors and staff – participate in nearly 130 meetings with Congressional offices. We discussed a handful of issues:

- Overview of bleeding disorders and HTCs: With so many new Members and staff, we spent time on bleeding disorders and HTCs 101.
- Overview of 340B program and its importance to HTCs: We walked through the importance of 340B program income to allow HTCs to serve all of their patients and the ways that HTC participation in the program might differ from other covered entities.
- Discussion of new access to care issue – alternative funding model: This is the newest access to care challenge, where ERISA plans are dropping coverage of specialty drugs and then referring patients to manufacturer patient assistance programs to get access to their drugs.



NC advocates do a team high-five after 8 meetings

We did not have a concrete “ask” for these issues this year; we decided that going back to educating Members of Congress and their staffs was worthwhile since there are so many new faces this Congress, plus it allows for more Alliance members to participate. For the alternative funding model issue, we did ask for offices to let us know if they want to work with us on the issue.

We received great feedback from the offices with whom we met. There was broad interest in learning more about our community, support for HTC participation in 340B, and concern about the alternative funding model. We believe that the advocates also all had a great time – with meeting on Zoom this year (a platform very familiar to staff and Members of Congress, as well as all of us!), many more Hill folks participated on video, which made for better meetings.

In follow up to the Hill Day, we are now planning to reach out to the handful of offices that indicated an interest in working on the alternative funding model, as well as the staff for the House and Senate Committees with jurisdiction over the issue (House Education and Labor, and Senate Health, Education, Labor and Pensions). We are hoping to work with these staffers to develop the policy solution to the issue that could be advanced this Congress. This Hill strategy complements other efforts that the Alliance is undertaking with our partners, including outreach to payers, state insurance commissioners, manufacturers, etc.

Article can be found here: <https://hemoalliance.org/washington-update-may-2021/>

The Hemophilia Alliance is a not-for-profit organization that comprises federally funded hemophilia treatment centers (HTCs) that either have, or are seeking to have, pharmacy programs under Section 340B of the Public Health Service Act. The purpose of “the Alliance” is to promote the common interests of their member HTCs. In addition to providing support through advocacy, they provide consultant expertise and organizational support in the following areas: Operations; Regulatory compliance; Payer relations; Legal updates affecting practices; Contract pharmacy.

Hemophilia of North Carolina 2021 Calendar of Events Highlights



<u>July 10, 2021</u>	Summer Gathering - Charlotte, NC
<u>July 10, 2021</u>	Summer Gathering - Raleigh, NC
<u>July 11, 2021</u>	Summer Gathering - Asheville, NC
<u>July 11, 2021</u>	Summer Gathering - Greenville, NC
<u>September 19, 2021</u>	Family Day - Charlotte, NC
<u>October 2, 2021</u>	Raleigh Festival & Walk - Morrisville, NC
<u>October 29, 2021</u>	Unión Latina event - TBA
<u>November 20-21, 2021</u>	Blood Brotherhood and SOAR Weekend Greensboro, NC
<u>December 4, 2021</u>	Holiday Celebration - Greenville, NC



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

HOW DOES
THIS FACTOR IN?

To find out about a prescription
option, talk to your doctor or visit
OnceWeeklyForHemophiliaB.com



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info@hemophilia-nc.org

www.hemophilia-nc.org

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OCTOBER 2, 2021

LAKE CRABTREE PARK

Hemophilia of North Carolina

FAMILY '21 FESTIVAL

& Walk for Bleeding Disorders

Raleigh, NC



*in person if conditions permit