

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SUMMER 2020

A MESSAGE FROM THE EXECUTIVE DIRECTOR

It is with great excitement that I announce the newest addition to the Hemophilia of North Carolina (HNC) staff, Rebecca Sadi. Rebecca started on June 1 as HNC's Operations Specialist and will be working with us part time. Rebecca will be handling the financial assistance requests, Medical IDs, financials, assisting with communications, and much more! While we aren't hosting in-person events right now, we wanted to give you the opportunity to get to know her by sharing her bio. Rebecca will look forward to meeting some of you virtually for now, and in person as soon as we are back to hosting our many events throughout the year!

Wishing you all health and happiness,
Charlene



Rebecca Sadi, HNC Operations Specialist

Rebecca has her Bachelor of Science Degree in Interior Design and Marketing from Meredith College. She has many years of work experience as a bookkeeper and as an administrative assistant. She aspires to be a great asset to Hemophilia of North Carolina. When Rebecca isn't at the office, she enjoys crafting and spending time with her family. Her family includes her husband, 21-year-old twin girls, and her three fur babies.

Important MASAC Recommendations

During the ongoing COVID-19 national health crisis, it is important that persons with bleeding disorders have an adequate supply of their clotting factor or non-factor replacement therapy (e.g.: Hemlibra®). It is always possible that there could be an interruption in a supply or delivery chain, making it difficult to get a refill on short notice. With this in mind, the National Hemophilia Foundation's (NHF) Medical and Scientific



Advisory Council (MASAC) has issued an important new recommendation to the bleeding disorders community: *patients with a bleeding disorder treated on regular prophylaxis should be able to obtain a prescription refill for their prophylaxis regimen when their home quantity reaches at a minimum an estimated two week's supply.*

HNC recommends that those of you who treat your bleeding disorder on a regular schedule (prophylaxis) reach out to your provider about getting an early refill so that you can keep a two-week safety cushion in your at-home supply during this period of national emergency. HNC and NHF are available to help if you have any questions.

The full MASAC recommendation can be found on the NHF website: tinyurl.com/masac2020

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Save The Date

HNC Unión Latina

1 de agosto, 2020

Que se anunciará

NHF Bleeding Disorders Conference

August 1-8, 2020

Virtual

HNC/HSC Teen Retreat

Dates TBA

Virtual

HNC/Wake Forest HTC event

August 22, 2020

Virtual

HNC/UNC HTC event

August 22, 2020

Virtual

HNC/ECU HTC event

August 22, 2020

Virtual

HFA Symposium

August 24-29, 2020

Virtual

HNC VWD Day

August 29, 2020

Virtual

HNC HOPE Family Retreat

September 11-13, 2020

Concord, NC

HNC Festival & Walk

October 17, 2020

Morrisville, NC

HNC Retiro de la Unión Latina

6-8 de noviembre, 2020

Carolina Beach, NC



*Hemophilia of
North Carolina*

260 Town Hall Dr., Suite A
Morrisville, NC 27560

(800) 990-5557

info@hemophilia-nc.org

www.hemophilia-nc.org

MISSION STATEMENT

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

Contact Numbers

Hemophilia of North Carolina

(800) 990-5557
(919) 319-0014
(919) 319-0016 (fax)

National Hemophilia Foundation

(800) 42-HANDI
www.hemophilia.org

Hemophilia Federation of America

(800) 230-9797
www.hemophiliafed.org

Community Health Charities

(919) 554-3272
www.healthcharities.org

About This Publication

THE CONCENTRATE is the official newsletter for Hemophilia of North Carolina. It is produced quarterly and distributed free of charge to requesting members of the bleeding disorder community.

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

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

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

Hemophilia Treatment Centers

East Carolina University Brody School of Medicine

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

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

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

PEDIATRIC:

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

St. Jude Affiliate Clinic at Novant Health

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

UNC Hemophilia and Thrombosis Center

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

Wake Forest University School of Medicine

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

Additional Medical Resources

Duke University Medical Center Hemostasis and Thrombosis Center

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

Mission Hospital Pediatric Hematology/ Oncology Program

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

Resource Information

National Hemophilia Foundation

www.hemophilia.org

Hemophilia Foundation of America

www.hemophiliafed.org

American Society of Pediatric Hematology/Oncology

847-275-4716
www.aspho.org

Centers for Disease Control & Prevention

1-800-311-3435
www.cdc.gov

Coalition for Hemophilia B

1-212-520-8272
www.coalitionforhemophiliab.org

ClinicalTrials.gov

A registry of federally and privately supported clinical trials conducted and service of the US National Institutes of Health. It gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health professionals.

Committee of Ten Thousand (COTT)

1-800-488-2688
www.cott1.org

LA Kelley Communications

1-978-352-7657
www.kelleycom.com

PAN Foundation

Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-866-316-7263
panfoundation.org

Patient Notification System

The Patient Notification System is a free, confidential, 24 hour communication system providing information on plasma-derived and recombinant analog therapy withdrawals and recalls.
1-888-UPDATE-U
www.patientnotificationsystem.org

Patient Services Incorporated (PSI)

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

World Federation of Hemophilia

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

VISION STATEMENT

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

Hemophilia of North Carolina is a chapter of the National Hemophilia Foundation, a member organization of the Hemophilia Federation of America, a member agency of Community Health Charities, a member of the NC Center for Nonprofits.

HNC's Response to COVID-19

While Hemophilia of North Carolina (HNC) continues to forgo in-person events due to COVID-19, HNC recognizes the importance of education and support. Therefore, many in-person events have been transformed into virtual ones with the hope that most community members are able to participate from the comfort and safety of their own homes. Information about these events can be found within this newsletter and on the HNC website. As soon as it is safe to resume hosting in-person events, HNC staff will happily begin planning those and look forward to getting the community back together again! Until then, HNC will continue to host online opportunities for the community to gather, learn, and connect.

In addition to hosting events, HNC has been disseminating information from both national organizations, the Hemophilia

Federation of America and the National Hemophilia Foundation, as well as the five North Carolina hemophilia treatment centers, in an effort to make sure our community is as informed as possible.

Thanks to the Hemophilia Alliance Foundation and generous individual donors, HNC has been able to create a COVID-19 assistance fund to help community members who have been impacted financially by the current environment. Gillian Schultz, HNC's Program Manager, has been working for weeks to touch base with all HNC members to make sure they know that HNC is here for them. HNC is not an average membership organization; it is a family. HNC will continue to support the community by providing support, outreach, education, and assistance throughout this unique time and beyond.

Onboarding of New Hemophilia of North Carolina (HNC) Board Members

By: Phil Poovey, Vice President

On May 10, 2020, the current HNC Board of Directors began a program of onboarding the four new members who were approved to join the HNC Board of Directors on July 1, 2020. Our new members have already been sitting in on current board meetings to observe the process and learn how the meetings work. They will receive new member packets with materials and forms to be completed to prepare them to serve two-year terms as your new board.

The first session dealt with the development and history of Hemophilia of NC, from 1977 to the present, the structure of the board and duties of the officers, and the vision and mission of HNC. We discussed the different

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May 16 Onboarding Training

Your Voice, Your Time, Your HNC Needs Assessment

How much does your voice matter? It turns out, a lot! Hemophilia of North Carolina (HNC) wants to hear from you, its members, to find out if your needs are being met and about your ideas about programs, events, and services moving forward.

Do you see new events advertised and think, *That's not for me?* Do you read about services and think that they don't apply to you? Tell HNC why, so that future opportunities can be planned that will meet your needs. Do you see new events advertised and think, *How do I sign up?* HNC wants to hear from you too.

Please use your voice and take the time to complete the HNC Needs Assessment. It is open to all adults in the bleeding disorders community, whether you have a bleeding disorder or care for someone with a bleeding disorder. If you have adult children outside of your home who may not be receiving HNC's communications, please ask

them to provide their input as well. Your feedback is anonymous. HNC hopes to receive at least 100 responses to the Needs Assessment by December 31, 2020. As an appreciation for your time, everyone who completes the Needs Assessment will be entered into prize drawings held every three months throughout the year. The first two winners have already been chosen. The next prize drawing will be on September 30, 2020. Maybe you will be the winner!

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

Now, more than ever, your voice is needed!



QR Code
HNC Needs Assessment

Onboarding of New Hemophilia of North Carolina (HNC) Board Members

continued from previous page

types of bleeding disorders and how they impact the lives of our members, the services provided by HNC, and the relationships with the pharmaceutical companies whose products are used by our members.

The next onboarding event reviewed the materials and forms in the new board member binders, an introduction to the financial structure and reports provided by the treasurer to the board, and the nature and roles of the three standing HNC Board Committees: Internal; Governance; and External. New members have been paired with current board members who will serve as mentors to share their knowledge of how HNC works to serve our members, the nature and purpose of the board meetings, and to answer any questions or concerns the new members might present.

The onboarding sessions are designed to allow the new members to begin their terms as well-informed board members to meet and address the continuing challenges we all face during the COVID-19 pandemic. We meet using the Zoom platform and will continue using electronic and virtual media to provide leadership for HNC to move ahead with developing new and innovative ways of serving our membership.

Charlotte Family Festival & Walk Goes Virtual

June 28, 2020

Over the past few months, the world has changed. Along with that change, there has been a need for events to go virtual while it is not safe to gather together in person. That goes for Hemophilia of North Carolina's (HNC) largest fundraiser in Charlotte, the Family Festival & Walk for Bleeding Disorders! As soon as HNC decided to take the Festival & Walk virtual, staff and volunteers "hit the ground running" to make the event a success. Throughout the month of June, HNC held a different challenge each week:

- June 1-7: Take a short video of you or someone in your house preparing for the walk
- June 8-14: Post a "Funniest COVID-19 Quarantine" video
- June 15-19: Do 18 reps of a physical activity, donate \$18 to your team, and challenge someone else to do the same
- June 22-28: Walk between 2.5K and 5K

The challenges are culminating with the walk event, including activities, announcements, prizes, and more, streaming on Facebook live! For information about the Virtual Family Festival & Walk, please visit www.hemophilia-nc.org/festival.

Consumer Medical Symposium Rescheduled

May 1, 2021

The health and safety of the bleeding disorders community are of utmost importance to Hemophilia of North Carolina (HNC). Due to the COVID-19 pandemic, HNC has decided to cancel and reschedule the first annual Consumer Medical Symposium, originally planned for July 11, 2020. With North Carolina still in the process of reopening in July, the only options for HNC were to decide whether to cancel or hold the event virtually. As this was the first of what HNC hopes to be an annual event, it was decided that it would be more successful if held in-person. Therefore it has been rescheduled for May 1, 2021. More details to follow in the coming months.

HNC/HSC Teen Retreat Goes Virtual

It is with mixed emotions that Hemophilia of North Carolina (HNC) and Hemophilia of South Carolina (HSC) staff have decided not to host the annual Teen Retreat. Arguably one of the most fun events of the year, this event brings together NC and SC teens from across state lines. The teens look forward to four days of activities, informal education, and time to hang out. While teens won't be able to zipline or roast s'mores together, HNC/HSC staff are actively looking at how to engage teens virtually. And there may be some s'mores involved! Stay tuned for more information, as well as dates for the 2021 Teen Retreat, which will take place at Camp Canaan in Rock Hill, SC!

VWD Education Day

August 29, 2020

Virtual

Save the date for the VWD Education Day which will take place on August 29, 2020. Expect a day of education and camaraderie just for people affected by von Willebrand disease (VWD). Hear from experts about the types of VWD, treatment options, and challenges that you might face as someone affected by the most common bleeding disorder. More information will be available on the Hemophilia of North Carolina website soon.

Have a Splashing Good Time at the HNC Family Retreat

September 11-13, 2020

Concord, NC

The Hemophilia of North Carolina (HNC) Family Retreat is heading back to the Great Wolf Lodge once again, September 11-13. Families who have a child diagnosed with a bleeding disorder, aged 12 and under, are invited to attend. There will be a combination of educational programs, social activities, and free time so that you can build relationships with other families raising a child with a bleeding disorder, while also being able to enjoy the amenities that the Great Wolf Lodge offers. The Family Retreat provides an invaluable opportunity for both parents and children

to connect and bond with fellow community members. This is one of HNC's most popular events of the year. More information will be available on our website this summer. Priority registration will be given to families who have never attended a Family Retreat before and who have a child twelve or under.

*Please note that HNC will continue to monitor the ongoing COVID-19 crisis, and will always keep your health and safety as its number one priority.




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Hemophilia Treatment Centers Events Going Virtual

Hemophilia of North Carolina (HNC) is working with the Hemophilia Treatment Centers (HTC) at East Carolina University, UNC Chapel Hill, and Wake Forest Baptist Health to confirm the details of the partnered events as they go virtual.

In 2019, HNC applied for a grant through the Hemophilia Alliance Foundation that would allow HNC and the HTCs to partner on an event in each of the cities that the HTCs serve. Each program was to feature speakers and topics that the HTCs saw as a need in their community. The "Game Day Gathering"

took place with the Charlotte HTCs on February 1. When the COVID-19 pandemic hit, HNC reached out to the Hemophilia Alliance Foundation, which granted an extension for the project. Though HNC was hopeful that the community would be able to get together in person again by August, it is still not possible, and HNC is grateful that the programs will be able to transition to a virtual setting.

Stay tuned to the HNC website for more information about these events.

Save the Date for Fall Events

Hemophilia of North Carolina (HNC) hopes that the community will be able to be together in person again later this year. Save the dates for the following events to be held in person if possible; however if not, virtually:

September 11-13, 2020 – HNC HOPE Family Retreat, Concord, NC

October 17, 2020 – Raleigh Family Festival & Walk for Bleeding Disorders, Morrisville, NC

November 6-8, 2020 – Retiro de la Unión Latina, Carolina Beach, NC

December 5, 2020 – HNC Holiday Celebration, Greenville, NC

Training in Texas: Chapter Leadership Seminar

March 9-12, 2020

Frisco, TX

Each year, the National Hemophilia Foundation (NHF) hosts the Chapter Leadership Seminar in order for staff and board members from each state or local organization to come together. This year, more than 80 chapter representatives from around the country gathered in Frisco, Texas, to learn from NHF, guest speakers, and one another.



Chapter Leadership Seminar Attendees

The training was very informative, with topics that included fundraising and donor engagement, led by Gail Perry, author of *Fired-Up Fundraising* and Chapel Hill resident. The agenda also included information on supporting the diverse needs of the community, training for board members, and much more. Additionally, with the COVID-19 situation escalating while at the conference, chapter leaders connected in small groups to discuss what the future will hold. With so many changes afoot, it was an invaluable experience to gather with other chapter leaders and brainstorm about how to move forward and explore new opportunities for support and virtual programming.

HNC Goes Virtual

When everything shut down due to the COVID-19 crisis, Hemophilia of North Carolina (HNC) staff realized very quickly that people were going to need to continue connecting during this time of social distancing. It seemed obvious that HNC should continue providing opportunities to connect virtually. Over the past few months, several events have been held via Zoom, a video-chat, teleconferencing platform that allows people to connect through their computer or their phone.

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HNC Goes Virtual *continued from previous page*

Virtual Coffee Chat

March 28, 2020

Eight HNC members from across North Carolina joined the first virtual event, the HNC Coffee Chat at 11am. Over the hour, attendees connected and shared how they were holding up as the stay-at-home quarantine was just starting.

HNC/HSC Teen Talk

April 3, 2020

HNC partnered with Hemophilia of South Carolina (HSC) for a Teen Talk. Hearing from parents of teens with a bleeding disorder, and hearing about canceled rites of passage including prom, final school musical concerts or performances, and graduations, both chapters realized how important it is for teens to have the opportunity to connect.

Kids Virtual Trivia

April 4, 2020

Nine children joined the Kids Virtual Trivia event where they played a riveting game of Jeopardy! Topics included “Bleeding Disorders,” “Math,” “Nursery Rhymes, Fairy-tales, & Books,” “Science,” and “Name That Landmark.” There was lots of laughter and friendly competition, and HNC looks forward to hosting this event again.

World Hemophilia Day Pizza Party

April 17, 2020

World Hemophilia Day is held every April 17 on the birthday of Frank Schnaebel, the founder of the World Federation of Hemophilia (WFH). Since this year no one was going to be able to get together in person to celebrate, HNC and HSC decided to partner for a virtual pizza party. Thirty-five families attended from both North Carolina and South Carolina. Everyone introduced themselves and attendees learned about the WFH Humanitarian Aid Program, which provides factor to developing countries across the globe. Hearing about the lack of treatment in these places puts into perspective how fortunate we are in the United States to have access to treatment for bleeding disorders. After the video, participants played a Kahoot! Trivia game, with questions about World Hemophilia Day, bleeding disorders the WFH, and general trivia. A special thank you goes out to DrugCo Health for sponsoring this event. Because of its sponsorship, HNC and HSC were able to reimburse attendees for their pizza.

Blood Brotherhood: Virtual Tai Chi

May 3, 2020

By: Matt Igelman

The NC Blood Brotherhood held its first ever virtual event during these trying and ever changing times! On Sunday, May 3rd, the guys logged into Zoom and got a chance to be active during this time where the typical gym, pool, and fitness facilities are closed. Rick Starks, also known as the “Tai Chi Guy,” got everyone moving for an amazing music filled hour of fluid, thoughtful motion through his mastering of Tai Chi. It was a great renewed feeling for all, as we learned more about Tai Chi for health and happiness and the benefits to the bleeding disorders community. If you don’t know the “Tai Chi Guy,” check him out online at www.rickstarks.com. His website has everything from upcoming events, Tai Chi Research, to online sessions. You won’t regret getting your body moving through Tai Chi as the Blood Brothers thoroughly enjoyed it.

Women’s Coffee Chat

May 9, 2020

It was a small but largely successful gathering of women for the Women’s Coffee Chat on the Saturday before Mother’s Day. The event was open to women with a bleeding disorder, moms, and other female caregivers. Over the hour, the women spent time getting to know each other and enjoying each other’s company.

Challenge Accepted: Laugh! Virtual Viewing Party

May 21, 2020

How can laughing help someone with a bleeding disorder? Thanks to a YouTube series called *Challenge Accepted*, created by Genentech, HNC members got to find out! *Challenge Accepted* was inspired and made especially for the bleeding disorders community. Episode 6: “Laugh,” guest stars Emmy winner and bleeding disorders community advocate Alex Borstein. After watching the video, attendees had a conversation about the benefits of laughter. Helping to break the ice, allowing people to feel more comfortable, and reducing stress were just some of the reasons that laughter is important. People shared some jokes and funny movies that they like to watch. Especially during these challenging times, it’s important that everyone takes time to laugh every day. Thank you to Genentech for sponsoring this event.

HNC NEWS & INFORMATION

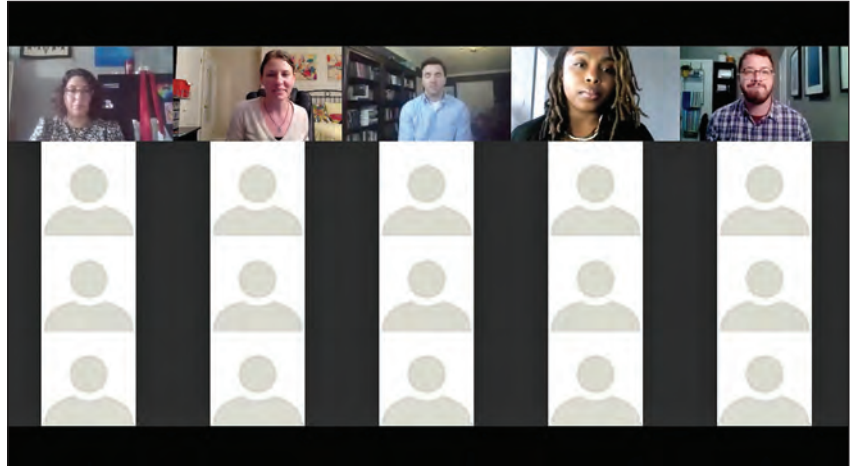


Virtual Advocacy: A New Way to Advocate

Like so many other events, plans for Hemophilia of North Carolina's (HNC) Legislative Days, scheduled for June 15-16 in Raleigh, have moved to a virtual platform. With this, HNC staff took this as an opportunity to offer more advocacy-focused events for the bleeding disorders community leading up to the Virtual Legislative Day on June 16.

Webinars were scheduled for May 13, June 10, and June 15. The May 13 webinar was entitled *The Importance of Connecting with Public Officials*. HNC was pleased to welcome Senator Jeff Jackson as the special guest. Senator Jackson, who represents Senate District 37 in the NC General Assembly, shared his insights about what's happening in the NC Senate, how COVID-19 is affecting this year's legislative session, and how vitally important it is that legislators hear from the communities they represent. Kimberly Ramseur from the Hemophilia Federation of America (HFA) and Nathan Schaeffer from the National Hemophilia Foundation (NHF) also joined. They spoke about how online advocacy works, and shared best practices for communicating virtually. They also discussed how to get a bill passed and what you need to do specifically as a member of the bleeding disorders community.

Read more about the June 10 and June 15 webinars, as well as the virtual Legislative Day on June 16, in the next edition of *The Concentrate*.



May 13 webinar with NC Senator Jeff Jackson

Adult Retreat Goes Virtual

June 5-8, 2020



2020 has been a challenging year. Hemophilia of North Carolina (HNC) has been adjusting its ways of providing community support and education since mid-March, when everything was shut down to combat the spread of COVID-19. Although HNC had hoped that the community could be back to together by June, it soon became clear that would not be the case so HNC staff began working tirelessly to revamp the Adult Retreat to a completely virtual event. The Adult Retreat became HNC's first multi-day event to be held entirely on Zoom!

On Friday, 25 adults from the bleeding disorders community from across North Carolina joined together for a virtual *Meet & Greet*. Attendees participated in a fun filled Kahoot that tested

their knowledge of general trivia and bleeding disorders facts, and also got to know each other better.

Saturday included a variety of sessions throughout the day, including *Nurturing Relationships*, led by Dave Robinson from the Hemophilia Federation of America (HFA), *The Power of Empowerment*, led by Tanya Stephenson from Sanofi Genzyme, *Expecting the Unexpected*, led by Besty Koval from Takeda, and a heart pumping fitness session led by Johnathan Blake from HFA. Johnathan provided modifications to the fitness session so that no matter what someone's fitness level was, and no matter their mobility, they could participate. As with most large HNC events, the day also included a vendor visit so that attendees could talk with the event sponsor about their products and services.

On Sunday, attendees started their day by visiting a breakout session that addressed their specific place in the community: there was the Blood Brotherhood session for men with bleeding disorders, led by Jennifer Maahs from Novo Nordisk; a SOAR session for women with bleeding disorders, led by Christie van Horne; and The Caregivers Roundtable which was for parents, spouses, and partners, led by HNC's

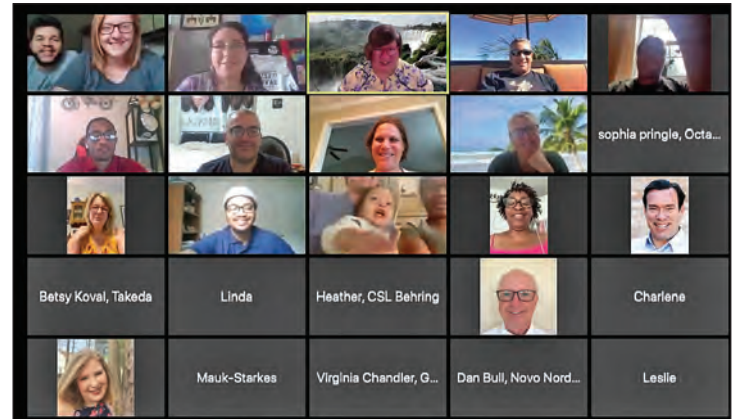
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Adult Retreat *continued from previous page*

Board Vice President, Phil Poovey. In the afternoon, everyone learned more about *The Science of Gene Therapy* with a presentation led by Dr. Tami Singleton from BioMarin. Not even Tropical Storm Cristobal, which was affecting New Orleans where Dr. Singleton was presenting from, could dampen the presentation. Attendees once again got to visit with the sponsors on Sunday to find out more about their products and services.

Finally, on Monday night, attendees signed in one last time for a Q&A Session with Dr. Alice Ma from UNC and Dr. Guy Young, from the Children's Hospital of LA, about *COVID-19 and Bleeding Disorders*. There were lots of great questions about the effects of the novel coronavirus on people with bleeding disorders as well as general information about COVID-19. The evening ended with a brief wrap-up and drawings for a variety of raffle prizes.

HNC would like to thank all the sponsors, speakers, HFA, attendees, and volunteers for their support of the Virtual Adult Retreat.



In the Fall Edition

Several events took place during the month of June, while this edition of the newsletter was in the process of being printed. Read about the Virtual Charlotte Festival & Walk, Legislative Day, and SOAR Education Days in the Fall Edition of *The Concentrate*.

Explore
HEAD-TO-HEAD
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► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

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Actualización del Programa Unión Latina

El objetivo del Programa Unión Latina es proporcionar ayuda y soporte a los miembros de habla Hispana de la comunidad que sufren desordenes hemorrágicos. Aun cuando los eventos en vivo están por el momento suspendidos, el propósito del Programa Unión Latina sigue siendo el mismo: proveer un sentido de comunidad y educación. El evento que fue originalmente programado para el 16 de Mayo, ha sido reprogramado para el 13 de Junio. Por favor infórmese mas al respecto en la edición del Otoño de *The Concentrate*. Hemofilia de Carolina del Norte (HNC por sus siglas en Ingles) pronto tomara una decisión respecto al evento de la Unión Latina que esta planeado por ahora para el 1ero de Agosto, en el área de Raleigh. Por el momento por favor reservar los días 21 de Noviembre y 5 de Diciembre, para los eventos de fin del año, así como también los días 5-7 de Noviembre para el Retiro de la Unión Latina, a realizarse en Carolina Beach.

El Programa Unión Latina otorga apoyo y educación a los individuos de origen Latino que sufren de enfermedades hemorrágicas y sus familias en Carolina del Norte. El programa se ofrece en Español y es posible gracias al subsidio de Takeda. Para mas información, visite el sitio web de HNC.

Evento de la Unión Latina

13 de Junio del 2020

El día 13 de Junio, miembros de Hemofilia de Carolina del Norte (HNC, por sus siglas en Ingles) tendrán la oportunidad de congregarse virtualmente en un evento que ayudara a mantenerse conectados durante este difícil momento que estamos experimentando.

El tema por tratar será Atención Plena. Esta presentación explora como la Atención Plena puede beneficiar nuestro cuerpo, nuestra alma, y también promover un estilo de vida saludable.

Los asistentes tendrán la oportunidad de experimentar ejercicios muy simples para lograr atención plena y poder cultivar esta practica.

Les recomendamos leer mas acerca de este evento en la edición de Otoño de *The Concentrate*.

Cómo tratar un trastorno hemorrágico durante una pandemia: respuesta para seis preguntas frecuentes sobre la COVID-19

La Fundación Nacional de Hemofilia (National Hemophilia Foundation, NHF) y otras instituciones están monitoreando los efectos de la pandemia global

El autor: Ian Landau

Mientras el mundo continúa luchando contra la pandemia de la COVID-19, la comunidad con trastornos hemorrágicos sin duda tiene muchas preguntas sobre los efectos específicos de la enfermedad en las personas con trastornos hemorrágicos. A continuación encontrará la respuesta de algunas de las preguntas y las inquietudes más frecuentes.

¿Tener un trastorno hemorrágico significa que tengo más riesgo de contraer el coronavirus?

Tener un trastorno hemorrágico no lo predispone más a contraer ninguna infección viral, incluida la COVID-19. Sin embargo, al igual que en la población general, algunos segmentos de la comunidad con trastornos hemorrágicos tienen más riesgo de que la enfermedad sea grave. Estos incluyen adultos mayores y personas de cualquier edad que tienen afecciones médicas subyacentes graves además del trastorno hemorrágico, como enfermedad cardiovascular, diabetes, obesidad, enfermedad renal, hipertensión arterial y asma. Comuníquese con su equipo de atención médica para hablar sobre las inquietudes específicas relacionadas con la salud que pueda tener.

continúa página siguiente

Cómo tratar un trastorno hemorrágico durante una pandemia...

viene de la página anterior

En cuanto a limitar la exposición a la COVID-19, las personas con trastornos hemorrágicos deben seguir las mismas recomendaciones que el resto del público: lavarse las manos con jabón regularmente, no salir, practicar el distanciamiento social y utilizar una máscara u otra protección en la cara cuando deban salir de su casa.

Si contraigo la COVID-19, ¿estaré más propenso a hemorragias?

Por ahora, se considera que la COVID-19 no causa que las personas tengan más hemorragias de lo normal. Sin embargo, en los casos en que el virus causa tos grave, hay mayor preocupación por hemorragias en la cabeza y hemorragias en la garganta y los pulmones, las cuales son todas potencialmente mortales y requieren atención médica inmediata.

Si contrae la COVID-19, comuníquese con su centro de tratamiento de la hemofilia (hemophilia treatment center, HTC) o con su hematólogo para que los médicos que lo traten por el virus puedan coordinar su atención de cerca con los que tratan su trastorno hemorrágico.

¿Debo hacer algún cambio en mi tratamiento y debo tener a mano un suministro mayor al normal de mis medicamentos para el trastorno hemorrágico durante esta crisis?

Durante esta época, los expertos recomiendan que se cumpla el plan de tratamiento habitual tal como lo indicaron sus proveedores de atención médica. A las personas que se tratan en su casa, el Consejo Asesor Médico y Científico de la NHF les recomienda tener disponible siempre un suministro de 14 días de productos de factor durante épocas de crisis, incluida la pandemia de la COVID-19.

¿Qué debo hacer si necesito ir a la sala de emergencias para tratar una hemorragia, la sospecha de un puerto infectado u otro problema?

Al igual que en épocas más normales, no debe ignorar inquietudes graves relacionadas con su trastorno hemorrágico. Si necesita ir a la sala de emergencias para recibir un tratamiento, hágalo. Sin embargo, asegúrese de llamar con antelación para que el personal sepa que usted irá y por qué. Este aviso previo permite al personal de la sala de emergencias prepararse para ayudarlo del modo más seguro, eficaz y eficiente posible.

Pronto tengo una cita en mi HTC o con mi hematólogo. ¿Debo ir?

Llame antes de acudir al HTC o a la clínica. El personal del HTC o del consultorio del proveedor le informará cómo proceder si se considera que es necesaria una visita en persona. Muchos HTC y proveedores de atención médica están realizando visitas de telemedicina. Esto significa que puede acudir a su cita en forma remota desde su casa utilizando su teléfono inteligente, tableta o computadora. Consulte con su HTC o consultorio médico para ver si esta es una opción para usted.

¿Adónde puedo ir para obtener la información y los recursos más confiables y recientes sobre trastornos hemorrágicos y la COVID-19?

Visite el centro de información sobre la COVID-19 de la NHF en su sitio web para enterarse de las novedades, reproducir seminarios web del Ayuntamiento sobre la COVID-19 de la NHF y recibir actualizaciones importantes del Director Ejecutivo de la NHF, Leonard Valentino, MD.

Además, puede visitar la página de recursos para la COVID-19 de la Federación de Hemofilia de América y los anuncios y declaraciones de la WFH sobre la COVID-19 de la Federación Mundial de Hemofilia (World Federation of Hemophilia, WFH).

De HemAware. Reimpreso con permiso.

SOAR Program Update

Have you ever seen Hemophilia of North Carolina (HNC) post about SOAR and wonder what it is? SOAR is HNC's program to support women and girls with bleeding disorders. Through educational opportunities, advocacy to raise awareness about women and girls with bleeding disorders, and support, SOAR continues to be a source of connection for women in the North Carolina bleeding disorders community.

As HNC has gone virtual over the last few months, the SOAR Educational Day, scheduled originally for June 27, has been changed to a virtual event, taking place June 30-July 2. HNC also provided an opportunity for women to connect during the Women's Coffee Chat on May 9. In addition to events, HNC moderates a private SOAR Facebook group for women with bleeding disorders.

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

SOAR is a program of HNC for women and girls with a bleeding disorder, including those diagnosed with von Willebrand disease, hemophilia A and B, rare factor deficiencies, platelet disorders, and carriers of any of these disorders (both symptomatic and 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.

SOAR Education Days

June 30-July 2

The COVID-19 crisis has caused Hemophilia of North Carolina (HNC) to make many changes to its calendar of events, including canceling some, rescheduling others, and making events virtual. The SOAR Education Day, originally scheduled for June 27, has been rescheduled to June 30-July 2, to take place virtually through Zoom. Over the three nights, women will have the opportunity to connect and learn about managing their bleeding disorders as women.

There will be sessions on self-advocacy, bleeding disorders, a group art project, and time to connect and share experiences. Read about the event in the Fall edition of *The Concentrate*.



Hemophilia, a Brother's View

By: Riley Schultz, HNC member

Hemophilia is a blood disorder in which someone is missing a type of factor in their blood (there's 9 I think) and without that extra factor, blood clotting is hard. This does not mean that if a person with Hemophilia gets a paper cut, they will bleed to death, it's not that insane. That's why this stuff called factor exists. It's one specific type of factor taken from a volunteer's blood and it's *really* expensive to make. Once the person with hemophilia has factor, their levels of that factor go down quickly. That's why factor isn't a one-time treatment and is often administered at least twice a week.

Being the older brother of a kid with hemophilia can be stressful. Your brother can't usually do as much as you can and has to do certain sports so they don't get a serious bleed. Because of HNC, I get to make friends with other people that I would've never seen in my life.

Riley is 12 years old and has a brother, age 9, with hemophilia.

Our Young Voices is a place to spotlight the youth of the North Carolina bleeding disorders community. Do you have something you would like to share in a future edition of *The Concentrate*? Email info@hemophilia-nc.org.

HNC sends heartfelt congratulations to 2020 graduates, along with messages from their families!



Riley Blair:

Riley Blair graduated from Overhills High School this year and is off to Penn State in the fall. Congrats to Riley! Everyone is so proud of you and can't wait to see what your future holds!



Austin Caldwell:

2020 graduate of North Carolina Central University
Bachelor of Business Administration/Marketing
Proud member of HNC and NYLI



Cayton Elderdice:

2020 Holly Springs High School graduate summa cum laude!! So proud of this girl!! Loves to attend HNC events!



Bethany Mattson:

Bethany Mattson is graduating from high school and on the Deans list with her Associates Degree from Stanly Community College all in the summer of 2020. We are so proud of what she's accomplished, her love for helping people, her heart for volunteering and who she has become. She is taking a gap year to work, travel, spend more time volunteering and she will start college in 2021 for the Therapy Program.



Alysiah Taylor:

Alysiah L Taylor
Class of 2020
Graduated from Hillside New Tech and will be attending Shaw University in the fall.

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

World Hemophilia Day Pizza Party



Adult Retreat

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- Opportunity
- Partnership
- Empowerment

HOPE Program Update

Do you see “HOPE Program” and wonder what it is? HOPE is Hemophilia of North Carolina’s (HNC) program to support families who have a child 12 or under diagnosed with a bleeding disorder. While events usually are held in person to support these families, HNC continues to support the community virtually at this time. On April 4, HNC held an online Kids Trivia Game so that kids could get together

with one another even though they can’t get together in person. HNC is looking forward to the Family Retreat in September which provides an invaluable opportunity to connect with other families.

In addition to scheduled events, HNC moderates a private HOPE Facebook group and a Parent Mentoring Program to help support parents with newly diagnosed children, or those who are looking for a little more support.

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

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



Blood Brotherhood

Blood Brotherhood Program Update

Hemophilia of North Carolina (HNC) is looking to grow the Blood Brotherhood Program

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

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

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



Unión Latina Program Update

The Unión Latina Program is aimed at providing support and education for Spanish speaking members of the bleeding disorders community. Although events currently are not being held in person, the goals remain the same: to provide a sense of community and education. The Unión Latina event that was originally scheduled for May 16 was rescheduled for June 13. Read more about it in the Fall Edition of *The Concentrate*. Hemophilia of North Carolina (HNC) will make a decision soon about the August 1 Unión Latina event currently planned for the Raleigh area. Save the date for November 21 and December 5 to finish up the year and the Unión Latina Retreat to be held from November 6-8 in Carolina Beach.

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



HNC Relaunches North Carolina Advisory Board for Bleeding Disorders

By: Steven Humes, HNC Board President

For a number of years there was an entity called the North Carolina Advisory Board for Bleeding Disorders (NCABBD), which was initially started by Hemophilia of North Carolina (HNC) and the leadership of the Region IV-North Hemophilia Treatment Center (HTC) Network. The Board was composed of staff members of HNC and HTCs in North Carolina, as well as consumers. The Board met quarterly and offered an opportunity for those involved to share information and provide feedback on HTC services and HNC programming. It was particularly helpful in identifying unmet needs of the patient population from healthcare, educational, and emotional support perspectives.

For various reasons, attendance and membership declined over the years, and it became difficult to convene a consistent group of people. Thus, it was decided to shut down the group, at least temporarily. However, as new HTCs have entered the network in the past few years and HNC has expanded its reach, HNC staff and volunteers began to think about reviving the group in order to improve communication among HTCs, HNC, and consumers.

An online survey was developed to assess interest in the group among the HTCs and determine the feasibility of relaunching it. It became clear from the survey that there was broad support for rekindling the Advisory Board, and an initial meeting was held via Zoom on Friday, April 24. Steven Humes, who chaired the group before his retirement as the Region IV-North Regional Coordinator and who is now the Board President of HNC, led the meeting.

Continued next page



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

SCIENCE AND THE COMMUNITY

come together, great things happen.

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HNC Relaunches North Carolina Advisory Board for Bleeding Disorders *continued from previous page*

During the meeting, there was a lengthy discussion of how HTC's and HNC are responding to the COVID-19 pandemic and how HTC's might recruit consumer members for the NCABBD going forward. It was decided to continue to convene meetings of the Board on a quarterly basis, and Steven Humes agreed to continue chairing the group at least in its start-up phase. The next meeting will take place on Friday, July 31, from 1:00 to 4:00, either in person at the HNC office in Morrisville or via Zoom.

If you are a consumer who would be interested in joining the NCABBD and can commit to attending a quarterly meeting, please contact Charlene Cowell at charlene.cowell@hemophilia-nc.org. HNC is particularly interested in having a diverse group of members (geographic, type of bleeding disorder, race, ethnicity, age, and gender).

Community Spotlight

We've been a part of the Hemophilia of North Carolina for a short period of time, but the education, resources, and support we've received have been remarkable. I support the Hemophilia of North Carolina and the Family Festival and Walk because this organization gives hope. Before we found out about the organization, my daughter felt alone with her bleeding disorder. Although I am a medical professional, I could only offer her so much help and education myself. For the first time my daughter isn't asking why she has a blood disorder but how can she get involved and help others.

~ Toccara Young



Farewell, Schoolcraft Family!

Over the years, many in this community have met the Schoolcraft family. The boys are so cute it's impossible to forget them! Hemophilia of North Carolina (HNC) staff wanted to take a moment to say farewell to the Schoolcrafts as they move to California for their next adventure. Shannon and Troy Schoolcraft have been active members of the HNC community, attending most events throughout the year all across the state. Early on, they became actively engaged in the HOPE Program, for families with children ages 12 and under with a bleeding disorder, and became one of the first HNC Community Leaders. Through their role as Community Leaders, they held events in smaller areas of the state in order to provide outreach to individuals and families in those areas.

The Schoolcrafts have also been one of "the teams to beat" when it came to the Raleigh Festival & Walk. Their team, Team Schooly, could always be found at the top of the fundraising charts. Their fundraising efforts have allowed HNC to do so much within the community and the Schoolcrafts have been a huge part of making those efforts happen -- from raising the funds to hosting the events. Thank you to the entire Schoolcraft family for your many years of dedication to the NC bleeding disorders community, and best of luck in your new home in CA!





Happy birthday to Jamie!

Hemophilia of North Carolina (HNC) wants to celebrate your important milestones! Want to celebrate your birthday, anniversary, or event with HNC?

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

2020 Friends of HNC

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

General Donations & Annual Giving Contributions

Gay Bogges
Mark & Jo Anne Buckley
Ronald Burt

Irene Cowell
Marlo Davis
Shannon Elderdice

Lois & Kenneth Grant
W. Allen & Sue Heafner
Drs. David Howell & Sara Miller

Winnifred Meeker-O'Connell

in Memory of Allen J. Eads and Jason Eads
Betty Cole

In honor of Charlene Cowell successfully completing her MPA!
Karyn Davis

COVID-19 Financial Assistance Fund
Karyn & Kyle Davis
Linda & Allen Kurtz

*Facebook Fundraisers**
Kaitlin Bartholomew
Curtiss Reid Coleman

Giving Tuesday
Phillip Poovey

Employee Giving
Lynood Best
Daisy Bratton

Teme Levbarg
Paul Lindsay
Brenda Plassman
Phillip Poovey
Charles and Katherine Register
John Sakakeeny
Gillian & Karl Schultz

**Note: We cannot always see if someone does a Facebook fundraiser. If you have done one for HNC and would like to be recognized, please email us at info@hemophilia-nc.org*

George D. McCoy Scholarship Fund
Barry Howard

Thank You



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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How to Help Your Child with a Bleeding Disorder Cope with Anxiety and Stress in the Pandemic

Advice for families in the bleeding disorders community during the COVID-19 pandemic and beyond

By: Donna Behen

The COVID-19 pandemic has many families on edge right now. Jobs are being cut, routines are disrupted, and with social distancing requirements in place in most parts of the country, parents are juggling the demands of working at home with keeping their children healthy, happy and occupied with constructive activities, including online learning.

Families in the bleeding disorders community are dealing with all of these new stressors, of course, but that's on top of the unique everyday challenges that come with managing a bleeding disorder.

"Living with a bleeding disorder or parenting a child with a bleeding disorder can be very stressful anyway, but adding a worldwide pandemic just magnifies this stress," says Robert Loudon, MSW, LCSW, a social worker at Indiana Hemophilia & Thrombosis Center in Indianapolis.

What can you do to help nurture and protect your child's emotional well-being during times of crisis? Here's what Loudon and his fellow Indiana Hemophilia & Thrombosis Center social workers Gail Jordan, MSW, LCSW; DeAuntae Lawson, MSW, LSW; and Ashley Parmerlee, MSW, LCSW, recommend:

Keep your normal routines

Kids thrive on structure, so as much as possible stick to your normal household routines, including regular bedtimes, meals, chores, etc. That consistency helps kids, especially younger ones, feel calm and secure.

Be honest but reassuring

Talk to your children about what's going on, but in a way that doesn't induce or raise their anxiety. You want to create an environment where children feel comfortable expressing their concerns and asking questions, and where you can address any misconceptions they may have.

Check in with your children frequently to assess their current understanding and stress surrounding the crisis. Be on the lookout for signs of anxiety and depression, including changes in appetite, sleep disruptions, aggression, irritability, and fears of being alone or withdrawn.

Take care of your own physical and mental health

As parents, you should be modeling how to cope with stressful situations in positive ways by maintaining healthy habits, including exercise, adequate sleep and establishing some alone time, when possible.

Stay positive

Remind your children that being homebound is temporary, and that even in trying times, you can always find reasons to be grateful.

"While this is a time of uncertainty, it is also a time to be thankful for those around us," Loudon says. "It gives us the ability to appreciate how precious time is, and how we can use these extra moments in a productive way."

On a practical level, the slower pace at home can make the home infusion process calmer and easier to schedule. "It may also enable kids to be more hands-on in the process, and possibly allow adolescents to take on a more independent role," Loudon says.

Keep in touch with your HTC

If you have any questions or concerns, contact your local hemophilia treatment center (HTC). The social workers are there to help.

Says Loudon: "Everyone is feeling very uncertain about everything going on, so we are trying to be as available as possible and well versed in all resources that could benefit our patients so that we can point them in the right direction when they need it."

From HemAware. Reprinted with permission.

What Health Coverage Is Available To Individuals & Families Without Job-Based Coverage?

Reprinted with permission from the Hemophilia Federation of America (HFA) and National Hemophilia Foundation (NHF)

As a community, we know how important it is for people with bleeding disorders to maintain comprehensive health insurance. **There are insurance options available to you if you are experiencing job or other economic impacts of the ongoing coronavirus pandemic.**

Your options will depend on: 1) **the state where you live**, 2) your household's **monthly income right now**, including unemployment insurance or other benefits, and 3) your household's projected **annual income for the entire calendar year**, including earnings before losing your job, from unemployment insurance and other temporary benefits, and income you expect to earn later in the year.

MEDICAID EXPANSION COVERAGE.

In 37 states, Medicaid is available to anyone with an income that qualifies.

Medicaid is usually available for \$0 or very low premiums, and you can sign up at any time.

- **Medicaid expansion states:** Eligibility is based on your household's **current monthly income**, including any severance pay or unemployment insurance. It doesn't matter how much you earned before you lost your job - Medicaid considers only your new income level. A single person with currently monthly income below \$1467 or a family of four with current monthly income below \$3013 will qualify. (This includes people with no income.) **If you live in one of the 37 Medicaid expansion states, you should go to the website for your state's Medicaid program and enter your information; the website will let you know if you qualify for Medicaid coverage.**

- Other Medicaid coverage: Some people with incomes too high to qualify, or who live in one of the fourteen states that have chosen not to expand Medicaid, might still qualify for public health insurance based on current monthly income. This is especially true for children, pregnant women, and, to a lesser degree, parents. **To explore coverage options for children, visit www.InsureKidsNow.gov.**

SUBSIDIZED COVERAGE IN THE INDIVIDUAL MARKET.

Most people who do not qualify for Medicaid will qualify for subsidized coverage in the individual market ("ACA marketplace"). Subsidies are available in all 50 states and can cover all or almost all of the cost of premiums.

- Subsidies are calculated based on how much money a household expects to earn for the entire calendar year. The lower a household's projected income, the more generous the subsidy.¹
- **Most households have just 60 days after losing their job-based coverage to sign up for insurance coverage in the ACA marketplace.**

COBRA COVERAGE FROM A JOB.

Under a law known as "COBRA," most employers are required to offer families the option to "continue" in their job-based coverage, even if the employed family member is laid off. Because under COBRA, **the family is responsible for paying the full premium** (including any amount previously paid by the employer), COBRA will usually be much more expensive than other options – so you should look carefully at all your options before signing up for COBRA. People have 60 days after they lose their job-based coverage to sign up for COBRA, and can enroll by contacting their employer's HR department directly.

PROTECT YOURSELF: AVOID KEY MISTAKES!

- Beware of imposter websites. Unfortunately, some misleading, look-alike websites sell skimpy forms of coverage (e.g., short-term health plans) that do not meet ACA consumer protection standards and will not provide adequate coverage for your bleeding disorder. Families who want to get comprehensive coverage should always go to a ".gov" website.
- Don't wait too long to apply. Many people have just 60 days following a loss of employer-sponsored insurance to sign up for an insurance plan in the ACA marketplace or via COBRA.
- Don't forget to provide required documents. When you sign up for coverage you may be asked for documentation of your address, your income, and when you lost coverage. People who don't provide that information quickly may not get coverage, so make sure you gather as much information as possible ahead of time and respond promptly to any follow-up requests for documentation.
- Check your spam and junk folder to make sure that nothing falls through the cracks!

Your national organizations are here to help. Please contact **NHF** or **HFA** if you have questions about how to navigate coverage issues.

This post draws heavily upon a March 17, 2020, article by Christen Linke Young of the USC-Brookings Schaeffer Initiative for Health Policy. You can find the full article here: tinyurl.com/uscbrookings

¹ There is one exception: due to an unfortunate glitch in the law, your household must expect to earn at least 100% of the Federal Poverty Level (\$12,760 per year for an individual, or \$26,200 per year for a family of four people) for all of calendar year 2020 in order to qualify for subsidies.

HOW CAN PEOPLE SIGN UP FOR MARKETPLACE COVERAGE?

Visit www.HealthCare.gov to start the process of signing up for coverage. Most people who lost coverage due to a job loss will qualify for a "Special Enrollment Period" (SEP) and can follow the appropriate prompts at www.HealthCare.gov.

National Meetings Go Virtual: Join in from home!

National Hemophilia Foundation (NHF) Bleeding Disorders Conference

August 1-8, 2020

Every year NHF's Bleeding Disorders Conference brings together thousands of families and passionate professionals for in-person education and networking. This year, in order to keep the bleeding disorders community safe and help prevent the spread of COVID-19, NHF has made the decision to host the 2020 Bleeding Disorders Conference virtually. The virtual educational conference will be full of interesting sessions and fun networking activities. Everyone will be able to find something to pique their interest or strengthen their professional skills. Affected individuals and families will find sessions on nearly every aspect of living with a bleeding disorder, from the basics of hemophilia and VWD to the latest in gene therapy treatment. More information can be found on the NHF website: events.hemophilia.org/ehome/506749

Hemophilia Federation of America (HFA) Symposium

August 24-29, 2020

HFA's Symposium is an annual community-centered educational event that draws thousands of members from the bleeding disorders community together to share information, learn about new advancements, and build a network of support! Now that HFA's Symposium is going virtual, the organization looks forward to having even more community members be able to join online in August. More information can be found on the HFA website: hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium

Federal rule allows health plans to discount manufacturer copay assistance.

Reprinted with permission from the Hemophilia Federation of America (HFA)

May 28, 2020

On May 7, 2020, the U.S. Department of Health and Human Services finalized a rule that affects individuals who rely on patient copay assistance programs. The HHS rule (the "2021 Notice of Benefits and Payment Parameters," or NBPP) allows health insurers to continue using accumulator adjusters for the coming plan year. This means that a health insurer can exclude manufacturer copay assistance amounts when calculating a patient's overall deductible or out-of-pocket maximum. The upshot, for those whose health plans include an accumulator: much higher out-of-pocket costs and a serious barrier to access to care.

In comments submitted to HHS earlier this year, HFA and many other patient advocates stressed that manufacturer copay assistance programs serve as a critical lifeline for many people who live with chronic health conditions and rely on prescription medications. Just weeks ago, HFA and other members of the All Copays Count Coalition wrote again to HHS Secretary Azar, warning that copay accumulators present especially serious threats to access to care amid the ongoing COVID19 crisis. Unfortunately, HHS disregarded this input when the agency chose to finalize the NBPP's accumulator adjuster provisions.

HFA and allied groups will continue to advocate for federal and state policies that prioritize patient access to their prescription medications. Notably, the NBPP specifically provides that state laws preserving the value of copay assistance for patients (as enacted last year in Virginia, West Virginia, Arizona, and Illinois) remain in effect for state-regulated health plans – so advocates plan to redouble their efforts at the state level.

In the meantime, we need to hear from you! If you learn that your copay assistance will no longer be credited toward your deductible or out-of-pocket maximum, please share your story with HFA's Project CALLS. Collecting data on the impact of accumulators allows us to make a case for change when we ask lawmakers to take action to protect patients from these harmful health plan tactics.

What are copay assistance/ accumulator adjusters?

Watch a video from the National Hemophilia
Foundation and learn more about this
important resource in less than four minutes:
<http://ow.ly/sxyK50zVrTU>

There is proposed legislation in North Carolina, NC SB 432, which would prohibit the practice of "accumulator adjustment programs", which prevents patients from counting assistance from third-party payers toward their deductible. Hemophilia of North Carolina (HNC) has signed onto a letter in support of the accumulator adjuster portion of this bill and will continue to monitor the situation in North Carolina.

**If you have questions or have been impacted by this, please contact HNC at (919) 319-0014 or HFA's Project Calls:
www.hemophiliafed.org/for-patient-families/navigate-insurance/project-calls/
(202) 836-2530
projectCALLS@hemophiliafed.org**

Hemophilia of North Carolina 2020-2021 Calendar of Events Highlights



<u>June 28, 2020</u>	<u>Charlotte Festival & Walk – Virtual</u>
<u>June 30-July 2, 2020</u>	<u>SOAR Education Days – Virtual</u>
<u>August 22, 2020</u>	<u>HTC Partnered Events with ECU, UNC, WF - Virtual</u>
<u>August 29, 2020</u>	<u>VWD Education Day – Virtual</u>
<u>August 2020 (dates TBD)</u>	<u>HNC/HSC Teen Activities – Virtual</u>
<u>September 11-13, 2020</u>	<u>HOPE Family Retreat</u>
<u>October 17, 2020</u>	<u>Raleigh Festival & Walk – Morrisville, NC</u>
<u>November 6-8, 2020</u>	<u>Unión Latina Retreat – Carolina Beach, NC</u>
<u>November 21, 2020</u>	<u>Unión Latina – Asheboro, NC</u>
<u>December 5, 2020</u>	<u>Unión Latina (en la celebración navideña) – Greenville, NC</u>
<u>May 1, 2021</u>	<u>Medical Symposium – Chapel Hill, NC</u>



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ADVATE® is right for you.


[Antihemophilic Factor (Recombinant)]

For more information, please visit AdvateRealLife.com

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Not an actual patient.






HEMOPHILIA OF NORTH CAROLINA

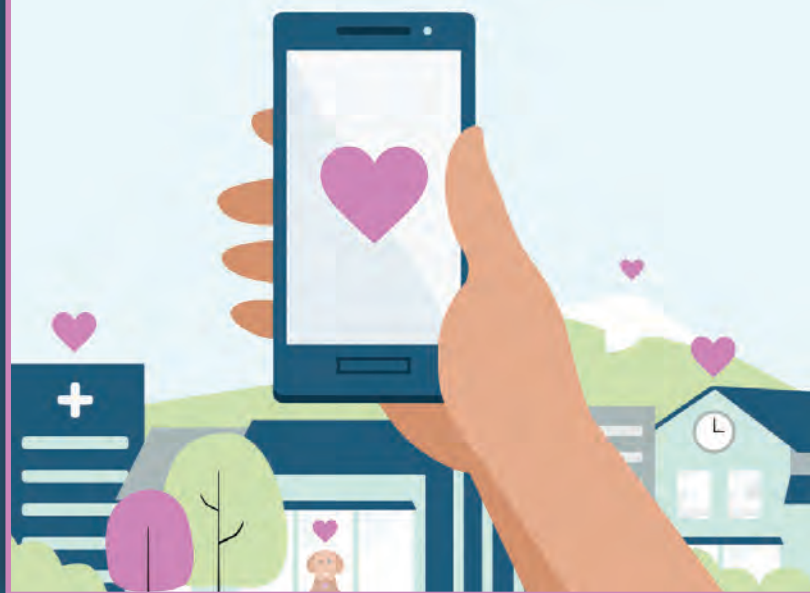
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