

# THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SPRING 2021

## Exciting and Enticing Programs at HNC



Did you know that Hemophilia of North Carolina (HNC) plans programs and events for EVERYONE in the North Carolina bleeding disorders community? Read on to find out more about how you can get involved, participate, connect with others, and even have some fun!

If you are a parent or caregiver of a child who has a bleeding disorder, at times you may feel overwhelmed and isolated. But it doesn't have to be that way. The **HOPE Program** provides the opportunity to learn about raising a child with a bleeding disorder as well as the chance for your kids to grow up with other

kids who also are affected by bleeding disorders. Throughout the year, HNC holds educational programs with topics such as going to daycare and school, dealing with emergencies, basics about bleeding disorders, helping siblings to cope with a brother or sister who has a chronic medical condition, infusions and other medical treatment, sports and activities that can be done safely with a bleeding disorder, and so much more! HNC also helps your children to learn more about bleeding disorders *Continued page 14*

## Are you on NC Medicaid?

There is currently a huge change in NC Medicaid (called Medicaid Transformation). If you are on Medicaid in North Carolina, you will need to take action.

Historically, North Carolina's Division of Medical Assistance paid for all eligible physical health services on a fee-for-service basis directly through payments to enrolled providers and health systems. Under Medicaid Transformation, North Carolina will contract with prepaid health plans (PHPs) to provide physical health benefits and services for a capitated, or fixed, amount per enrollee.

**Medicaid beneficiaries will need to enroll in a new plan because of these changes.**

Hemophilia of North Carolina (HNC) held a virtual event with the Medicaid Department in December. If you want a copy of the recording, notes, and list of resources, please contact HNC (info below).

•Open enrollment started on March 15 - Look for communication from the Medicaid Department in the mail and on their website.

•You will need to pick a primary care physician (PCP). If you do not select one by

*Continued page 21*

*Important!*  
**NC  
MEDICAID  
CHANGES**

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## Save The Date

**World Hemophilia Day**  
April 17, 2021

**HNC Festival & Walk**  
April 17, 2021  
Virtual

**HNC Medical Symposium**  
May 1, 2021  
Virtual

**HNC/HSC Teen Retreat**  
August 7-10, 2021  
Rock Hill, SC

**HNC Festival & Walk**  
October 2, 2021  
Morrisville, NC

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

**HNC Holiday Celebration**  
December 4, 2021  
Greenville, 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](http://www.hemophilia.org)

#### Hemophilia Federation of America

(800) 230-9797  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

#### Community Health Charities

(919) 554-3272  
[www.healthcharities.org](http://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](http://www.hemophilia.org)

#### Hemophilia Foundation of America

[www.hemophiliafed.org](http://www.hemophiliafed.org)

#### American Society of Pediatric Hematology/Oncology

847-275-4716  
[www.aspho.org](http://www.aspho.org)

#### Centers for Disease Control & Prevention

1-800-311-3435  
[www.cdc.gov](http://www.cdc.gov)

#### Coalition for Hemophilia B

1-212-520-8272  
[www.coalitionforhemophiliab.org](http://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](http://www.cott1.org)

#### LA Kelley Communications

1-978-352-7657  
[www.kelleycom.com](http://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](http://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](http://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](http://www.unneedpsi.org)

#### World Federation of Hemophilia

1-800-520-6154  
[www.wfh.org](http://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.*

Welcome, Fleming!

## HNC's Director of Philanthropy



We're so excited to announce that Hemophilia of North Carolina (HNC) is growing! For many years now, HNC staff and board have recognized the need to have someone dedicated to fundraising and development in order to sustain the organization for many years to come. After a thorough search, HNC is thrilled to share that

Fleming Samuels will be HNC's first Director of Philanthropy!

Fleming recently joined HNC with over ten years' experience in professional fundraising. At her prior position as Development Director at The ArtsCenter in Carrboro, Fleming promoted and

increased member satisfaction, raised the organization's profile, and helped to bring a culture of philanthropy to guests and staff. She has a broad range of experience in nonprofit capitalization, from securing funds for political organizations that educate state legislators on current environmental legislation, all the way to ensuring her children's local PTA secures enough funding for the year.

Her passion for sustaining nonprofits in North Carolina comes from her deep roots in this state, and she hopes to leverage these relationships into increased awareness and support for services to people with bleeding disorders and the communities these programs serve. Fleming lives in Chapel Hill with her husband, two daughters, and their dog Shirley. She spends her free time helping with her daughters' schools, enjoying live music, fishing, and needlepointing pillows – a talent her grandfather taught her and that she has enjoyed all her life.

## A Family Affair: Volunteering for HNC

Did you know that some of our longest-standing volunteers come from family members connected with Hemophilia of North Carolina (HNC) staff and board members? Chances are, if you've come to an HNC event, you've interacted with them -- or seen them running around trying to make sure the event went off without a hitch. From event execution to proofing the newsletter, they are always there for whatever needs to be done. Oftentimes these reliable, selfless individuals go under-thanked and without special recognition. I wanted to write a short note to publicly share my heartfelt appreciation for these family members who give tirelessly to a cause that their loved ones have committed to through the board or employment with HNC. Without these volunteers, HNC would not be as strong as it is today. So to all of these family members, we appreciate you!

~ Charlene, HNC Executive Director

*Family is the support you will never have to pay for because come rain, or shine, they will be there to cheer you on with every of your life goals.*



TheRightMessages.com

## UNC HTC Adult Clinic is Moving

### Did you know



If you are a patient at the Adult Clinic of the UNC Hemophilia Treatment Center, you should have received a My Chart message or letter in the mail letting you know that the Adult Clinic is moving. **Beginning on March 17**, the Adult Clinic will be located on the 4th Floor of the UNC Faculty Physicians Center at Eastowne at 100 Eastowne Drive, Chapel Hill, NC 27514. **The phone number remains 919-966-4736.** This change will not affect your level of care. For more information about the UNC Faculty Physicians Center at Eastowne, please visit their website: [www.uncmedicalcenter.org/uncmc/hospitals-locations/profile/unc-eastowne/](http://www.uncmedicalcenter.org/uncmc/hospitals-locations/profile/unc-eastowne/)



# The Charlotte Family Festival & Walk for Bleeding Disorders Virtual Again

April 17, 2021



No one predicted that the COVID-19 pandemic would last through at least the spring of 2021 back in March of last year when the first cases of COVID-19 were reported in North Carolina. When Hemophilia of North Carolina (HNC) first postponed and ultimately transitioned the Charlotte Festival & Walk to a virtual event last year, the thought was definitely not in anyone's mind that the same would be true for 2021. But the safety of this community is the most important thing to HNC, so again, the decision was made to hold the 2021 Charlotte Family Festival & Walk for Bleeding Disorders virtually this year.

The fundraising goal is \$70,000, and with your help, HNC will meet that goal! Through your support of this vital fundraiser, HNC can maintain its programs and services. One of HNC's most important services, the financial assistance program, has been utilized more than ever over the past year. It is because of fundraisers like the Festival & Walk that HNC can continue to provide this service. Over the past year, this program has provided COVID-19 relief, emergency financial assistance, and critical medical IDs to the bleeding disorders community.

Leading up to April 17, there will be activities and challenges posted online for you to participate in. Then on April 17 at 10 am, join HNC on Zoom and Facebook Live to celebrate your accomplishments, the bleeding disorders community, and World Hemophilia Day.

There is still time to raise money for the Charlotte Family Festival & Walk for Bleeding Disorders. Visit [www.hemophilia-nc.org/festival](http://www.hemophilia-nc.org/festival) for more information. You can make a difference in the life of someone with a bleeding disorder today!



## World Hemophilia Day

April 17, 2021



World Hemophilia Day is about bringing the bleeding disorders community together from around the world. The COVID-19 pandemic has made that more important than ever! April 17 marks the 31st World Hemophilia Day. This year's theme is Adapting to Change, sustaining care in a new world. Help to raise awareness about bleeding disorders by sharing how you have adapted to change during these unprecedented times, and what you are doing to help sustain that change.

Hemophilia of North Carolina (HNC) will be recognizing World Hemophilia Day during the Virtual Charlotte Walk festivities on April 17. In addition, the Wells Fargo Duke Energy Center in Charlotte will

be lit up red in observance of World Hemophilia Day.

For more information as well as resources and World Hemophilia Day tools and information, visit [www.wfh.org/en/events/world-hemophilia-day](http://www.wfh.org/en/events/world-hemophilia-day).

# Medical Symposium: Don't Miss It!

May 1, 2021  
Virtual

Save the date for the first Hemophilia of North Carolina (HNC) Consumer Medical Symposium. This event was originally scheduled to take place in spring 2020 but was postponed and ultimately canceled due to the COVID-19 pandemic. HNC is looking forward to holding the first Consumer Medical Symposium on May 1, 2021. This will be a virtual event, taking place on HNC's Zoom platform, for the entire bleeding disorder community.

There is so much information out there about living with a bleeding disorder as well as new medical advances over the past few years. But how much do you understand? And how much of the information that you have seen is accurate? Hear from the experts in the field of hematology -- your medical providers -- about the more scientific side of bleeding disorders. Possible sessions will include genetics, novel therapies, understanding rare bleeding disorders, hemophilia, VWD, and more. More information is available on the HNC website.

## HNC Summer Conference

Hemophilia of North Carolina (HNC) was hoping to be able to get the community together for the first in-person event since the COVID-19 pandemic hit this coming July. Though trends are improving, with the first event scheduled as a large conference with many people in the community together, HNC has made the decision that it is not in your best interests to hold this event yet. The staff at HNC is working hard to come up with other possible activities to replace the Summer Conference, so be on the lookout for further communications.



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See half-life, clearance and other PK data from the crossover study comparing **Jivi®** and **Eloctate®**.

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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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# Attention TEENS: Join the Carolina Crew this AUGUST!

August 7-10, 2021

Rock Hill, SC

Save the date for the annual Teen Retreat, scheduled for August 7-10 at Camp Canaan in Rock Hill, SC!

At this time, Hemophilia of North Carolina (HNC) and Hemophilia of South Carolina (HSC) are closely watching what develops with the COVID-19 pandemic over the next few months to determine whether or not the event will be able to happen in person. HNC will keep you updated on any decisions that are made.

Wondering who the Teen Retreat is for? Of course, you know it's for teens. But did you know that it's for ALL teens in the community?

- If you are ages 13-18,
- diagnosed with a bleeding disorder, and/or
- the sibling or child of a person with a bleeding disorder,

then this retreat is for you!! Teens will be allowed to bring one friend or family member with them as long as that person is also a teen.

HNC and HSC are partnering to provide this fun, educational, and interactive weekend designed especially for teens in the community. This is a great opportunity to meet new friends, share laughs, challenge yourself, and prepare for your future. If you've never been to one of the HNC/HSC Teen Retreats, please check out the HNC Facebook page for photos.

Be on the lookout for an announcement soon. If the event is held in person, HNC will provide busing from the East Carolina University Hemophilia Treatment Center in Greenville and the HNC office in Morrisville.



## Teen FUN Day

December 12, 2020

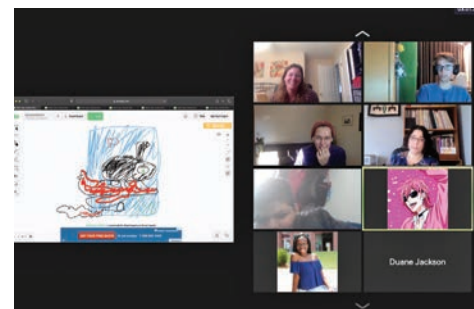
On December 12, 2020, Hemophilia of North Carolina (HNC) held its first Teen FUN Day. While the plan wasn't to hold the first of what will hopefully become an annual event virtually, the state of the pandemic made it necessary. Teens from North Carolina, California, and the Netherlands participated in the event.

There were icebreakers and games, an advocacy roundtable with other teens and young adults from around the country who have become strong advocates for the bleeding disorders, and a GutMonkey virtual Leading Edge program which provided two hours of workshops focusing on connection, resiliency, and, of course, FUN!

GutMonkey has been delivering the Pfizer-sponsored Leading Edge teen programs to the bleeding disorder community for 14 consecutive years and has delivered 230 programs with over 25,000 participants from all 50 states.

While the teens weren't able to meet in person, they were able to experience an interactive experiential program where they played games, participated in a scavenger hunt, and shared in cooperative drawing among other unique experiences.

Hopefully, the Teen FUN Day in 2021 will be able to take place in person. HNC is looking forward to developing more programming just for teens.



# Understanding Plasma Safety

December 15, 2020



While some people in the bleeding disorders community use recombinant factor products, others continue to utilize products manufactured using plasma. Understanding how plasma is collected and utilized is something that is important for anyone with a bleeding disorder to know. Therefore, Hemophilia of North Carolina partnered with Grifols in order to educate community members about plasma safety.

Virginia A. Kraus, RN, MSN, reviewed the plasma collection and manufacturing process, including all the steps necessary to help ensure the safety of donated plasma. She discussed donor screening and collection, as well as the multiple duplicated testing procedures, along with the viral inactivation and removal steps in the manufacturing process. Virginia and participants also discussed the ongoing surveillance for emerging pathogens and commitment to safety to ensure high quality, plasma-derived coagulation factor.

# Virtual Family Feud

January 16, 2021

Almost 50 people joined Hemophilia of North Carolina's (HNC) first event of 2021 – Virtual Family Feud! Two teams were randomly selected to compete against each other to win. The focus of the Family Feud game was about bleeding. The team that knew the most won! It was a fun afternoon for families to get together and learn a little bit more while having a great time. Thank you to Octapharma for partnering on this event.

# Constructive Conversations

February 4, 2021

Several members of the Hemophilia of North Carolina (HNC) community gathered on Zoom for an evening of motivational strategies and interviewing techniques to help guide tough conversations that you may have when talking about bleeding disorders. Rachel Cooper-Leal, Patient Affairs Liaison with Pfizer, shared videos and ideas for *Constructive Conversations*. Attendees were able to use the scenarios from different videos to discuss more positive ways of communicating. Thank you to Pfizer for providing this event!

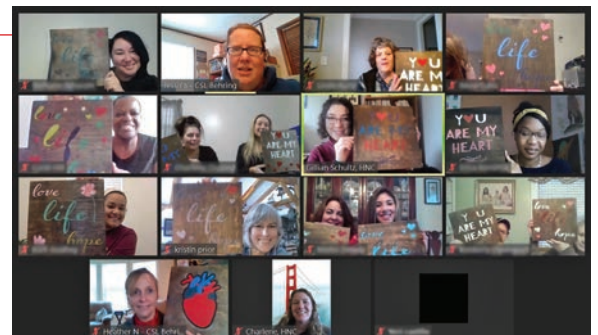


# Painting Party and Women's Luncheon

February 13, 2021

On February 13, Hemophilia of North Carolina (HNC) invited women from across the state to join them on Zoom for a virtual painting party and luncheon. The women heard from Kristin Prior, Common Factors Advocate from CSL Behring, about what it was like for her to find out about her son's diagnosis with a bleeding disorder and what it was like for her to be diagnosed with a bleeding disorder as an adult. Like so many others, symptoms that she had been dealing with for many years finally made sense once she received a diagnosis. Following the presentation, HNC members participated in a "Board and Brush" project where they had the opportunity to choose from one or two painting projects.

It was a fun afternoon connecting with other women from across North Carolina. Thank you to CSL Behring for sponsoring this event.



# Expect the Unexpected

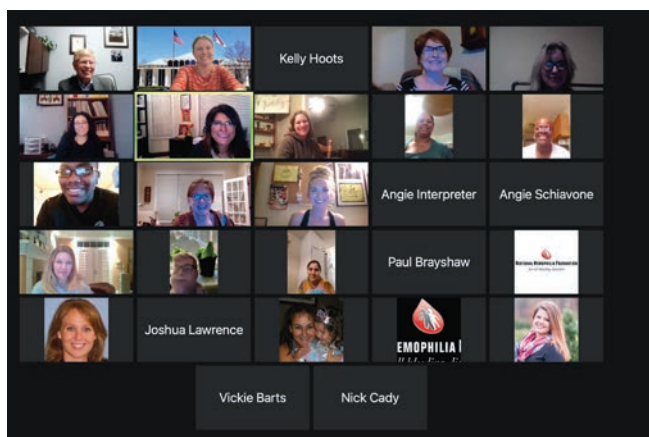
February 18, 2021

Preparing for an emergency is something everybody should do, whether or not they have a bleeding disorder. However, having a bleeding disorder adds an additional level of need when planning for emergencies. On February 18, nearly 50 Hemophilia of North Carolina (HNC) members got together on Zoom to learn more. Betsy Koval, Clinical Specialist with Takeda, presented *Expect the Unexpected: Prepare for Anything*. Knowing what to pack in a “go bag,” what to tell Emergency Room staff, and getting ready to travel were just some of the topics covered in this very informative educational presentation. Thank you to Takeda for sponsoring this event.



# Accumulator Adjusters: An Important Issue

February 25, 2021



While the Accumulator Adjuster Program (AAP) is an unfamiliar term to many, it is becoming an increasing problem for individuals with private healthcare trying to access their medication. Under an AAP, the insurance can accept third-party co-pay assistance for out-of-pocket costs associated with a prescribed drug but then not credit that amount toward the patient’s overall deductible. Examples of third-party co-pay assistance are pharmaceutical manufacturer coupons or assistance programs, nonprofit organization assistance, or even assistance from your local church or community foundation. So even if a patient is getting assistance to cover the high cost of their medication, the insurance is accepting those third-party payments but isn’t crediting them to the patient’s deductible. Therefore, the patient

is still stuck with the full bill and usually doesn’t realize it until March or April when they get the notice that this must be paid before insurance will approve their next medication refill.

Hemophilia of North Carolina (HNC) held an informative virtual meeting recently to educate the community about AAPs. This event was available in English and Spanish. Speakers included the National Hemophilia Foundation’s (NHF) Senior Director of Payer Relations, Kollet Koulianos, who broke down exactly how AAPs work, why they are so harmful to patients with bleeding disorders, and how NHF has been advocating on this issue. Then participants heard from Randolph Cloud, President of Randolph Cloud and Associates, a lobbyist who works on behalf of nonprofits. Randolph shared what is happening in North Carolina to resolve the issue of AAPs.

HNC will be advocating on this important issue throughout 2021. To get involved, contact Charlene Cowell, HNC Executive Director, at [charlene.cowell@hemophilia-nc.org](mailto:charlene.cowell@hemophilia-nc.org). NHF also advocated for this on a national level as part of their Washington Days event.

To learn more about the complicated and scary practice of AAPs, NHF has developed a short and easy-to-understand video: [www.hemophilia.org/news/copy-accumulator-adjustments-what-are-they-and-how-they-can-affect-you](http://www.hemophilia.org/news/copy-accumulator-adjustments-what-are-they-and-how-they-can-affect-you)

# In the Summer Edition

Read about the Annual Meeting, Bleeding Disorders Awareness Month, the Charlotte Family Festival & Walk, advocacy events, and other spring virtual “dinners” and events in the Summer Edition of *The Concentrate*.



Hemophilia of North Carolina (HNC), like so many other organizations and businesses, has been bracing for the inevitable financial impact of COVID-19. From event sponsorships to Walk fundraising, the impact has the potential to significantly reduce HNC's ability to serve the bleeding disorders community. Therefore, in addition to the individual donor recognitions listed on page 17, HNC wants to give a special note of appreciation to the companies that have continued supporting HNC's efforts during the last few months.

### Teen Day

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## Excitantes y Tentadores Programas y Eventos



Sabia que Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés) planea programas y eventos para TODOS Y CADA UNO en la comunidad de Carolina del Norte que sufre de enfermedades hemorrágicas? Continúe leyendo para conocer mas de estos programas y de que manera usted puede involucrarse, participar, conectar con otros en la misma situación, e incluso pasar momentos divertidos!

Si usted es un padre o alguien que proporciona cuidados a un niño con problemas hemorrágicos, en ciertos momentos usted puede sentirse agobiado y hasta aislado. Pero la realidad no tiene que ser así. El Programa **HOPE** ofrece la oportunidad de conocer mas acerca de como criar un niño con enfermedades hemorrágicas, así como también dar la oportunidad a estos niños a crecer con otros niños que sufren de desordenes hemorrágicos similares.

Durante el curso del año, HNC ofrece programas educativos con variados temas que varían desde asistir a la guardería y escuela, como enfrentar emergencias, conocimientos básicos de desordenes hemorrágicos, ayuda a los hermanos a como manejarse con un hermano o hermana que sufre de una condición medica crónica, infusiones y otros tratamientos médicos, deportes y actividades que pueden practicarse de manera segura por niños con estas condiciones de sangrado, y mucho mas! HNC también ofrece asistencia a su hijo a conocer mas de su condición hemorrágica a través de experimentos científicos, divertidos y hasta sucios! Juegos, manualidades artísticas, y otras actividades. Estas familias se reúnen para aprender y conectarse, y crear una comunidad. **HOPE** realiza eventos como retiros, otros eventos orientados hacia las familias y niños, y cenas educativas.

En el caso de hombres con enfermedades hemorrágicas, HNC es parte de **Blood Brotherhood Program** (Programa de Hermandad de Sangre), esto les facilita conectarse con otros en situación similar. Algunos de los temas de interés para varones que sufren de estas enfermedades, tales como manejo del dolor, edad avanzada, y terapia física; pero mas que eso, **Blood Brotherhood** proporciona simplemente la oportunidad de reunirse con otros en situación parecida. Algunas actividades pueden ser clases de cocina, de tai-chi, de jardín, una partida de pool, natación, o algún otro tipo de evento social que sirva de excusa para reunirse y divertirse. En el transcurso del año, HNC realiza múltiples eventos de **Blood Brotherhood**, desde paseos por el día hasta retiros de fin de semana.

Las mujeres que sufren de enfermedades hemorrágicas a veces sienten que nadie las escucha o incluso que han pasado años sin poder recibir un diagnostico. Aquí es cuando el **Programa SOAR** les puede proveer soporte. Poseer conocimientos y recursos proporcionan a las mujeres la ventaja de poder abogar por el mejor cuidado posible.

Conocer acerca de los problemas que las mujeres con problemas hemorrágicos enfrentan – desde la pubertad, menstruación, partos, y menopausia – ayudan a la mujer a estar mas empoderada. HNC también apunta a educar al publico en general acerca de mujeres con desordenes hemorrágicos, desde campañas en redes sociales, exhibiciones en conferencias medicas, y recursos. Los eventos ofrecidos por **SOAR**, al margen de dar educación, pueden también ser actividades como yoga o pintura, las cuales proporcionan una manera entretenida de escape.

*continúa página siguiente*

### Excitantes y Tentadores Programas y Eventos *viene de la página anterior*



Los eventos **SOAR** tienden a durar horas, dado que las participantes comparten sus experiencias e historias, las cuales son una forma de soporte en comunidad. Algunos de estos eventos incluyen **Retiros SOAR**, noches solo de mujeres, y cenas educativas.

Para los miembros de habla hispana de HNC, el **Programa Unión Latina** brinda toda la educación e información de recursos enteramente en Español. Navegar por la vida cuando el idioma materno es Español a veces resulta muy difícil. Si a eso le agregamos el sufrir de desordenes hemorrágicos, es

aun mas complicado. La **Unión Latina** asiste a los miembros que hablan Español ofreciendo temas tales como enviar a los hijos al colegio, seguro, autodefensa, educación relativa a desordenes de sangramiento, y mucho mas. En los años recién pasados, HNC ha incursionado en traer un interprete a sus presentaciones a fin de tener traducción simultanea al Español. La Unión Latina incluye siempre en sus eventos alguna actividad divertida, tal como un paseo al zoológico, Dave & Buster's, cocina practica, o algunas otras, así como también un retiro anual.

**Los adolescentes** enfrentan muchos cambios a medida que van incorporándose a la vida adulta. Conocer como manejar sus propios desordenes hemorrágicos es muy importante y necesario. Esta es una edad en que los contactos sociales son especialmente importantes. Es por esa razón que HNC ofrece cada año un Retiro Para Adolescentes, en conjunto con Hemofilia de Carolina del Sur con el fin de conectar a estos jóvenes con otros y tal vez conocer un poco mas al mismo tiempo. Desde competencias en circuitos de cuerdas altas y deslizamientos, carreras en canoas, juegos y mas, los adolescentes logran aprender mucho no solo acerca de ellos mismos, sino además de cuanto son capaces de lograr. HNC esta en proceso de brindar mas eventos y actividades para apoyar el Desarrollo de estos adolescentes.

Adicionalmente a los programas de apoyo de HNC, existen muchas otras actividades y eventos planeados a lo largo del año en los cuales la gente puede participar.

El apoyo, la dedicación y los recursos son ofrecidos en una variedad de ambientes. Si usted sufre de desordenes hemorrágicos, tiene derecho a recibir la ayuda que necesita. Por favor comuníquese con Gillian Schultz, Gerente del Programa HNC, si existe la inquietud de tocar un tema en particular que HNC pudiera presentar.



Aunque debido a la pandemia las cosas se presentan de una manera un tanto diferente, HNC sigue manteniendo los programas mencionados mas arriba de manera virtual, desde Reuniones Anuales, retiros, cenas educativas, juegos al atardecer, conversaciones con café, y mas. Estas actividades son realizadas de forma distinta por el momento, sin embargo, HNC no ha cesado de proveer educación, otorgar recursos y soporte a la comunidad con problemas hemorrágicos. Lea con atención el informativo para conocer todas las oportunidades ofrecidas para los meses entrantes. Ojalá encuentre algo motivante para unirse a HNC!



# Accumulator Adjusters: Un Tema Importante

25 de Febrero del 2021



Mientras el Accumulator Adjuster Programa (AAP) es un tema poco familiar para muchos, este se está volviendo un problema en aumento para aquellos individuos que tienen seguro de salud privado y que intentan tener acceso a su medicación.

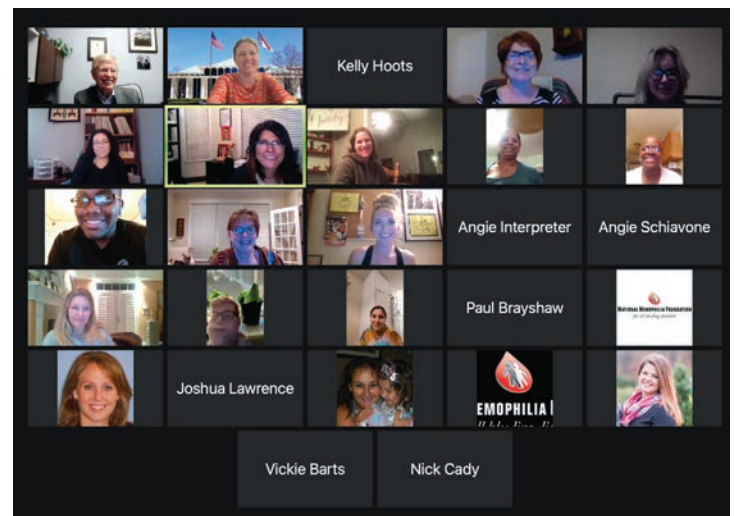
Bajo un AAP, el seguro puede aceptar co-pagos de terceros como gastos de bolsillo asociados con un remedio prescrito, pero luego puede no acreditar esa cantidad en el deducible acumulado por el paciente. Ejemplos de co-pagos a terceros pueden ser cupones de la farmacéutica fabricante del remedio, o programas de asistencia, ayuda de organizaciones sin fines

de lucro, o incluso su iglesia o comunidad. De tal manera que aun cuando el paciente esté recibiendo asistencia para cubrir los altos costos de sus remedios, el seguro está aceptando esos pagos de terceros, pero no los agrega como crédito al deducible del paciente. Por lo tanto, el paciente termina con cuentas completas y normalmente no se entera hasta Marzo o Abril, cuando recién se dan cuenta que estas deben pagarse antes que el seguro apruebe su próxima dosis de remedio.

Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés) recientemente sostuvo una reunión informativa virtual con el fin de educar a la comunidad acerca de AAPs. El evento fue ofrecido en Inglés y Español. Algunos de los expositores incluyeron a Kollet Koulianos, Director de Relaciones de Pagos de la Fundación Nacional de Hemofilia (NHF por sus siglas en Inglés), quien explicó parte por parte como AAPs funcionan, por que son tan riesgosas para pacientes con enfermedades hemorrágicas, y como NHF se ha interiorizado de este tema y abocado a él. Luego los participantes escucharon la presentación de

Randolph Cloud, Presidente de Randolph Cloud y Asociados, un cabildista quien trabaja en representación de fundaciones sin fines de lucro. Randolph nos compartió que se está haciendo en Carolina del Norte para resolver este problema de AAPs.

HNC estará abogando por este importante tema durante todo el año 2021. Para involucrarse más, contactar Charlene Cowell, Directora Ejecutiva de HNC, a [charlene.cowell@hemophilia-nc.org](mailto:charlene.cowell@hemophilia-nc.org). NHF También estará abocada a este tema, a nivel nacional, durante el evento Washington Days.



**Para más información acerca de esta complicada y preocupante práctica de AAPs,  
NHF ha creado un video, fácil de entender:**

**[www.hemophilia.org/news/copay-accumulator-adjustments-what-are-they-and-how-they-can-affect-you](http://www.hemophilia.org/news/copay-accumulator-adjustments-what-are-they-and-how-they-can-affect-you)**

## What Women with Bleeding Disorders Need to Know About Joint Problems

**Research is recognizing more joint issues in women with bleeding disorders, including carriers. Here's how to get your concerns addressed.**

By: Kathryn Anne Stewart

Kolbie Clarke, 17, has mild hemophilia A and low von Willebrand factor, and when she started having joint issues playing soccer five years ago, she wasn't surprised. Her father and uncle have severe hemophilia, and Kolbie saw them deal with repeated knee and ankle bleeds.

Until recently, the medical community wouldn't have expected joint issues like Kolbie's. Now, that is changing.

A leading researcher in this area is Robert Sidonio Jr., MD, director of hemostasis and thrombosis clinical operations at the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta. Sidonio attended patient advocacy group meetings where carriers shared stories of joint bleeding. "It really hadn't been known that the carriers would be at any significant risk for joint bleeds," he says.

Since then, his research has uncovered evidence that indicates prior joint bleeding in hemophilia carriers, particularly those with levels less than 60%.

For women with bleeding disorders, seeking care from a hemophilia treatment center (HTC) is the first step to progress.

Data collected by HTCs populates the registries of groups such as the Centers for Disease Control and Prevention and the American Thrombosis and Hemostasis Network. "If you don't become an active part of those datasets, then it's really hard for us to do any research," Sidonio notes.

He urges all carriers, even those without a confirmed bleeding disorder diagnosis, to consider being evaluated at an HTC. It's possible that many carriers have mild hemophilia based on their clotting factor levels.

### How to Recognize Joint Issues

Joint bleeds are most likely in the knees and ankles in males and females with hemophilia, Sidonio says, and sometimes in

the elbows. "It typically starts off as a tingling, pins-and-needles sensation," he explains. "Then it progresses to warmth."

The joint may also look different, as swelling obscures typical contours of bones. Often the range of motion will decrease, and there will be pain.

To help tell the difference between a strain or sprain and a joint bleed, Sidonio encourages people to take pictures and talk about joint issues with their physicians, who may suggest an X-ray or a point-of-care musculoskeletal ultrasound. These tests can reveal a lot, especially if done within 12 to 24 hours of the injury, he says.

### What You Can Do

Sidonio recommends you document joint issues with a bleeding diary to record details such as the date, the duration and what makes it feel better. You can keep track on paper, download a bleeding app or use your phone's notes feature, as Kolbie Clarke does.

If you have lingering joint injuries, your HTC can help. Most have a dedicated physical therapist, and some have an orthopedic surgeon who visits throughout the year. You can also request that your joint range of motion be followed.

Information like this helps the medical community further its knowledge of women and joint issues. Sidonio says, "That's what really makes a difference."

Women with bleeding disorders are also encouraged to join the National Hemophilia Foundation's registry, Community Voices in Research (CVR). CVR connects the experiences of people with bleeding disorders to researchers investigating improving treatments and care.

*Reprinted from National Hemophilia Foundation: [hemaware.org/womens-health/what-women-bleeding-disorders-need-know-about-joint-problems](https://hemaware.org/womens-health/what-women-bleeding-disorders-need-know-about-joint-problems)*

## *Exciting and Enticing Programs at HNC* continued from page 1

through fun and messy science experiments, games, arts and crafts, and other activities. Families get together to learn, connect, and find community. HOPE events include the Family Retreat, other family and child-focused events, and educational dinners.

For men with a bleeding disorder, HNC is part of the **Blood Brotherhood Program** so that guys with a bleeding disorder can connect with other guys. Topics that are of interest to men with bleeding disorders could be presented, such as managing pain, aging, and physical therapy. However, more than that, the Blood Brotherhood provides the time to just get together with others who “get it.” It could be a cooking class, tai chi, gardening, a game of pool, swimming, or some other social event just to get together and hang out. Throughout the year, HNC holds multiple Blood Brotherhood events from single-day outings to weekend retreats.



Women with bleeding disorders might feel like no one is listening to them or that they have gone years before getting a diagnosis. That is where the **SOAR Program** can provide support. Information and resources help women to learn how to advocate for themselves so that they can get the best care possible. Learning about the issues that women with bleeding disorders face – such as puberty, menstruation, childbirth, and menopause – helps women to become empowered. HNC also aims to educate the general public about women with bleeding disorders, from social

media campaigns, to exhibits at medical conferences, to resources. At SOAR events, in addition to the education, there could be activities like yoga or painting that provide a fun outlet. SOAR events are known to last for hours as women share their experiences and stories which helps support the community. Some of these events include the SOAR Retreat, women’s nights out, and educational dinners.

For HNC’s Spanish-speaking members, the **Unión Latina Program** provides all of the education and resources entirely in Spanish. Navigating through life in America when your primary language is Spanish can be difficult enough. Add in a bleeding disorder and it becomes even trickier. The Unión Latina helps Spanish-speaking members through educational presentations on a wide range of topics including sending your child to school, insurance, self-advocacy, bleeding disorders education, and so much more. In the past couple of years, HNC has also begun bringing in interpreters to some events to simultaneously interpret the presentations into Spanish. Unión Latina events always include a fun activity, whether it’s a trip to the zoo, Dave & Buster’s, a cooking studio, or something else, as well as an annual retreat.

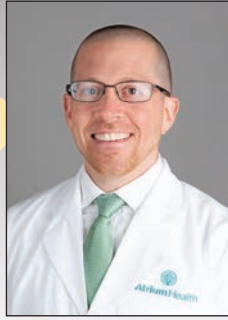
**Teens** face many changes as they are growing up into young adults. Learning how to manage their own bleeding disorder is so important and necessary. This is an age where social connections are especially important. That’s why HNC hosts a Teen Retreat every year along with Hemophilia of South Carolina to connect them with each other and maybe learn a little bit along the way too. From high-ropes courses, to zip-lining, canoeing, games, and more, teens learn a lot about themselves and what they are capable of. HNC is developing more events and activities to support the development of teens.

In addition to HNC’s support programs, there are so many different activities and events planned throughout the year for you to get involved with. Support for your bleeding disorder, advocacy, and other resources are provided in a variety of settings. If you have a bleeding disorder, there should be something to support you. Please let Gillian Schultz, HNC Program Manager, know if there is anything in particular that you would like HNC to present.

While times are a little different right now due to the pandemic, HNC has continued to provide these programs and services through virtual events, such as the Annual Meeting, retreat, educational dinners, game nights, coffee chats, and more. Though these activities might look a little different for the time being, the pandemic has not slowed HNC down from providing education, resources, and support for the bleeding disorders community. Read through the pages of the newsletter to see all the opportunities being provided in the coming months. Hopefully, there will be something that you see that entices you to join in with HNC!



## Community Spotlight



### Dr. Brendan Kleiboer, Levine Children's

Hemophilia of North Carolina (HNC) asked the new pediatric hematologist at Levine Children's to share some information about himself so that you could get to know him better

#### **Q: Where did you go to school?**

A: I have a degree in English Literature from the University of Michigan. Between college and medical school I spent two years serving in AmeriCorps volunteering in an after-school tutoring program in Dallas, TX (where I met my now wife!). I went to medical school at Michigan State University. I completed pediatric residency training at Levine Children's Hospital in Charlotte, NC and then my Pediatric Hematology/Oncology fellowship at the University of North Carolina at Chapel Hill. I returned to Charlotte in September 2020 to join the faculty at Levine Children's Cancer and Blood Disorder Center.

#### **Q: Did having von Willebrand disease inspire you to become a hematologist?**

A: It had everything to do with how I got interested in this work in the first place. Specifically, being around my own hematologist, who was an incredible role model, got my wheels turning about doing this work when I grew up! I consider it a great honor now to get to take care of kids and young adults with bleeding disorders.

#### **Q: Was there anything else that informed your career path?**

A: I was raised by parents who taught me the importance of taking care of those in need and the underserved, and I try to take that spirit with me to work every day.

#### **Q: What are your clinical interests?**

A: I am interested in all things non-malignant hematology, including pediatric bleeding and clotting disorders as well as the world of anemias.

#### **Q: What is your favorite part about your job?**

A: My favorite and most important job is educating my patients and their families about the conditions I see them for. Translating complicated medical information into understandable tidbits goes a long way toward making chronic conditions less scary and more manageable.

#### **Q: What do you see as the future for people with bleeding disorders?**

A: I am excited about the advancements we're making both in the diagnosis of bleeding disorders as well as their treatments. In fellowship, I was fortunate to be supported by a National Institutes of Health grant for my research on quality of life in pediatric patients with hemophilia, and I am excited by any advancement that improves outcomes while reducing treatment burden, especially in patients with bleeding disorders such as hemophilia.

#### **Q: What do you like to do for fun?**

A: I love to be outside as much as possible. I most enjoy trail running and hiking. My wife and I regularly visit the US National Whitewater Center in Charlotte where we like to kayak, zipline, run, and walk our dog, Bella.

#### **Q: Is there anything interesting about yourself that you're willing to share?**

A: When I was in fellowship at UNC, I was diagnosed with a relapse of testicular cancer and had

*Continued next page*

### Community Spotlight continued...

to go through chemotherapy and a big surgery, and am very happy to be healthy now. In our field we take care of kids with both cancer and bleeding disorders, so I now have something in common with both sets of kids and young adults I care for. It's given me a really unique perspective on what our patients go through, and I hope it has only helped me take care of them better.

I also want to add that I'm very excited to have been able to join the Pediatric Hematology/Oncology group at Levine Children's Hospital as a hemostasis and thrombosis specialist in the Hemophilia Treatment Center. The doctors who were formerly my mentors and teachers here in residency are now my colleagues, and I feel honored every day to get to work with them.

### Community Spotlight

Congratulations to Hemophilia of North Carolina (HNC) member and high school senior Jacob Hoernlein, who has advanced to the finals in the National Merit Scholarship Program competition. Jacob is one of 15,000 finalists from across the country. Of those, 7,500 will be named Merit Scholars and awarded a scholarship.

**Jacob Hoernlein**



*We're Listening*



At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

**We are grateful for having the chance to partner with you.**

—Your Pfizer Hemophilia Team

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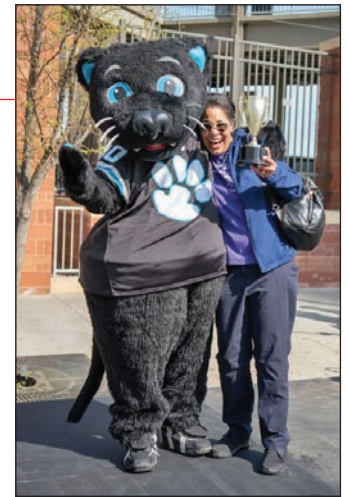


# Congrats to Dr. Bryant

Members of the Hemophilia of North Carolina (HNC) community already know the name



*Dr. Bryant.* Paulette Bryant, MD, is a Pediatric Hematologist–Oncologist at the St. Jude Affiliate Clinic at Novant Health Hemby Children’s Hospital in Charlotte, NC. Dr. Bryant is also a recently elected board member for the National Hemophilia Foundation (NHF)! Please join HNC in congratulating Dr. Bryant and thanking her for her service to the community, including her new volunteer role with the NHF.



**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](mailto: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

Mark and Jo Anne Buckley  
Jasher Fowles  
Tera Griffith  
W. Allen & Sue Heafner  
Michael Hoernlein

Ellen Kearney  
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Bret & Janet Stolp  
Brett Swope

*In honor of Charles & Katherine Register*  
Bret and Janet Stolp  
Dan Dalton

*In honor of Darien Leon Simmons*  
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*In memory of Marilyn McQuage*  
Frances S Hendrix  
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*COVID-19 Financial Assistance Fund*  
Rebecca Norman

*Giving Tuesday*  
Lori Conger

*Thank You* 

### Annual Giving Campaign

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Anonymous  
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*In Honor of Cheryl Wimberly*



# As a Parent, I Can Only Show Up With What I Know

By: Joe Macdonald

One thing that struck me over the head when I became a parent was an awareness that I bring my whole self to the table. When treating bleeds and other surprises, I show up with what I know — no more, no less. I cannot respond to my child beyond my ability to process what goes on in the moment. Whatever job I do, good or bad, is the best I have to offer.

When doctors diagnosed my oldest son with severe hemophilia A, or factor VIII deficiency, I knew nothing about what my family faced. I did not have life experience I could draw upon when treating or offering support to my boy.

Looking back, the moment of diagnosis became a time of crisis. Nothing prepared me for something so unexpected. What could I do to help my son and my family? The helpless moment brought anxiety, and somehow, I felt it were my fault that hemophilia reared its ugly head in my child.

My family's saving grace came from the hemophilia treatment center. As we discovered a new community complete with new friends in the same medical situation, I realized our situation could improve by educating ourselves about our son's bleeding disorder. I believe that learning new ways to be in the world opens many doors to various possibilities. A safe and nurturing environment equipped me to face many medical issues with faith and determination.

Over time, I found that many fathers of newly diagnosed children shared many of my initial concerns. I expressed my guilt and received support from others like me. As the father of the house, I discovered that my expectation to fix every problem myself was unrealistic. I carried guilt that was not mine to hold. Perhaps there was a different approach to solving some of the issues that were staring me in the face. I could offer the unconditional love of a parent, and support and encourage my stinky little son.

I took advantage of every education seminar conducted through the two prominent organizations in the bleeding disorders community, the National Hemophilia Foundation and the Hemophilia Federation of America. Both organizations provide safe places to process issues that occur when raising children with chronic bleeding disorders.

I met people in the medical industry, thereby extending my reach to those that are well-equipped with pertinent information regarding treatment and care. Meeting parents from different

areas of the country offered crucial ways to find community and reminded my family that we share our diagnosis with others. We found time to take a breath and rediscover hope in the middle of our circumstances.

I look back on the man that stood in front of a medical team as they diagnosed our newborn son with the foreign term "hemophilia." My first thought is, "That poor guy did not know anything about a strange-sounding diagnosis."

I also admire him because he proved to the world that he was strong. He knew that more education brought empowerment and a sense of freedom, even in a medical crisis. He faced the journey all for the love of the stinky little boy that was placed in his arms, and redefined him as a daddy. I promised him I would move heaven and earth to provide him with a safe place to grow up and learn about hemophilia for himself.

We can only respond in ways that we know. We do not become parents and receive an instruction manual that teaches us how to walk through our children's lives, or tells us if we should follow path A or path B. Our directive comes through on-the-job training. In the process, we discover beautiful moments of joy beyond description, all stemming from this new person in the world. Life never is the same, nor would I want it to be.

Through my stinky boy, I discovered far more than a bleeding disorder. I found love in ways I never thought possible. I am grateful for the journey.

*Reprinted from Hemophilia News Today: [hemophilianewstoday.com/2021/02/04/parent-showing-up-knowledge-support/](https://hemophilianewstoday.com/2021/02/04/parent-showing-up-knowledge-support/)*



# HNC Receives Grant to Distribute Bike Helmets

Hemophilia of North Carolina (HNC) is very excited to have been awarded the North Carolina Department of Transportation (NCDOT) Bicycle Helmet Initiative Grant and will be receiving 50 helmets to distribute to children in the bleeding disorders community. The Bicycle Helmet Initiative began in 2007 and has distributed thousands of helmets. The grant is funded by the sale of the "Share the Road" specialty license plates.

As part of the grant process, HNC held an educational program during the Annual Meeting to help educate parents about bicycle safety. Jen Newman, Physical Therapist from the UNC-Chapel-Hill Hemophilia Treatment Center (HTC), and Lora Joyner, Physical Therapist from the ECU HTC, presented *Health and Wellness for Children with a Bleeding Disorder*, during one of the HOPE Program sessions on March 20. This session, geared towards parents, helped them to understand safe activities to keep kids physically active, while focusing on the benefits of riding a bike, how to size a bike for a child, and how to measure a child for a helmet. Then on April 3, HNC held a session for children with bleeding disorders focusing on bike safety, including the rules of the road and why they should wear a helmet.

In order to receive a bicycle helmet, parents who attended either the session at the Annual Meeting or whose children attended the session on April 3 were given the opportunity to complete an application for a helmet. Helmets will be awarded to children based on need, size availability, and inventory. Siblings are eligible as well. Though it is unknown if there are additional helmets available at the time of printing of this edition of *The Concentrate*, applications will be provided to the HTCs for any additional helmets to help their patients access a bike helmet if in need.

More information about the NCDOT Bicycle Helmet Initiative can be found here: [www.ncdot.gov/initiatives-policies/safety/bicycle-helmets](http://www.ncdot.gov/initiatives-policies/safety/bicycle-helmets)



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# NC ABLE: Save funds without risking your public support

Achieving a Better Life Experience (ABLE) accounts are designed for those with the occurrence of a disability before the age of 26. The NC ABLE Program was launched in 2017 and allows eligible individuals the opportunity to save and fund a variety of qualified disability expenses while maintaining Medicaid, SSI<sup>1</sup>, and other public support programs. NC ABLE accounts can help pay for a variety of expenses, such as:

- Education
- Transportation
- Housing
- Health and Wellness
- Financial Management
- Legal Fees
- Assistive Technology
- and more

NC ABLE accounts can be opened by an eligible individual who is the account owner, or by the account owner's parent, guardian, or person acting under a power of attorney. NC ABLE accounts are open to eligible individuals throughout the US. The account can be funded by the account owner, family, or friends, and in some cases, funds can also be transferred to a NC ABLE account from a 529 college savings account. It is important to know that account owners can contribute up to \$15,000 per year to a NC ABLE account, and individuals that qualify for the NC ABLE Program have a greater annual allowance for contributions to their account with the ABLE-to-Work provision.<sup>2</sup> Overseen by the Department of State Treasurer and the Board of Trustees, NC ABLE currently has over 1,200 account holders with more than \$10.7 million in assets and an average account balance of nearly \$8,700.<sup>3</sup>

Learn more about this resource here: [www.nctreasurer.com/links/nc-able](http://www.nctreasurer.com/links/nc-able)



<sup>1</sup> ABLE account balances up to \$100,000 are excluded from assets for the purpose of determining SSI eligibility.

<sup>2</sup> For employed account owners, the annual contribution limit is increased by the lesser of the person's earning and the Federal one-person poverty limit for the prior year.

<sup>3</sup> As of Feb 6, 2021.

## ACA Marketplace Reopened Until May 15

The Affordable Care Act (ACA) Marketplace – also known as “Obamacare” – has reopened through May 15, 2021. Uninsured individuals are able to enroll during this time. Additionally, if someone is already enrolled in a plan through the Marketplace but wants to switch their plan, they can do so. President Biden signed an executive order in January to open up the federal health insurance marketplace for three months.

For more information about plans, visit: [www.healthcare.gov](http://www.healthcare.gov).





# Passage of the Hemophilia SNF Access Act: A Huge Legislative Accomplishment



The National Hemophilia Foundation (NHF) is thrilled to announce that its top legislative priority in 2020, The Hemophilia SNF Access Act, was included in the end-of-year omnibus federal spending and economic relief package passed by Congress on December 21, 2020 (HR 133, The Consolidated Appropriations Act, 2021).

This critical legislation will rectify a long-standing problem to improve access to skilled nursing facilities (SNFs) for Medicare beneficiaries with hemophilia and other bleeding disorders. NHF has heard from many community members over the years about challenges accessing SNF facilities due to the way that Medicare reimburses bleeding disorders treatments.

The legislation, introduced in January 2020 in the Senate by Senators Bob Menendez (D-NJ), Michael Enzi (R-WY) and Sheldon Whitehouse (D-RI) and in the House in February 2020 by Representatives Darin LaHood (R-IL), Brian Higgins (D-NY), Debbie Dingell (D-MI) and Gus Bilirakis (R-FL), is the culmination of years of continued efforts by NHF and other bleeding disorders organizations.

“We have been advocating to improve access to skilled nursing facilities for Medicare beneficiaries with bleeding disorders for many years,” said Dr. Leonard A. Valentino, President and CEO of the National Hemophilia Foundation. “NHF applauds Congress for enacting this vital legislation, which will benefit the hundreds of Americans with bleeding disorders who are Medicare beneficiaries as soon as October 1, 2021. It may seem like a small shift in policy, but it will have a huge impact on our community.”

The bill was a top talking point for the 450 volunteer advocates with bleeding disorders who participated in NHF’s annual advocacy event, Washington Days, on February 28th and many other advocates contacted their Congressional representatives in support of the bill throughout the year. “Our thanks go not only to our lead champions and their tireless staff who pushed for the SNF change to be included in the year end bill, but also to the hundreds of bleeding disorders advocates – patients, families and hemophilia treatment center staff – who raised their voices in support of the bill this year. We could not have done it without you!” said Nathan Schaefer, NHF’s Vice President of Public Policy.

*Reprinted from the National Hemophilia Foundation: [hemophilia.org/news/nhf-applauds-congressional-enactment-of-the-hemophilia-snf-access-act](https://hemophilia.org/news/nhf-applauds-congressional-enactment-of-the-hemophilia-snf-access-act)*

## Your Story Matters

Change happens because people like you share their story. When it comes to advocacy, these stories are what drive legislative decisions. So if the bleeding disorders community isn’t sharing their stories with policymakers, who will? No legislative background or specialized education is needed to create positive change for this community. All that is needed is your voice and story! Interested in learning more? Contact Charlene at [charlene.cowell@hemophilia-nc.org](mailto:charlene.cowell@hemophilia-nc.org).



## Are you on NC Medicaid? *continued from page 1*

**May 14**, they will auto-select one for you. It is important that you select a PCP that understands your bleeding disorder.

More info here: [www.ncmedicaidplans.gov](http://www.ncmedicaidplans.gov)

### Questions?

Call or email HNC at (919) 319-0014 or [info@hemophilia-nc.org](mailto:info@hemophilia-nc.org)

HNC is here to help!

# NC Advocates Went to DC, Virtually

March 1-5, 2021

There were no cars or train rides to get to the National Hemophilia Foundation's (NHF's) annual Washington Days event this year, but advocates were still able to make their mark on Washington, DC. Thanks to technology, North Carolina advocates could still meet with their U.S. Senators and Representatives from the comfort of their own homes. With nine advocates from around the state and eight appointments, it was a busy and productive day filled with virtual meetings!

The "asks" included:

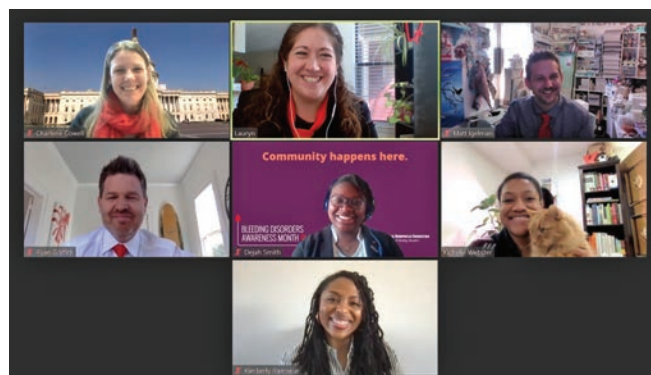
- Affordability and Access to Care
- Prohibiting accumulator adjuster programs (AAPs) on a federal level. A description of AAPs can be found in the article on page 8.
- Improving access to coverage during the COVID-19 public health emergency, including incentives for states like NC to expand Medicaid, subsidies for people to maintain employer-sponsored coverage via COBRA, and subsidies for marketplace plans for people eligible for unemployment insurance but not COBRA.
- Continued funding and support for federal programs that support the bleeding disorders community:
  - **National Institutes of Health (NIH):** Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
  - **Centers for Disease Control and Prevention (CDC):** Funds Hemophilia Treatment Center (HTC) surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
  - **Health Resources and Services Administration (HRSA):** Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as PT and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all of their patients.



NC Advocates Meeting with Huston from Rep. Deborah Ross' office



NC Advocates Meeting with Garrett from Sen. Tillis' office



Meeting with Kichelle from Representative Alma Adams' office (and her four-legged assistant)

Hemophilia of North Carolina (HNC) needs your voice to ensure that our policymakers are aware of the importance of these issues for the bleeding disorders community. Interested in learning more about Washington Days, the asks, or how you can get involved? Please contact Charlene Cowell, HNC Executive Director, at [charlene.cowell@hemophilia-nc.org](mailto:charlene.cowell@hemophilia-nc.org).

# Hemophilia of North Carolina 2021 Calendar of Events Highlights



<a href="#"><u>April 17, 2021</u></a>	<a href="#"><u>Charlotte Festival &amp; Walk - Virtual</u></a>
<a href="#"><u>May 1, 2021</u></a>	<a href="#"><u>Medical Symposium – Virtual</u></a>
<a href="#"><u>August 7-10, 2021</u></a>	<a href="#"><u>HNC/HSC Teen Retreat - Rock Hill, SC</u></a>
<a href="#"><u>October 2, 2021</u></a>	<a href="#"><u>Raleigh Festival &amp; Walk - Morrisville, NC</u></a>
<a href="#"><u>November 20-21, 2021</u></a>	<a href="#"><u>Blood Brotherhood and SOAR Weekend Greensboro, NC</u></a>
<a href="#"><u>December 4, 2021</u></a>	<a href="#"><u>Holiday Celebration - Greenville, NC</u></a>



## 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\*\*](https://HemDifferently.com)

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

**BiOMARIN**

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**HEMOPHILIA OF NORTH CAROLINA**

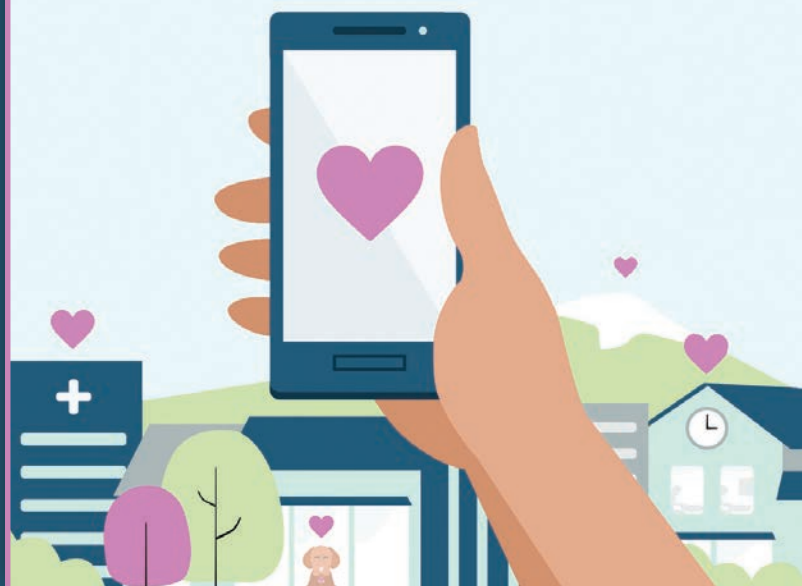
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