

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

SPRING 2020

HNC'S UPDATE ON COVID-19

As this edition of *The Concentrate* is being sent off for printing, Hemophilia of North Carolina (HNC) is actively monitoring developments regarding the coronavirus, COVID-19 outbreak. With a state of emergency declared and recommendation by the CDC to cancel or postpone events with more than 50 people for the next eight weeks, HNC has had to make the difficult decision to postpone all March and April events including the HNC/HTC Partnered events with the HTCs at Wake Forest Baptist, UNC Chapel Hill, and ECU, and the Charlotte Family Festival & Walk; as well as cancel the fishing event scheduled on May 2. HNC is currently evaluating whether other events scheduled in May, including the Blood Brotherhood event on May 3 and the Unión Latina event on May 16, can be held virtually, through a Zoom webinar. As soon as decisions are made about these, as well as future HNC events, announcements will be made through email and social media. HNC appreciates your understanding during this difficult time.

For information about the coronavirus, COVID-19, visit the CDC website: www.cdc.gov/coronavirus and the NC Department of Health website: www.ncdhhs.gov/divisions/public-health/coronavirus-disease-2019-covid-19-response-north-carolina

The 6th Annual HNC Family Festival & Walk in Uptown Charlotte

POSTPONED DUE TO CORONAVIRUS CONCERNS

Date to be announced
Charlotte, NC

As this newsletter is going through the final production stages, Hemophilia of North Carolina (HNC) staff is diligently working to reschedule the Charlotte Family Festival & Walk for Bleeding Disorders. Notifications will be sent by email as soon as HNC has a new plan in place. If you are not receiving HNC email announcements, please contact info@hemophilia-nc.org to request to be added to HNC's email database.

More than ever, your support is needed to provide critical

Continued page 5



In this Edition:

UPCOMING EVENTS	Page 5
RECENT EVENTS	Page 7
SUPLEMENTO DE LA UNIÓN LATINA	Page 11
OUR YOUNG VOICES	Page 12
SOAR SUPPLEMENT	Page 14

Save The Date

World Hemophilia Day
April 17, 2020

HNC Family Festival & Walk
Postponed
Charlotte, NC

HFA Symposium
Postponed
Baltimore, MD

HNC Fishing Event
Cancelled
Charlotte, NC

HNC Blood Brotherhood Event
May 3, 2020
Chapel Hill, NC

Unión Latina Event
May 16, 2020
Charlotte, NC

NHF Inhibitor Summit
May 29-31, 2020
Denver, CO

HNC Adult Retreat
June 5-7, 2020
Lake Junaluska, NC

HNC Legislative Days
June 15-16, 2020
Raleigh, NC

CHES Inhibitor Camp
June 26-29, 2020
Lakewood, PA

HNC Blood Brotherhood Event
June 27, 2020
Location TBA

SOAR Education Day
June 27, 2020
Greensboro, NC

HNC Medical Symposium
July 11, 2020
Chapel Hill, 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 Moye Boulevard
Pediatric Hematology/Oncology
MA Suite 333
Greenville, NC 27834
Phone: (252) 744-4676

Hemophilia Treatment Center of Levine Cancer Center and Levine Children's Hospital

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

St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital Hematology & Oncology Clinic

301 Hawthorne Lane, Suite 100
Charlotte, NC 28204
Phone: (704) 384-1900

UNC Hemophilia and Thrombosis Center

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

Wake Forest University School of Medicine

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

Additional Medical Resources

Duke University Medical Center Hemostasis and Thrombosis Center

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

Mission Hospital Pediatric Hematology/ Oncology Program

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

Resource Information

National Hemophilia Foundation

www.hemophilia.org

Hemophilia Foundation of America

www.hemophiliafed.org

American Society of Pediatric Hematology/Oncology

847-275-4716
www.aspho.org

Centers for Disease Control & Prevention

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

Coalition for Hemophilia B

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

ClinicalTrials.gov

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

Committee of Ten Thousand (COTT)

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

LA Kelley Communications

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

PAN Foundation

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

Patient Notification System

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

Patient Services Incorporated (PSI)

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

World Federation of Hemophilia

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

VISION STATEMENT

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

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

A MESSAGE FROM THE EXECUTIVE DIRECTOR

It is with mixed emotions that I announce Karyn Davis' departure from Hemophilia of North Carolina's (HNC) Manager of Operations position. Karyn started with HNC in September 2015 and we immediately knew that she would be a wonderful addition to the small staff. Karyn's enthusiasm to help, compassion, and experience were only a very small part of what she brought to HNC. It didn't take long to see how committed Karyn is to the bleeding disorders community. HNC wasn't just a job for Karyn, it has been a passion. I know that I can speak on behalf of the community when

I say that Karyn is going to be sorely missed.



HNC Staff at the 2020 Volunteer and Special Guest Dinner (from left to right) Charlene Cowell, Gillian Schultz, and Karyn Davis

Over the years, Karyn's entire family has been actively involved in supporting the growth of HNC through countless volunteer hours. They've helped build our teen retreats, walks and many other events to make them more impactful. This just shows how important the bleeding disorders community is to the entire Davis

family. As an organization, we are extremely grateful for their dedication and commitment to HNC.

While Karyn is leaving her position for personal reasons, she remains committed to HNC and the members we serve. Her passion for this community has not wavered within her decision. Karyn is going to change roles from Manager of Operations to a dedicated volunteer. I look forward to working with Karyn in this new capacity. I also appreciate all that she has given and will continue to give to the community. It has been evident how deeply she cares and I feel very fortunate to have worked beside her for almost five years.

With the staff transition, HNC staff and board will continue to assess the structure and strategy of the organization. As we look to the future and the changing needs of the bleeding disorders community, we have already undertaken a Member Needs Assessment, which is discussed on page 5. This assessment will help guide the direction of HNC, including what positions our organization will need in the future in order to meet the needs of the changing community. HNC was founded by community members and I can assure you that the organization will remain community-driven.

Warm regards,
Charlene Cowell, Executive Director

Meet HNC's Newest Board Members

Hemophilia of North Carolina (HNC) held the election for its Board of Directors at the Annual Meeting on March 7 in Raleigh and would like to welcome newly elected board members Garima Gupta, Amy Hadley, Ellen Kearney, and Lucy Kucmierz. At the same time, on behalf of all members, HNC would like to extend a heartfelt thank you to members of the Board of Directors who will return for the upcoming year, and acknowledge Tiffany Hargett, Tyronna Hooker, Michelle Vanhook, and Sushant Patil, who are completing their terms on the Board of Directors, for their time and commitment they've given to HNC and the members of this community.



Garima Gupta, MBA – Clarksburg, VA

Garima is a Global People leader who helps organizations to build inclusive workplaces, processes and have robust conversations about the future of workplace. After a successful career working in Asia-Pacific working in Financial services, Retail and FMCG organizations

building a continuous learning culture and focusing on creating Management with empathy and learning about cultural sensitivity and global workplaces, Garima moved to US and she now works with non-profits that are scaling up and are moving the needle in the field of Health, Education, Migrant rights and Human rights to work with leaders and employees to create a better employee experience where people feel they belong and advises leaders to focus on Talent Management, Coaching and investing in future leaders. Garima enjoys reading fiction and poetry and travelling.

Continued next page

Meet HNC's Newest Board Members *continued from previous page*



Amy Hadley –
Holly Springs, NC

Upon graduating Elon University in 2001 with a Sports Medicine and Health Awareness BS, Amy moved to Washington DC where she worked for a non-profit aimed to raise money to remove undetonated landmines from Cambodia and Vietnam.

This amazing experience further instilled the drive to help others. Amy moved back to North Carolina in 2003, and in 2004 began her career in Clinical Research. Working at Duke University, PPD, Quintiles/IQVIA, and currently at Covance/LabCorp. During her 16 year career in clinical research, she has worked with patients, care givers, doctors, advocacy groups, and countless organizations whose missions are to advance healthcare and improve lives. Amy had held various global leadership roles across multi-disciplinary fields, and currently is Head of Strategic and Commercial Risk at Covance. At home, Amy enjoys spending time with her family: husband, Ryan; Brayden, 11 year old son; Anderson, 7 year old son; Cooper, 7 year old '4 legged' son of the American Bulldog decent; and Baxter, 3 year old '4 legged' son of the Boston Terrier decent. Amy is excited about the opportunity to join the HNC board to help drive the mission and serve the patients and families it supports.

years and is currently Director of Benefits for a local Raleigh organization working primarily in benefits, payroll, HRIS and compliance. She has served on the board of TSHRM and she has been a volunteer with Dress for Success and looks forward to lending her time and talents to HNC.



Lucy Kucmierz –
Cary, NC

Lucy is originally from Fredonia, NY, and lived in Tampa, FL before moving with her husband and three children to Cary, NC in 1999. Lucy is a graduate of SUNY Fredonia where she received her Bachelor of Science Degree in Education. She also has a Non-Profit Management

Certificate. She has been working with non-profits for over fifteen years in various roles including membership, events, and office management. Lucy lives in Cary with her husband of 30 years. Together they have three grown children, one old dog, two purrfect cats, and three granddogs.



Ellen Kearney, MBA –
Raleigh, NC

Ellen is a native of Norwalk, CT but has lived in Raleigh with her husband Mitch and two children, DJ and Sydnee since 2007. They have one furbaby, Bailee. Ellen graduated from Southern Connecticut State University with a BS in Management and from

Sacred Heart University with an MBA in HR Management. She holds various HR certifications and is a licensed Life and Health producer. She is currently a Ph.D. candidate, with a concentration in Human Resource Management, at Capella University. Ellen has been an HR professional for over 20



The 2019-2020 HNC Board of Directors: thank you for your service to the community (missing from photo, Sushant Patil)

Help Drive HNC into the Future

HNC Needs Assessment

Hemophilia of North Carolina (HNC) needs YOUR help! The programs and services that are delivered to the community have been developed over the years based on the needs of HNC members.

Is what HNC doing working for you?

Do you find benefit from HNC's offerings?

Is there something else that you would like to see from HNC in the future?

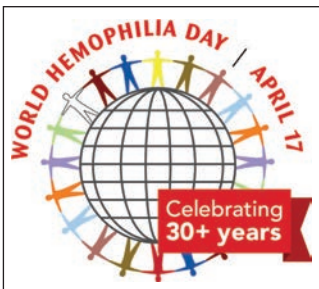
In order for HNC to continue its mission of delivering supportive programs and services, it is important to hear from you, the members of the bleeding disorders community. Please help to provide that input by completing the HNC Needs Assessment. All adults are encouraged to participate. If you have adult children outside of your home who may not be receiving HNC's communications, please ask them to provide their input as well. Whether you participate in as many events as you can or you have never been to an HNC event, it is important to hear from you. Your feedback is anonymous.

HNC hopes to receive at least 100 responses to the Needs Assessment. As an appreciation for your time, everyone who completes the Needs Assessment will be entered into prize drawings held throughout the year. 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



World Hemophilia Day

April 17, 2020



April 17 will mark the 30th World Hemophilia Day! The theme of the 30th anniversary is "Get+involved" as a call to action for everyone and to drive forward the World Federation of Hemophilia's mission of "treatment for all". Help to raise awareness of inherited bleeding disorders and make access to adequate care possible everywhere around the world.

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

Hemophilia of North Carolina (HNC) will recognize World Hemophilia Day on April 17 with buildings lit red in North Carolina.

Join in the Celebration! The 6th Annual HNC Family Festival & Walk in Uptown Charlotte

continued from page 1



services to people affected by bleeding disorders across the state. Regardless of the time or place, HNC is counting on people like you to meet this year's fundraising goal of \$70,000.

Register as an individual, start a team, and/or sign up to volunteer. If you are already registered, keep up your fundraising. When a new date is announced, plan to bring your family, friends, coworkers, and 4-legged friends with you to the Family Festival & Walk in Charlotte.

HNC Adult Retreat

June 5-7, 2020

Lake Junaluska, NC

Save the date for the 2020 Hemophilia of North Carolina (HNC) Adult Retreat, from June 5-7 at the beautiful Lake Junaluska Conference and Retreat Center in the North Carolina mountains! All adults, including men with bleeding disorders, women with bleeding disorders, moms, dads, and caregivers, are invited for a weekend of education and connection. There will be sessions for everyone, as well as breakouts for men and women in the community. More information will be available soon on the HNC website, or you can contact the HNC office at (800) 990-5557.



2019 Adult Retreat Attendees at the end of a great weekend

HNC Consumer Medical Symposium

July 11, 2020

Chapel Hill, NC



Hemophilia of North Carolina (HNC) is excited to announce its first ever consumer Medical Symposium scheduled to take place in July.

There is so much information out there about living with a bleeding disorder as well as 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 from Hemophilia Treatment Centers around North Carolina, and 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 will be available soon on the HNC website.

Regional Men's Retreat - Your Feedback is Needed for this Possible Future Event

Hemophilia of North Carolina (HNC) is reaching out to all men in the community. HNC, along with Hemophilia of South Carolina, the Virginia Hemophilia Foundation, and the Hemophilia Association of the Capital Area, have been talking about the possibility of hosting a regional men's retreat in 2021. HNC is asking that ALL men, including dads, blood brothers, and husbands/partners take a short survey to see if there is enough interest to move forward with this event.

Please visit: www.surveymonkey.com/r/MT77RP6 or scan the QR code.



More Summer Events and Retreats You Won't Want to Miss

Hemophilia of North Carolina (HNC) staff is busily planning for summer events and retreats. Be sure to stay tuned to the HNC website and check your email notifications as event registrations open for these upcoming events:

HNC/HSC Teen Retreat on August 13-16 in Rock Hill, SC. HNC will once again partner with Hemophilia of South Carolina for this four-day event. See the Our Young Voices section on page 12 of this newsletter for more information.

HNC VWD Education Day on August 29 in Greensboro, NC. Did you know that von Willebrand disease (VWD) is the most common bleeding disorder? Find out more about living with VWD at this one-day event.

HNC Blood Brotherhood Retreat Gathering on June 27, location to be determined.

HNC SOAR Education Day on June 27, in Greensboro, NC. See the SOAR page of this newsletter on page 14 for more information.

HNC Travel Raffle Sends One Member to New Orleans!

January 9, 2020
Morrisville, NC

Members and supporters of the community came out to the Hemophilia of North Carolina (HNC) Travel Raffle Drawing event held at Ruckus Pizza, Pasta and Spirits on January 9, or tuned in to the live feed to see if they would be the big winner of a fabulous trip to one of seven destinations around the world. The lucky ticket was #112. The happy winner, an HNC member from the Winston-Salem area, has selected New Orleans, Louisiana, as his destination. Bon voyage to the big winner!

HNC staff and board members appreciate all who participated in the Travel Raffle fundraiser to support HNC's programs and services, by either purchasing a ticket or coming out to Ruckus for the drawing event. A special thanks to Ruckus for donating back a percentage of the proceeds of the night to HNC!



HNC Staff get ready for the raffle drawing

Game Day Gathering

February 1, 2020
Charlotte, NC



The first of four events that Hemophilia of North Carolina (HNC) planned with the North Carolina Hemophilia Treatment Centers (HTC) took place at Reedy Creek Park in Charlotte. Both Charlotte HTC's, HTC of Levine Cancer Institute and Levine Children's Hospital and St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital, partnered together with HNC to host a fun event for Charlotte area families.

Board games and puzzles were set up as members arrived, and some families brought their own games, so it didn't take long for the games to begin! Once everyone had their lunch, the HTC's tag-teamed a presentation about transitions that occur while living with a bleeding disorder. People heard from the social workers, Dr. Hinson, Dr. Bryant, and Dr. Knovich about transitions at different stages of life. To end the presentation, there was a lively "Hot Potato" trivia

game, where everyone passed (more like tossed) a teddy bear around to the music. When the music stopped, the person holding the teddy bear had to answer a question based on information heard in the presentation. It was a lot of fun!

This event wouldn't have been possible without a grant from the Hemophilia Alliance Foundation. Thank you to both HTC's, HTC of Levine Cancer Institute and Levine Children's Hospital and St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital, for partnering with HNC on this event. Events with the HTC's at Wake Forest Baptist Health, UNC Hemophilia and Thrombosis Center, and ECU Brody School of Medicine are being scheduled for later in the year.



Bowling with HNC

February 8, 2020

Charlotte, NC



The rain (and even some snow) was falling as HNC members got together at Bowlero in Uptown Charlotte. As everyone arrived, people got their bowling shoes, some food, and prepared to bowl. Before heading to the lanes, CSL Behring Gettin' in the Game Athlete, Tim Grams, led people in a stretch to help them loosen up their muscles so they were properly warmed up.

While one group of people were bowling, Tim shared his story of swimming, mountain climbing, and more, even while living with

hemophilia. Then, the two groups switched, so that everyone had a chance to bowl and listen to Tim's presentation. In addition to bowling, the ping-pong table was hopping, with lots of fun had by everyone. Even though it was a dreary day outside, inside, it was bright and cheery as friends caught up, met new people, and had a great time. Thank you to CSL Behring and DrugCo Health for sponsoring this event.



HNC Volunteer and Special Guest Dinner

March 6, 2020

Raleigh, NC



As traditionally done in the past, Hemophilia of North Carolina (HNC) held its Annual Volunteer and Special Guest Dinner on the evening before the Annual Meeting. The dinner, for HNC volunteers, advocates, and large donors, is a way for HNC's staff and board of directors to say a special thank you to those who have gone above and beyond during the past year to help support HNC's mission and vision.

Guests were treated to a buffet dinner and presentation. This year's guest speaker, Mike Sweeney, is the Program Director for Nonprofit Services of Triangle Nonprofit & Volunteer Leadership Center. Mike spoke about the impact that volunteers make on organizations like HNC and encouraged all who attended to continue to make a difference through volunteerism.

***"Alone we can do so little; together we can do so much."** - Helen Keller*

Mike Sweeney, Program Director for Nonprofit Services of Triangle Nonprofit & Volunteer Leadership Center

HNC Annual Meeting : Advocacy Matters

March 7, 2020

Charlotte, NC

The Hemophilia of North Carolina (HNC) Annual Meeting was held on March 7-8 at the Hilton Raleigh North Hills. For the first time, the Annual Meeting was a two-day conference to allow members more time to get to know one another and learn about important topics in the bleeding disorders community. This year's theme, *Advocacy: How it Can Help YOU*, provided multiple opportunities to learn about different types of advocacy, including legislative and personal advocacy, and the importance of sharing one's own story and experiences to make a difference in their own life, and the lives of other people affected by bleeding disorders across North Carolina.



Nathan Wilkes kicks off the 2020 HNC Annual Meeting with his session on Advocacy

Even with the growing concerns about the coronavirus, about 125 members checked in with HNC when they arrived on Saturday morning. To allow people time to drive in from around the state, registration was held later than has been typically scheduled in the past. Once people checked in, they had the opportunity to visit with the event sponsors, and attendees who had never attended an Annual Meeting before had the chance to learn about what to expect for the weekend at the First Time Attendees session.

Nathan Wilkes started the meeting off with a session about why advocacy is so important to the bleeding disorders community. The word advocacy is heard so frequently, but why do we do it? What does it mean? And how can we do it? By Nathan's sharing more about what it means to advocate, along with personal stories, attendees got to learn more about why it is so important for the bleeding disorders community.

Following Nathan's keynote session and lunch, attendees had the opportunity to select from a number of breakout sessions, including *Transitioning from Pediatric to Adult Care*, led by Lora Joyner from East Carolina University (ECU) Hemophilia Treatment Center (HTC), *Financial Wellness*, led by Kenton Jones from Triangle Family Services, and the *Rare Bleeding Disorders Roundtable*, led by Gillian Schultz, HNC Program Manager. *The Complementary and Alternative Therapies for Bleeding Disorders* was changed into a roundtable conversation led by Charlene Cowell, HNC Executive Director.

Following the breakout sessions, people visited the event sponsor booths, participated in the Industry Roundtable Session, and then attended the HNC Business Meeting. At the Business Meeting, the financial health of HNC was discussed along with the election of the Board of Directors for the 2020-2022 term. All nominees were elected to the Board of Directors.

After the sessions ended for the day on Saturday, a few members attended the Meet & Greet where they had the opportunity to network and get to know other HNC members in a relaxed and casual environment. Dinner was provided on Saturday evening, and then members either stayed in the hotel on Saturday night or went home for a good night's sleep before coming back on Sunday.

Sunday morning seemed extra early with the time change for Daylight Savings Time taking place while everyone slept. Following a delicious breakfast, Kimberly Ramseur from the Hemophilia Federation of America (HFA) presented *How to Talk to your Legislator*, where tips and tricks were given, as well as opportunities for some role playing. Simultaneously, a session on *Sharing Your Story* was being presented in Spanish by Patricia Espinosa-Thomson from Takeda, as part of HNC's

Continued next page

HNC Annual Meeting *continued from previous page*



The Advocacy Panel encourages members to meet with legislators to tell their story

and the importance of hearing from the people who are directly affected. This was an interactive Q&A style session with a lot of participation from the members and informative answers from the panel. Then, at lunch, Advocacy Awards were presented to HNC members who have joined HNC's advocacy efforts in Washington D.C. for NHF's Washington Days, and at the state capital for HNC's Legislative Days.

To close out the meeting, Dr. Alice Ma, from the HTC at UNC Chapel Hill presented *Current and Future Treatments for ALL Bleeding Disorders*. Starting with von Willebrand disease, then moving on to hemophilia, and the rarer bleeding disorders including rare factor deficiencies and platelet disorders, Dr. Ma shared about current treatments available. She also shared information about novel therapies for hemophilia A and B, as well as information about gene therapy. At the end of the session, she answered questions from the audience.

Children and teens were not left out of the weekend. Daycare was provided by Peak City Sitters for all ages. Children 4-12 also learned about the human body thanks to a workshop from High Touch, High Tech, they learned about identifying animals through a workshop from the Museum of Natural Sciences, they found out all about dry ice thanks to the scientists at Mad Science, and had time on a game truck. The 9-12 year olds also learned about bleeding disorders in the session, *Building Blocks and You*, led by Chelsea Frimpong from NHF. The teens participated in some of the general sessions with the adults, and learned about personal advocacy from Austin Caldwell, who is an HNC member and is part of NHF's NYLI program.



Unión Latina program. After a break and time to visit once again with the sponsors, attendees chose from one of several breakout sessions, including the Blood Brotherhood session, *Facing the Pain of Hemophilia*, presented by Myles Ganley and Hope Woodcock-Ross of Aptevo; the HOPE session, *Basics of School Advocacy*, presented by Gillian Schultz, HNC Program Manager; the SOAR session, *Advocating for Yourself as a Woman*, presented by Jasmine Paldauri from the National Hemophilia Foundation (NHF); and the Partners & Spouses Roundtable session, facilitated by Charlene Cowell, HNC Executive Director.

The Advocacy Panel at the meeting allowed attendees to hear from HNC members Tiffany Hargett and Joseppe Vilchis, along with LT McCrimmon who is the Deputy Legislative Director for Governor Roy Cooper, as they each shared their experience with advocating



They heard from young adults in the community, Austin Caldwell and Christopher Gatewood, who sat in their seats not too many years ago and had some interesting insights to share with the teens. On Saturday, the teens also took a field trip to Frankie's Fun Park where they rode the rides and played the games. Pictures of all the kids and teen activities can be found on pages 12-13 of this newsletter.

After a full weekend, everyone went home, hopefully having learned something new and meeting some new people.

HNC would like to thank the sponsors, HFA, NHF, volunteers, and members who all contributed to make the 47th Annual Meeting a success.

Dr. Alice Ma during her presentation on the Current and Future Treatments for ALL Bleeding Disorders

Actualización del Programa Unión Latina

Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés) planea proporcionar otro año de oportunidades educativas para miembros de la comunidad de habla hispana que sufren de desordenes hemorrágicos.

Les recomendamos agendar las siguientes fechas para estos eventos de la Unión Latina: 16 de Mayo en Charlotte, 1 de Agosto en Raleigh, 21 de Noviembre en Asheboro, y 5 de Diciembre en Greenville. De la misma manera también habrá una sesión de la Unión Latina durante la Reunión Anual, el 8 de Marzo. Adicionalmente el Retiro de la Unión Latina será los días 5 al 7 de Noviembre en Carolina Beach.



El Programa de Unión Latina proporciona apoyo y educación a individuos de origen latino y sus familias en Carolina del Norte, quienes son afectados por enfermedades hemorrágicas. Este programa es proporcionado en Español y es posible gracias al auspicio de Takeda. Para mas información, visite el sitio web de HNC.



Unión Latina at the HNC Annual Meeting

Donde Encontrar Valiosos Recursos Para Vivir con un Desorden Hemorrágico

Criar un hijo con un desorden hemorrágico y a la vez manejar la vida de un adulto con desorden hemorrágico puede ser un desafío muy grande. Encontrar los recursos educativos apropiados puede ayudar a que la experiencia resulte un poco mas llevadera. Una comunicación abierta con su doctor es fundamental, adicionalmente la Fundación Nacional de Hemofilia (NHF por su sigla en Inglés) ha desarrollado un sitio web que proporciona información y recursos para cada situación en su vida, llamado *Steps for Living*.

Lo mas genial de este sitio web es que toda la información allí presentada esta también en Español.



La información incluye datos básicos acerca de desordenes hemorrágicos, además de guías referente a cada etapa de la vida, como: Primeros Pasos (recién nacido a 8 años), Paso Siguiente (9 a 15 años), Un Poco Mas Allá (9 a 15 años), Siendo Adulto (16 a 25 años), y Llegando a la Cima (Adultos).

Este sitio web incluye artículos útiles para leer e incluso para imprimir, y mas! No deje de visitar stepsforliving.hemophilia.org/es/inicio.

Attention TEENS: Join the Carolina Crew this AUGUST!

August 13-16, 2020

Rock Hill, SC

The Teen Retreat is 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.

Hemophilia of North Carolina (HNC), in partnership with Hemophilia of South Carolina (HSC), is providing this fun, educational, and interactive weekend designed especially for teens in the community. If you've never been to one of the HNC/HSC Teen Retreats, please check out the HNC Facebook page for photos.

Teens will head back to Camp Canaan in Rock Hill, SC to enjoy a great weekend of fun and educational programming. This is a great opportunity for meeting friends, sharing laughs, challenging yourself, and preparing for your future.

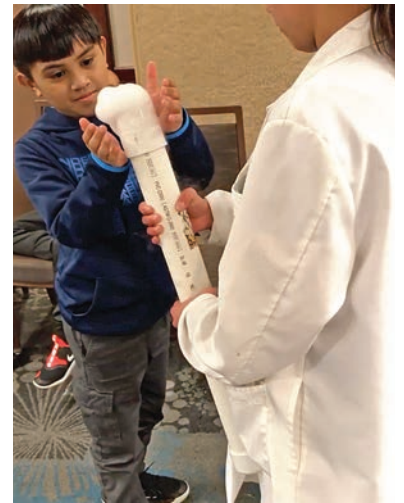
Forms for registration will be available soon on the HNC website, so be on the lookout. HNC will provide busing from the East Carolina University Hemophilia Treatment Center in Greenville and the HNC office in Morrisville.



Kids and Teens at the Annual Meeting

March 7-8, 2020

Raleigh, NC



The Kids and Teens Tracks at this year's Annual Meeting had a lot of fun (and sometimes educational) activities. Here's a peek at what the kids were up to while the adult sessions kept their parents busy.

SOAR Program Update

If you are a woman with a bleeding disorder or a mom of a daughter with a bleeding disorder, you are not alone. The Hemophilia of North Carolina (HNC) SOAR Program provides support for women with bleeding disorders. Opportunities to connect with other women around North Carolina included the SOAR breakout session at the Annual Meeting on March 8, the Adult Retreat, on June 5-7, and at the SOAR Education Day on June 27. Other programs are being looked at for later in the year. In addition, as part of the SOAR Program, HNC advocates for and raises awareness about women and girls with bleeding disorders at conferences throughout the year. In 2020, HNC is planning to exhibit at the North Carolina Nurse's Association Conference and the North Carolina Dental Hygienists Conference.

SOAR is a program of HNC for women and girls with a bleeding disorder, including those diagnosed with von Willebrand disease, hemophilia A and B, rare factor deficiencies, platelet disorders, and carriers of any of these disorders (both symptomatic and non-symptomatic). The mission is to improve the quality of life for girls and women with bleeding disorders, so that they may SOAR to their full potential.

Please contact Gillian Schultz, HNC Program Manager, for more information about the SOAR Program at soar@hemophilia-nc.org or by calling the HNC Office at (800) 990-5557.



SOAR breakout session at the Annual Meeting

SOAR Education Day for Women

June 27, 2020
Greensboro, NC

Last year, members of the community asked for more programming just for women with bleeding disorders. Hemophilia of North Carolina (HNC) was listening and has brought back the SOAR Education Day for women with bleeding disorders. Though still in the planning stages, sessions are being planned to help provide emotional and social support as well as education about managing a bleeding disorder as a woman. The event is open to all women diagnosed with a bleeding disorder, as well as carriers of a bleeding disorder, and moms of daughters with a bleeding disorder. More information will be available soon on the HNC website. If you have ideas for topics, please contact Gillian Schultz, HNC Program Manager, at soar@hemophilia-nc.org.

In the Summer Edition of *The Concentrate*

Hemophilia of North Carolina reminds you to check the summer edition of *The Concentrate* to find out about the rescheduled events with the HTC's at Wake Forest Baptist Health, UNC Chapel Hill, and East Carolina University. The summer edition will also bring you event reports from HNC's Spring Calendar of Events, and information about HNC's upcoming events scheduled for Fall 2020 -- so stay tuned!

HNC Community Connections Groups

How many people do you know in your town or city who are affected by a bleeding disorder? If you are like most people, not many, if anyone. Having a sense of community has been found to be beneficial for emotional support when managing a chronic illness or condition so that you don't feel isolated or alone.

Hemophilia of North Carolina (HNC) realizes its members are spread across North Carolina. With many of the larger events planned in the larger cities across the state (Charlotte, Greensboro, Raleigh, Winston-Salem), HNC understands that you are probably looking for support where you live. Community Connections Groups are planned to provide this support for you. They are led by Community Leaders who are HNC community member volunteers with the desire to give back. Meetings are casual, allow children to play together, and adults to chat and connect. Groups have been formed in Asheville, Lexington/Winston-Salem, and Wilmington. There are many areas of North Carolina that could benefit from a Community Connections Group. If you are interested, please contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or by calling or texting her at (919) 272-6000.



Read below about the Community Connections held in Winston-Salem on February 1:

By: Erin Otey, Community Connections Leader

On February 1st, I hosted an HNC Community Connections event in Winston-Salem. We gathered at Creekside Lanes for a good time of bowling and eating pizza. Not only was the bowling a lot of fun, it was very enjoyable to connect with other HNC members and get to know each other. I feel like Community Connection Events are a great way to strengthen the bleeding disorders community because they provide an opportunity to spend time together and share life with each other.

Interested in joining an existing Community Connections Group or starting one in your part of NC?

Contact Gillian Schultz, HNC Program Manager, for more information.

gillian.schultz@hemophilia-nc.org or (919) 272-6000

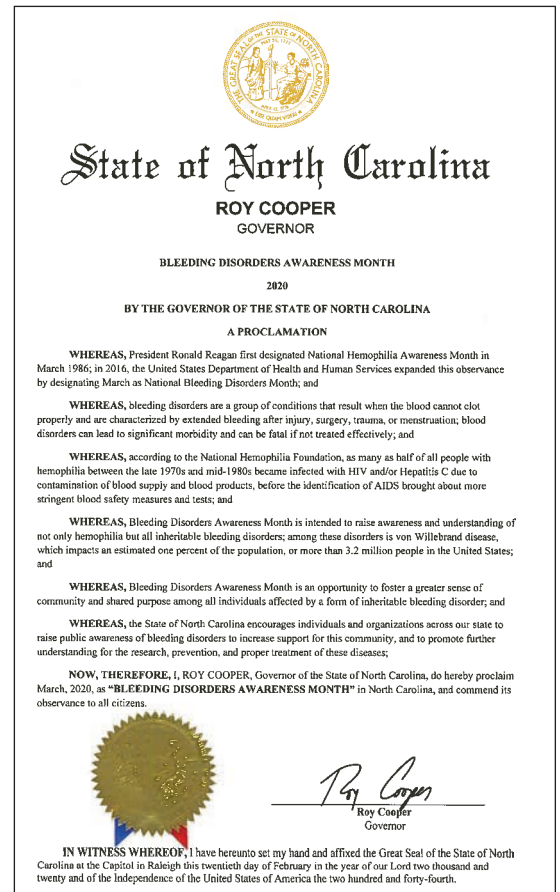
March: Bleeding Disorders Awareness Month!

Thanks to Hemophilia of North Carolina (HNC) members around the state for working with their city and state leaders to get proclamations declaring March as Bleeding Disorders Awareness Month in cities across North Carolina! In addition, Governor Roy Cooper has declared March as Bleeding Disorders Awareness Month for the state of North Carolina. We thank our state and local government leaders for their support! If you want to get a proclamation in your city for next March, please contact the HNC office to find out how.

HNC members also helped to spread the word and raise awareness for bleeding disorders throughout the month of March by sharing Hemophilia Federation of America and HNC social media posts about bleeding disorders as well as participation in the National Hemophilia Foundation Red Tie Campaign reaching thousands of people.

Although it's important to participate in the awareness opportunity that Bleeding Disorders Awareness Month provides, HNC hopes members will continue to promote awareness throughout the year.

North Carolina proclaims March as Bleeding Disorders Awareness Month



An advertisement for Genentech Hemophilia A. It features a smiling man with a beard, wearing a red vest over a dark jacket, standing in front of industrial equipment. The text reads: "The hemophilia treatments of today were once the dreams of yesterday. Proof that when SCIENCE AND THE COMMUNITY come together, great things happen." Below this is the Genentech logo and "Hemophilia A" with the tagline "A Member of the Roche Group". At the bottom, it says "Let's put science to work". A copyright notice at the bottom left reads "©2019 Genentech USA, Inc. All rights reserved. M-US-00001601(v1.0)".



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

HOPE Program Update

The HOPE Program provides support for families who have a child twelve or under diagnosed with a bleeding disorder. Activities and events are meant to support the entire family, including the parents, diagnosed children, and siblings. Growing up with a bleeding disorder is a family matter, and it affects everyone in the household. Hemophilia of North Carolina (HNC) continues to provide support for

families through educational dinners, the HOPE Family Retreat, educational resources, a private HOPE Facebook group, and the Mentoring Program. The Parent Mentoring Program provides connection with another parent who is raising a child with a bleeding disorder.

If you are looking to be connected with someone through the Mentoring Program, have ideas for events in your area, or are looking for information about a particular topic, 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

Men with a bleeding disorder have a safe place to connect and share experiences with other guys

who have a bleeding disorder in Hemophilia of North Carolina's (HNC) Blood Brotherhood Program. Throughout the year, at large meetings and smaller local events, men with a bleeding disorder can connect, learn from one another, and most importantly, have a great time.

In 2020, there are several events being planned. There was a session at the Annual Meeting about pain management. On May 3, mark your calendar for an afternoon of "therapeutic gardening" and lunch. There will also be sessions for the Blood Brotherhood at the Adult Retreat from June 5-7, and plans are in the works for an event on June 27. Stay tuned for details about each of these events and more in the coming months.

Please let us know what kind of activities and events you are looking for. As the community continues to age, and younger guys

are experiencing greater outcomes than in past generations, HNC wants to know what kinds of programs you would like to see. 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 or if you have questions.

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



Unión Latina Program Update

Hemophilia of North Carolina (HNC) is looking forward to providing another year of educational opportunities for Spanish speaking members of the bleeding disorders community. There was a Unión Latina session at the Annual Meeting on March 8. Save the dates for the following Unión Latina events: May 16 in Charlotte, August 1 in Raleigh, November 21 in Asheville, and December 5 in Greenville. In addition the 2020 Unión Latina Retreat will be from November 5-7 in Carolina Beach.

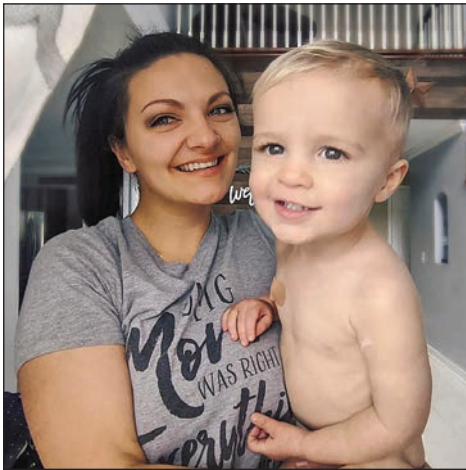
The Unión Latina Program provides support and education to Latino individuals and families in North Carolina who are affected by bleeding disorders. Programming is provided in Spanish and is possible thanks to a grant from Takeda. For more information, call, text or email Gillian Schultz, HNC Program Manager, at (919) 272-6000 or gillian.schultz@hemophilia-nc.org

Caregiver's Corner

"Caregiving often calls us to lean into love we didn't know possible." ~Tia Walker, author

HNC recognizes the dedicated, and often heroic role of the caregiver in the life of a person diagnosed with a bleeding disorder. *The Concentrate's* new Caregiver's Corner is an opportunity for caregivers in the community to share their successes and challenges with one another. If you have a story you'd like to share, please email info@hemophilia-nc.org to be included in a future edition of Caregiver's Corner.

By: Kaitlin Bartholomew, caregiver to one-year-old Carson



Kaitlin and Carson celebrate a successful infusion.

"Today we tried something different. I decided not to wrap Carson up in a blanket to see how he would do getting his factor VIII infusion. He laid down, didn't touch anything he wasn't supposed to, and took it like a champ per usual.

Also want to shine some light on Jonathon who has started infusing Carson on the days where I'm running behind and there aren't enough hours in the day. The team our boy has behind him is why he is the way he is!

This kid's courage and strength continues to amaze me every day!!!!"

Jonathon plays an important role on the caregiver team.



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

Barbara Albright
Andrew & Patricia Andrews
Richard Atwood
Daisy Bratton
Robert L. Cole
Lori Conger
Charles & Sue Cowell
Irene Cowell

Marlo Davis
Patricia Desantis
Chiqui Enierga
W. Allen & Sue Heafner
Thomas Hunter
Diane Johnston
Lynn Jones
Linda & Allen Kurtz

Phillip Poovey
Charles & Kathy Register
Doreen Sanfelici
Matthew Screpetis
Nancy Smoak
Daryl Steinbraker
Brent White

In Honor of The Hargett Family

Marlin & Barbara Hargett
Irving & Roberta Swope

In Honor of William Heafner

Susan Heafner-Heun

In Honor of Phillip Poovey

Sylvia Herbert

In Memory of Paul H. Everhart

Michael S. Everhart

In Memory of Christopher McNeill

Betty Judd

In Memory of George D. McCoy

Phillip Poovey

In Memory of Matt Speight and Honor of Branson Hurst

Cheryl H. Mendez

CARS Donation for Charity

Joseppe Vilchis

*Facebook Fundraisers**

Carla Barbee
Tammy Lee Chavis in
memory of Chris Oxendine
Laquenta Caldwell-Moody
Curtiss Reid Coleman
Steven Humes
Jecorei Lyons

**If you hold a fundraiser to benefit HNC on your Facebook page, please contact the HNC office about your donation.*

Workplace Giving, Another Way to Give Back

Are you a state employee or does your employer offer an employee giving program?

For State Employees:

If you are interested in making Hemophilia of North Carolina (HNC) your designated charity, North Carolina state employees can opt to make contributions directly to HNC through a direct payroll deduction providing state employees and retirees an opportunity to choose how to direct their charitable contributions. Use SECC Code 1033 to choose HNC.

For Private Employers:

Check to see if Hemophilia of North Carolina (HNC) is an option for you to specify as your charity of choice through your workplace giving program, or choose United Way and designate Hemophilia of North Carolina as your United Way Campaign recipient charity.

If neither of these are options for you, please let your employer know that you want to add HNC to the available selections. HNC staff will be available to work with you and your employer throughout this process.



Space may still be available for these 2020 Summer Camps. Please follow instructions listed for each camp to access applications. Camps fill up quickly and campers are usually accepted on a first-come, first-served basis, so get your applications in as soon as possible to secure your spot.

Victory Junction Camp in Randleman, NC

Applications for 2020 camps are now open! For information on how to register for Summer Sessions (below) or about Victory Junction's Family our Young Adult Weekends, go to www.victoryjunction.org or call (336) 498-9055.

June 21-25, 2020 *Bleeding and Gastrointestinal Disorders*

June 28-July 1, 2020 *Neurological and Genetic Disorders*

Camp Carefree in Stokesdale, NC

Applications for 2020 camps opened in February. You can follow Camp Carefree on Facebook for announcements.

For additional information about Camp Carefree, the services they provide year-round, or to find out more about the Camp Weeks listed below, go to www.campcarefree.org, email directors@campcarefree.org, or call (336) 427-0966.

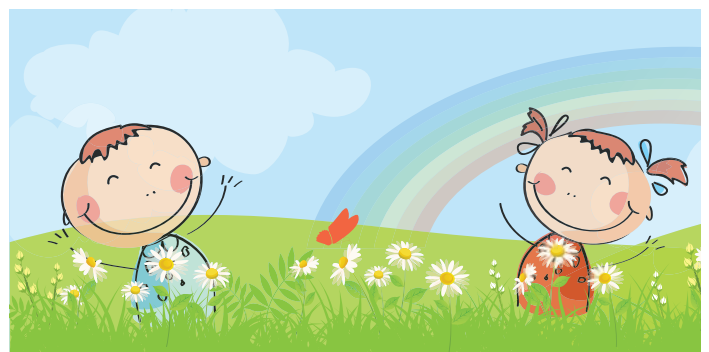
June 21-27, 2020 *Siblings Camp – well children with a chronically ill sibling*

July 19-25, 2020 *Kids Camp – well children with a chronically ill parent*

July 26-August 1, 2020 *Hemophilia, blood disorders, vWD & Turner's Camp*

Camp Rainbow at Camp Don-Lee in Arapahoe, NC

Camp Rainbow is available to patients of the East Carolina University Hemophilia Treatment Center (ECU HTC) in Greenville, NC. For information about Camp Rainbow or to find out if space is still available in the Summer Session this year, please call the ECU Hemophilia Treatment Center at (252) 744-4676, email Jacquelyn Sauls at saulsj@ecu.edu, or visit their website at www.ecu.edu/cs-dhs/pediatrics/Pediatrics-Camp-Rainbow.cfm



Both National Bleeding Disorders Organizations Select New President & CEO

Congratulations to both the Hemophilia Federation of America (HFA) and the National Hemophilia Foundation (NHF) for the selections of their new Presidents and CEOs.



Hemophilia Federation of America (HFA)

Sharon Meyers, M.S., CFRE is not new to HFA. She was serving as the interim CEO prior to being selected as the new CEO & President. She has over 15 years of healthcare and nonprofit leadership experience at the local, state, regional and national level, most recently as part of HFA's leadership and advancement team for the past four years. You can read more about Ms. Meyers in the article from January 2, *Hemophilia Federation of America Chooses Interim President and CEO to Lead the Charge*, on the News & Perspectives page of hemophiliafed.org.



National Hemophilia Foundation (NHF)

Dr. Leonard A. Valentino will be the next President & CEO of the NHF. He brings more than 35 years of research and clinical experience including work with Spark Therapeutics and the Hemophilia and Thrombophilia Center at Rush University Medical Center in Chicago. Under the leadership of Dr. Valentino, the NHF will continue to be at the forefront of education, advocacy, and research. You can read more about Dr. Valentino in the article from January 17, *National Hemophilia Foundation Announces Next CEO*, on the NHF & Community News page of hemophilia.org.

HNC Grant to Attend NHF Bleeding Disorders Conference in Atlanta

August 6-8, 2020
Atlanta, GA



Hemophilia of North Carolina (HNC) is still accepting applications for travel grants to attend this year's National Hemophilia Foundation (NHF) Bleeding Disorders Conference in Atlanta, GA, August 6-8, 2020.

Time is running out to take advantage of this wonderful opportunity to meet other families and learn from the experts from around the country, so don't miss out on your chance to attend this exciting conference.

HNC's grants may be used for event registration fees, transportation, lodging, and/or incidental expenses. Additional details and a grant application form can be found on the HNC website or requested by calling the HNC office at (800) 990-5557.

HNC Scholarship Deadline is May 1 – Apply Now!



Hemophilia of North Carolina (HNC) offers two scholarship programs for members of the bleeding disorders community nationwide. The application deadline is May 1. Contact the HNC office or visit the HNC website for an application or if you need more information.

The George D. McCoy Education Scholarship will award one recipient who is diagnosed with severe hemophilia A with a \$1,000 scholarship. The application deadline is May 1. Contact the HNC office or visit the HNC website for an application and more information.

The Diplomat Specialty Infusion Group/Hemophilia of North Carolina Education Scholarships allow for multiple awards ranging from \$500 to \$3,000. Candidates are persons affected by a bleeding disorder including anyone who: has been diagnosed with a bleeding disorder; is a caregiver of a child or adult affected by a bleeding disorder; has a sibling or a parent in the same household affected by a bleeding

disorder. At least one scholarship will be awarded to an applicant pursuing education in a health-related field.

The following resources can also help members find a variety of scholarship opportunities. Application deadlines will vary for each scholarship:

Beth Carew Memorial Scholarship from Colburn Keenan Foundation: visit www.colkeen.org

Hemophilia Federation of America: visit www.hemophiliafed.org/for-patient-families/resources/educational-scholarships-internships/

Hemophilia of North Carolina: visit www.hemophilia-nc.org/scholarships

LA Kelley Communications, Inc.: visit www.kelleycom.com/scholarships/

National Hemophilia Foundation: visit www.hemophilia.org/Community-Resources/Scholarships

2020 Washington Days Experience

By: Ahmed Al Badri, HNC member

My name is Ahmed Al Badri. I was born in Iraq with bleeding disorder (hemophilia A). Not just me, I have older brother with same disease. It wasn't a surprise because I have six uncles and 3 of them have hemophilia. Living in a country with big lack of education and information about hemophilia wasn't easy for my family. I could tell how much my parents suffered from that. I remembered when they spent days watching us when we had bleeding like as any other parents, they did everything to raise us with less bleeding. I moved to US – Charlotte, NC – in 2013 and became a member in Hemophilia of North Carolina (HNC) which made a huge difference in my new life. Moving to different country, culture and language weren't easy to me plus my bleeding disorder. Participating in HNC activates made big impact in my new life. I always hear about the National Hemophilia Foundation (NHF) Washington Days and hoping I will be able to attend one day.



Finally, I'm here in Washington D.C. with 460 advocates from around the country. We made eight meetings including Senators Burr and Tillis. It was an awesome experience for me. Walking in the hall and see a lot of signs with senators' and representatives' names. I felt comfortable and happy when saw a lot of representatives, senators, and aides who care about the bleeding disorder community. With their busy days, they have time to listen and write notes about what we want or ask. Being in Washington D.C. days for advocacy is very important for our bleeding disorders community for many reasons. One reason is to address our health issues to the government and follow up with them. Second of these reasons is to meet new folks from different states and make new friends from our bleeding community.

I just want to thank everyone who involved making this happen to me. NHF and HNC and all staff who is working in these organizations and are really doing a great job to HELP people with bleeding disorders. They are working to keep our voice heard and make a better life for bleeding disorder people.

You all are making a history for hemophilia people not in US only but for around the world.

Deep thanks from my heart.

Love you all

Ahmed

Continued next page

2020 Washington Days Experience *continued from previous page*

2020 NHF Washington Days “Asks”

This year’s Washington Days event focused on these important “asks”. Even if you didn’t go to Washington Days, the community needs your help with reaching out to representatives and senators across the country to express the importance of these two “asks”. Interested in helping? Call the Hemophilia of North Carolina (HNC) office for help drafting an email that you can share with your representatives.

1. Both the House (HR 5952) and Senate (S. 3233) introduced legislation that has the potential to end a longtime issue that the bleeding disorders (BD) community has faced. Skilled Nursing Facilities (SNFs) provide care for people that require medically appropriate care, especially after surgery or being hospitalized. SNFs receive a daily rate (per diem) for each patient under Medicare Part A. As we know, BD medication can be very costly. Most SNFs will not take patients with BDs because the costs of medication far exceeds that of the per diem provided by Medicare. This legislation would allow BD medication to be billed separate from the per diem given to SNFs, eliminating this barrier so that patients can get the care they need in order to heal properly in an appropriate setting.
2. Three federal programs rely on funding to continue their crucial work on behalf of the BD community: Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), and National Institutes of Health (NIH). As examples, the CDC conducts surveillance and prevention on blood safety. HRSA helps cover Hemophilia Treatment Center (HTC) services that aren’t typically covered by insurance, like physical therapy and social work. The NIH is working on research that may eradicate inhibitors. It’s important that the community remind representatives and senators of the significance of the work being done at the federal level for the BD community and ask that they support the funding required to make these programs possible.

Advocate for People with Bleeding Disorders in Raleigh

June 15-16, 2020
North Carolina Legislature
Raleigh, NC

Everyone has an important story to share, and that story is yours! Find out just how easy it is to tell your story to your state representatives and be an advocate for people with bleeding disorders by joining Hemophilia of North Carolina (HNC) at the state Legislative Day on June 16, 2020.

It is important to have as many members from around the state as possible participate and connect with their North Carolina state legislators. Members will visit their representatives in small groups, so even if it’s your first time, you’ll have the support of others when you meet with your representatives. By sharing your own story of how living with a bleeding disorder impacts you and your family, you become an advocate for others in the community so that legislators will consider the bleeding disorders community when making important decisions on behalf of residents in their district.

In addition to the Legislative Day on June 16, there will be a training dinner on Monday, June 15 at the Hampton Inn & Suites Raleigh Downtown, to help prepare you to speak with your legislators the following day. Then, on Tuesday, June 16, HNC will have a booth at the Halifax Mall to help raise awareness among legislative staff and the general public. The Halifax Mall is located between the two legislature buildings. There is a lot of foot traffic which will provide an excellent opportunity to raise awareness.

Additional information and registration forms will be available on the HNC website in late April. A limited number of hotel rooms will be available for attendees who have to travel from outside the Raleigh area. If you have questions or are interested in attending, please contact the HNC Office at (800) 990-5557 or info@hemophilia-nc.org.



HNC Advocates meet with NC State Senator Sam Searcy at the 2019 Legislative Day

Hemophilia of North Carolina 2020 Calendar of Events Highlights



<u>Postponed</u>	Family Festival & Walk for Bleeding Disorders – Charlotte, NC
<u>Postponed</u>	HFA Symposium – Baltimore, MD
<u>Cancelled</u>	Fishing Event – Charlotte, NC
<u>May 3, 2020</u>	Blood Brotherhood Event – Chapel Hill, NC
<u>May 16, 2020</u>	Unión Latina – Charlotte, NC
<u>June 5-7, 2020</u>	Adult Retreat – Lake Junaluska, NC
<u>June 15-16, 2020</u>	Legislative Day – Raleigh, NC
<u>June 27, 2020</u>	SOAR Education Day – Greensboro, NC
<u>June 27, 2020</u>	Blood Brotherhood Event – Location TBA
<u>July 11, 2020</u>	Medical Symposium – Chapel Hill, NC
<u>August 6-8, 2020</u>	NHF Bleeding Disorders Conference – Atlanta, GA
<u>August 13-16, 2020</u>	HNC/HSC Teen Retreat – Rock Hill, SC
<u>August 29, 2020</u>	VWD Education Day – Greensboro, NC
<u>September 11-13, 2020</u>	HOPE Family Retreat – Concord, NC
<u>October 17, 2020</u>	Family Festival & Walk for Bleeding Disorders – Morrisville, NC
<u>November 6-8, 2020</u>	Unión Latina Retreat – Carolina Beach, NC
<u>November 21, 2020</u>	Unión Latina – Asheboro, NC
<u>December 5, 2020</u>	Unión Latina (en la celebración navideña) – Greenville, NC
<u>December 5, 2020</u>	Holiday Celebration – Greenville, NC



Explore HEAD-TO-HEAD

Pharmacokinetic (PK) Study Data

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

Visit **PKStudies.com** to find out more.

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



©2020 Bayer. All rights reserved. All trademarks are the property of their respective owner. Printed in the USA 01/20 PP-JIV-US-1009-1





HEMOPHILIA OF NORTH CAROLINA

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

(800) 990-5557 • info@hemophilia-nc.org

www.hemophilia-nc.org

NONPROFIT ORG

U.S. POSTAGE

PAID

CARY NC 27511

PERMIT NO. 830

Change Service Requested

AmazonSmile: SUPPORTING HNC HAS NEVER BEEN EASIER



If you shop online, use AmazonSmile and turn your purchases into a donation to HNC!

AmazonSmile works just like Amazon, but by signing in through smile.amazon.com, and selecting Hemophilia of North Carolina as your charity, Amazon will donate

0.5% of the purchase price from your eligible AmazonSmile purchases to HNC. Find out more about AmazonSmile and how to register by visiting: smile.amazon.com/about

No matter when you're shopping online, if you use

smile.amazon.com/ch/56-1273974

AmazonSmile donates to Hemophilia of North Carolina!