Connecting with Others in the Bleeding Disorders Community

Hemophilia of North Carolina (HNC) is thrilled to announce that the 2019 Raleigh Family Festival & Walk will be back at Lake Crabtree Park and back to its customary October date – October 12!

The Family Festival & Walk is HNC’s biggest fundraiser. It is also a day of family-oriented fun that builds and strengthens the community of people affected by bleeding disorders in North Carolina. Great food, music, games, crafts, and more will be on hand for all to enjoy. Visit

In this Edition:

<table>
<thead>
<tr>
<th>Event Type</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>UPCOMING EVENTS</td>
<td>4</td>
</tr>
<tr>
<td>RECENT EVENTS</td>
<td>7</td>
</tr>
<tr>
<td>SUPLEMENTO DE LA UNIÓN LATINA</td>
<td>11</td>
</tr>
<tr>
<td>SOAR SUPPLEMENT</td>
<td>12</td>
</tr>
<tr>
<td>OUR YOUNG VOICES</td>
<td>13</td>
</tr>
</tbody>
</table>

Save The Date

<table>
<thead>
<tr>
<th>Event Name</th>
<th>Location</th>
<th>Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>HNC/HSC Teen Retreat</td>
<td>Rock Hill, SC</td>
<td>June 29 - July 2</td>
</tr>
<tr>
<td>Union Latina Retreat</td>
<td>Winston Salem, NC</td>
<td>July 13-14</td>
</tr>
<tr>
<td>CHES MUM: Moms Uninhibited Meeting</td>
<td>Santa Fe, NM</td>
<td>July 18-21</td>
</tr>
<tr>
<td>CHES Ladybugs</td>
<td>Santa Fe, NM</td>
<td>July 19-21</td>
</tr>
<tr>
<td>CHES Momentum Men’s Inhibitor Retreat</td>
<td>Santa Fe, NM</td>
<td>July 19-21</td>
</tr>
<tr>
<td>Educational Dinner</td>
<td>Greenville, NC</td>
<td>July 25</td>
</tr>
<tr>
<td>Blood Brotherhood Retreat</td>
<td>Pine Knoll Shores, NC</td>
<td>July 26-28</td>
</tr>
<tr>
<td>NHF Inhibitor Summit</td>
<td>Boston, MA</td>
<td>August 1-4</td>
</tr>
<tr>
<td>Raleigh Festival Team Captain Meeting</td>
<td>Morrisville, NC</td>
<td>August 3</td>
</tr>
<tr>
<td>Family Day Out</td>
<td>Clemmons, NC</td>
<td>August 17</td>
</tr>
<tr>
<td>Union Latina Event</td>
<td>Asheville, NC</td>
<td>August 24</td>
</tr>
<tr>
<td>Educational Dinner</td>
<td>Asheville, NC</td>
<td>August 30</td>
</tr>
<tr>
<td>Family Retreat</td>
<td>Concord, NC</td>
<td>September 7-8</td>
</tr>
<tr>
<td>NHF Annual Meeting</td>
<td>Anaheim, CA</td>
<td>October 3-5</td>
</tr>
<tr>
<td>Raleigh Family Festival &amp; Walk</td>
<td>Morrisville, NC</td>
<td>October 12</td>
</tr>
</tbody>
</table>

Raleigh Festival & Walk: Back to Lake Crabtree Park this October!

October 12, 2019
Lake Crabtree Park, Morrisville, NC

Hemophilia of North Carolina (HNC) is thrilled to announce that the 2019 Raleigh Family Festival & Walk for Bleeding Disorders will be back at Lake Crabtree Park and back to its customary October date – October 12!

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Continued page 10

Continued page 6

Community Connections gathering in Asheville on May 19

Connecting with Others in the Bleeding Disorders Community

HNC Community Connections provide small, casual gatherings across the state for anyone affected by bleeding disorders and their family members. The Community Connections Leaders are HNC members who are committed to giving back to the bleeding disorders community so that no one has to feel alone. Community Connections allow children to play

Having a bleeding disorder is tough. Whether well-managed with few to no complications, frequent bleeds, mild or severe disease, hemophilia, von Willebrand disease, platelet disorders, or other rare factor deficiencies; the effects of a bleeding disorder on an individual and family is hard. Having a COMMUNITY can help to ease some of the feelings of isolation and provide emotional support. That is where the Hemophilia of North Carolina (HNC) Community Connections can help!
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.

**MISSION STATEMENT**

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.

**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 (Collect)
www.healthcharities.org

**Resource Information**

National Hemophilia Foundation
www.hemophilia.org

Hemophilia Foundation of America
www.hemophiliafed.org

American Society of Pediatric Hematology/Oncology
847-275-4716
www.aspho.org

Centers for Disease Control & Prevention
1-800-311-3435
www.cdc.gov

Coalition for Hemophilia B
1-212-520-8272
www.coalitionforhemophiliab.org

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

Committee of Ten Thousand (COTT)
1-800-488-2688
www.cott1.org

LA Kelley Communications
1-978-352-7657
www.kelleycom.com

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

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

Patient Services Incorporated (PSI)
Assists persons with chronic medical illnesses in accessing health insurance and pharmacy co-payment assistance.
1-800-366-7741
www.uneedpsi.org

World Federation of Hemophilia
1-800-520-6154
www.wfh.org

**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**

**Hembry 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

**Hemophilia Federation of America**

(800) 230-9797
www.hemophiliafed.org

**American Society of Pediatric Hematology/Oncology**

847-275-4716
www.aspho.org

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Event Registration and Attendance Policy

Have you read Hemophilia of North Carolina’s (HNC) Event Policy recently? This policy was developed to help make sure that HNC resources are used effectively and efficiently. To summarize the Event Policy, all HNC events and activities (except for fundraisers) are offered free to all attendees, including food, overnight accommodations if applicable, and activities. HNC pays for these events with the support of its sponsors, fundraising events, and contributors, and most costs are charged on a per-person basis. In order to ensure that resources are used efficiently, the Event Registration and Attendance Policy describes what is expected when you register for an event. From who is given priority when registering and what happens if you are unable to attend an event that you have registered for, the policy details different scenarios. Every time you register for an event, you must agree to the Event Policy.

Why is this policy important?

Did you know that for a two-night event, like the Adult Retreat, the cost per person may be around $400? Most venues require that HNC provides their final guaranteed number of attendees for catering up to five days before and for hotel rooms sometimes weeks before the event takes place. When someone cancels at the last minute, or does not show up to an event, HNC still has to pay for those attendees, even if they are not there.

Please help HNC to be able to use its resources wisely and efficiently. When you register for an event, please take the time to read the Event Policy in full. If your plans change and you will not be able to attend an event, please make every effort to inform HNC ahead of time so that the resources are not wasted, and can be used in the best ways possible.

HNC Needs YOUR Input to Plan for 2020 and Beyond!

Hemophilia of North Carolina (HNC) is always looking at how to best serve the bleeding disorders community in North Carolina.

• Are the programs offered effective?
• Are you interested in the events that are offered?
• What is being done well and what should change?

All of these questions are essential in sustaining an organization that is dedicated to supporting its community.

In the next several months, HNC will be rolling out a Needs Assessment. While you likely receive many survey requests in your mail and email, please make this Needs Assessment a priority. HNC staff really needs your input in order to plan for the next decade! HNC will make announcements through email and social media to alert you to the Needs Assessment being sent out, so please be on the lookout for this information. When you receive the Needs Assessment, please take some time to complete it and return it to HNC. This not only helps HNC to carry out its mission, but it will help all members, so that their needs will be met for years to come.

Updates on the Board

Since the last Concentrate publication, there have been some updates to the Hemophilia of North Carolina (HNC) Board of Directors. Kelly Cribbs, announced as HNC’s next President beginning on July 1, 2019, had to step down for personal reasons. The board has nominated Steven Humes as HNC’s incoming President (July 1). Steve brings 11 years of experience with the HNC board, as well as many more years as the Regional Coordinator for the Region IV-North Hemophilia Treatment Center Network. Steve has recently retired from this position, adopted a dog, and recommitted himself to the bleeding disorders community in this new role.

In addition, Phil Poovey, who was announced in the last Concentrate as joining the board on July 1, will become HNC’s Vice President. While new to the board, Phil has been involved with HNC for more than 30 years.

Both Phil and Steve have a passion to serve HNC and those living with bleeding disorders. They have been in the community long enough to have seen significant changes in many respects. They’ve seen the growth of HNC, the advancement of treatment, the movement to support people with all bleeding disorders, and they are committed to the cause. There is no doubt that this dynamic duo, along with the rest of the dedicated board members, will continue working with HNC staff to meet the ever-changing needs of the community.
Union Latina Retreat
July 13-14, 2019
Winston-Salem, NC

The second annual Latin Union Retreat will be held from July 13-14 at the Hawthorne Inn & Conference Center in Winston-Salem. The weekend will feature education, networking, and fun with programming entirely in Spanish. Accommodations will be provided on Saturday night along with lunch and dinner on Saturday, and breakfast and lunch on Sunday. Hemophilia of North Carolina (HNC) will be providing gas cards to help members attend the Retreat. If other travel assistance is needed, please contact the HNC office so arrangements can be made.

We encourage all HNC members who are native Spanish speakers to attend this event. It will provide an opportunity to get to know other Spanish speaking HNC members in a supportive environment. The registration deadline has passed, but if you are interested in attending, please contact HNC at events@hemophilia-nc.org or by texting Gillian Schultz, HNC Program Manager at (919) 272-6000 to find out if space is still available.

Talk to your doctor to see if ADVATE® may be right for you.

For more information, please visit www.ADVATE.com
Join Fellow Blood Brothers at the Beach

July 26–28, 2019
Pine Knoll Shores, NC

Adult men (18+) with a bleeding disorder are invited for a weekend at the Trinity Center in Pine Knoll Shores on the Crystal Coast of North Carolina for the Blood Brotherhood Retreat. This event is open to men with a bleeding disorder and will feature a casual social agenda with time to get to know each other, make connections, meet new members of the community, or catch up with old friends.

Some of the planned activities include an evening campfire, a beachside picnic, roundtable discussions, and free time at the beach. The Trinity Center is just steps away from the beach with modest accommodations including guest rooms with private bathrooms and air conditioning. Meals and accommodations, along with sheets and towels, are provided for the weekend at no cost to attendees. Please register online at hemophilia-nc.org or by contacting events@hemophilia-nc.org before July 10 to reserve your spot.

SAVE THE DATE: Upcoming Educational Opportunities Across the State

Hemophilia of North Carolina (HNC) will be traveling across the state this summer with several educational opportunities.

IN GREENVILLE:
On July 25, HNC will head east to Greenville for a program in collaboration with CSL Behring and Realo Specialty Pharmacy, Back to School, 504 Plans in Your School, as families prepare for the upcoming school year.

IN CHARLOTTE AND RALEIGH:
In the spirit of preparing to go back to school, HNC will partner with Sanofi Genzyme in August for a CoRe conversation, Setting Educational Expectations in both Charlotte & Raleigh.

IN ASHEVILLE:
On August 30, HNC will travel west to Asheville and partner with CSL Behring and Drugco for an “On the Road Series” where attendees will learn about living with a bleeding disorder and all HNC has to offer the community.

All educational opportunities are free to the bleeding disorders community. For more information and registration for these events, please visit the HNC website, www.hemophilia-nc.org, email events@hemophilia-nc.org, or call the HNC office at (800) 990-5557.

Summer Fun for the Family

August 17, 2019
Clemmons, NC

Finish out the summer with some fun in the sun by coming out for the 4th Annual Hemophilia of North Carolina (HNC) Family Day Out at Tanglewood Park and Aquatic Center in Clemmons, NC.

At this event, people who attend can connect with others in the bleeding disorders community while also hearing more about upcoming events and opportunities to get involved at HNC. Regardless of your relationship to the community, this is a wonderful opportunity to meet and mingle with other families from across the state. The day includes lunch, games, and (optional) tickets to the Aquatic Center to swim, splash, enjoy the winding river, or take a turn on the water slides.

Registration is open on the HNC website through Monday, August 12, so please register today and be sure to specify whether or not you plan to visit the Aquatic Center. Tanglewood Park also features playgrounds, hiking trails, horse stables, pedal boats, and tennis courts. Members who wish to participate in these additional activities are encouraged to contact the park directly about fees and availability.
the HNC website to register as a participant or volunteer, form your walk team, and start fundraising today!

Want to get involved?

• Registration is now open, so please visit the HNC website and register today!!

• Start a team! Ask friends and family to support you and HNC by asking them to join your Walk Team. Free team t-shirts are available for teams that raise at least $150 by September 13.

• Attend the Team Captains Meeting in Morrisville on Saturday, August 3!

• Join the Raleigh Festival & Walk Planning Committee.

• Sign up to volunteer at the festival as an individual or with an organization you belong to (church, school, professional, company, etc.).

• Not sure how to get involved? Contact the HNC office for more information.

Help HNC reach its fundraising goal of $120,000 which supports HNC programs and services. Those needing more information can visit the HNC website or call the office at (800) 990-5557.

Family Retreat Returns to the Great Wolf Lodge

The Hemophilia of North Carolina (HNC) Family Retreat will be returning to the Great Wolf Lodge in Concord from September 7-8. Families who have a child or children with a bleeding disorder, ages 12 and under, are invited to attend. There will be a mixture of educational programming and free time to build relationships with other families, while enjoying the waterpark at the Great Wolf Lodge and other optional activities offered.

Year after year, members remark on how valuable this event is in helping them to manage their child’s bleeding disorder. All families, whether already connected or new to the community, can benefit from the ability to bond with fellow community members.

More information will be available in July. Registration will be required. Priority registration will be given to families who have a child or children age 12 or under diagnosed with a bleeding disorder.

Raleigh Festival & Walk: Back to Lake Crabtree Park this October!

continued from page 1

260 Town Hall Dr., Suite A, Morrisville, NC 27560 • (800) 990-5557 • info@hemophilia-nc.org • www.hemophilia-nc.org
Have you ever thought about climbing mountains? For some people with a bleeding disorder, the answer is probably no. But having severe hemophilia B didn’t stop Chris Bombardier from reaching for his dreams, and climbing the seven summits. In 2017, Chris partnered with filmmaker James Patrick Lynch and Believe Limited to document his journey to the top of Mount Everest! On November 2, join Hemophilia of North Carolina (HNC) for a special screening of the documentary Bombardier Blood. More information will be available in the coming months.

World Hemophilia Day Celebration in Charlotte

April 16, 2019
Charlotte, NC

Hemophilia of North Carolina (HNC) and Hemophilia of South Carolina (HSC) partnered together for a celebration of the 29th World Hemophilia Day, in Charlotte, NC. The evening began with a buffet dinner at the Embassy Suites Uptown Charlotte, followed by an activity led by Sanofi-Genzyme, Project Gratitude. This hands-on activity had individuals and families creating “Gratitude Trees” where they wrote down what they are grateful for on leaves that they could hang on the tree. Following the gratitude tree activity, everyone was encouraged to participate in the “21 Day Gratitude Challenge” where positive things and gratitude are written down in a special journal.

As the celebration this year fell on the eve of World Hemophilia Day, attendees were encouraged to wear red the following day and to come back to Uptown Charlotte to view the buildings lit up red. A special thanks to Childress Klein (Duke Energy Building), Cushman Wakefield, The Spectrum Companies, Tier REIT, Cousins Properties, Foundry Commercial, NASCAR, and Skyhouse Uptown for lighting it up red on World Hemophilia Day. And thank you to HNC member, Ryan Griffith, for his efforts to make it possible for so much of the Charlotte skyline to be lit up red to support raising awareness for people with bleeding disorders.

HNC and HSC are both grateful to the community in which they support. In addition, World Hemophilia Day provides the opportunity to raise awareness about bleeding disorders around the world. It is not known exactly how many people around the world have a bleeding disorder, but it is estimated that 75% of those people do not have access to adequate treatment and care. With all the challenges that are faced here in the United States surrounding healthcare and treatments for bleeding disorders, we are grateful to have the opportunities that many around the world do not have.
The sun rose on Uptown Charlotte on a beautiful Saturday morning. Mint Street in front of the Charlotte Knights BB&T Ballpark and Romare Bearden Park came alive as Hemophilia of North Carolina (HNC) members, volunteers, vendors, and participants came together to celebrate the 5th Annual Charlotte Family Festival & Walk for Bleeding Disorders.

With 400 people in attendance, HNC members and supporters spread awareness through the streets of Uptown Charlotte as they gathered in the event area and walked through the neighborhood attracting members of the local community to stop by to learn more about HNC and the community it serves.

It was a real nail-biter in the days leading up to the event to see if the $70,000 fundraising goal would be reached. In the final day, it was not only reached but surpassed with a total amount raised of more than $73,000! All of which will go towards supporting the many programs and services that HNC provides year-round.

There was plenty of fun at this year’s Festival with spin art, tabletop games, sand-art, face-painting by Stacy Ferguson, balloon art by Twist the Balloon Man, photo strips thanks to Fun Mugs Photo Booth, and music courtesy of Performance DJ. Kids at the Festival also had a chance to enjoy the basketball shoot-out activity area and a chance to win in a drawing for some great prizes.

Nobody left hungry with in-kind donors generously providing plenty of great treats for everyone to enjoy. Popcorn and ice-cream were donated by Marble Slab Creamery, and donated beverages included coffee from Starbucks and water from Pepsi.

Other food included pastries from Nova’s Bakery, bagels, fruit, granola bars, pizza, sandwiches from Will’s Doggn’ It Deli, and BBQ sandwiches from Sweet Lew’s BBQ. And of course, our four-legged friends enjoyed their own doggie treat bags thanks to HNC Program Manager, Gillian Schultz.

Carolyn Bruck, morning anchor, WCNC, got the festivities started while Jecoreiography and Performance DJ kept the crowd moving. HNC once again awarded the King, Queen, and Jr. Droplet awards to three people in the community who made a great effort to support the event and made special contributions to the Festival this year. Congratulations to this year’s Droplet winners Ryan Griffith, Jama Fleming, and William Hodges for their dedication to HNC and the Charlotte Family Festival, and thank you to Janice Anderson for making the winners’ sashes.

This year’s Hospital Cup challenge was neck and neck right up to the start of the event with Team Levine HTC edging out St. Jude Affiliate HTC for the first time. What made it extraordinary was that together the two Charlotte treatment centers raised a combined $3,515 and only $5 separated the two centers’ final fundraising totals. It wasn’t only the Hospital Cup competition that was too close to call until the final days with the top four teams battling for the top spot. In the end, Zackary and the Factor VIIIs surpassed the others with a final fundraising total of $4,075 with team Will Power right behind them raising an amazing $3,863. South Cows in Charlotte ($3,432) and Team G-Man ($2,025) completed the top four teams with the two HTC teams following close behind for fifth and sixth. In fact, the top six teams at this year’s Charlotte Family Festival & Walk for Bleeding Disorders raised a staggering total of $16,910! Congratulations to all members of these dedicated teams.

Continued next page
With the Walk complete, and lunch served, it was time for the raffle prize drawing. One lucky adult went home with a $100 Amazon Gift Card, while others won drawings for Charlotte Knights Baseball Prize Pack, 4 one-day passes to Daniel Stowe Botanical Gardens, or one of three Thirty-One Gift Baskets. Kids also had a chance to win raffle prizes including a Charlotte Hornets Frank Kaminsky autographed photo, Paw Passes to Great Wolf Lodge, or AMC Movie Passes. Finally, a raffle drawing for those who stopped by the tent of the Presenting Sponsor, Grifols, to find out the answer to a special trivia question. For a chance to win a $15 BP gas card, participants had to have the correct answer to how many Starbursts were in the HNC Piggy Bank. The answer: 80.

HNC would like to extend a special thanks to everyone who played a part in making this event a success. Without the support of every member, sponsor, volunteer, donor, and contributor, none of this would have been possible. Please visit the HNC website for a complete list of sponsors. It is inspiring to see this event growing each year, which allows HNC to continue meeting the mission of supporting the NC bleeding disorders community.

To see pictures and video clips of the event, please visit our Facebook page www.facebook.com/HemophiliaNC. More photos and videos will be added as they continue to roll in. If you aren’t already a page member, simply “like” us and continue to see HNC news, events, and pictures throughout the year.

SAVE THE DATE: Join us for the 12th Annual HNC Family Festival & Walk for Bleeding Disorders at Lake Crabtree Park in Morrisville on October 12, and the 6th Annual HNC Family Festival & Walk for Bleeding Disorders in Uptown Charlotte on April 18, 2020!
HTCs Gather from Around the Region
April 28-30, 2019
Ft. Lauderdale, FL

It was hard to believe another year had passed and was time again for the annual Southeast Region Hemophilia Network Technical Assistance and Training Meeting. Hosted in sunny Ft. Lauderdale, FL, this conference brought together all of the Hemophilia Treatment Centers (HTC) and Chapters from the Southeast region. Even with the beautiful weather, the agenda was jam-packed with a lot of great sessions, so nobody seemed to mind being indoors. In addition to sessions led by experts in the field, there were interactive sessions that allowed attendees to mingle with hematology staff from centers across the region.

Hemophilia of North Carolina (HNC) was represented by Charlene Cowell, Executive Director, who always finds the sessions and opportunities to connect with the HTCs to be invaluable. There have been many changes in the bleeding disorders community, including treatment options and the challenges of pain killers and mental health. By being present at conferences like these, HNC is able to hear from the provider’s perspective, understand what the HTCs are working on, and look for new ways to partner together.

Connecting with Others in the Bleeding Disorders Community
continued from page 1

Community Connections are being formed in several cities and towns across North Carolina, including Asheville, Wilmington, Mocksville, Lexington, Sanford, and Charlotte. Read more below about two of the Community Connections events that took place on May 18 and 19 in Leland, NC, and Asheville, NC. If you are interested in finding out more or would like to start a Community Connections group in your area, please contact Gillian Schultz, HNC Program Manager at events@hemophilia-nc.org or call or text (919) 272-6000.

Community Connections in Asheville:
HNC members in the Asheville area gathered for a picnic dinner in the park on May 19. Everyone met someone new and it was great to share stories among different generations within the bleeding disorders community. The kids all had a blast playing together and enjoyed the playground. They are looking forward to meeting again in a few months!

Community Connections in Leland:
Several HNC members got together and enjoyed great conversation and a delicious BBQ lunch at Brunswick River Park overlooking the Cape Fear River. It was a really nice day!
Actualization del Programa Unión Latina

El Programa Unión Latina de Hemofilia de Carolina del Norte (HNC por sus siglas en Ingles), sigue con su constante apoyo a la población de habla Hispana a través de todo Carolina del Norte. Así es como se efectuó un programa educacional el 4 de Mayo, en Dave & Busters en Cary, acerca del cual aparece un artículo en este boletín. Los próximos eventos incluyen un Retiro de la Unión Latina, a realizarse los días 13 y 14 en Wiston-Salem; 24 de Agosto en Asheville; 20 de Octubre en Concord; y 7 de Diciembre en la Celebración del HNC de Fin de Año en Ano en Durham.

El propósito del Programa de Unión Latina es apoyar y educar a individuos de origen Latino y sus familias que viven en Carolina del Norte y que son afectados por enfermedades hemorrágicas. El programa es administrado en Español y es posible gracias a la contribución de Takeda. Para mayor información al respecto, visite el sitio web de HNC.

Unión Latina Va a Dave & Busters

4 de mayo de 2019
Cary, NC
Por: Joseppe Vilchis, HNC member

Hemofilia de Carolina del Norte tuvo un evento educativo para los miembros del grupo de la Unión Latina en Dave and Buster’s. Establecido y dirigido por la Directora Ejecutiva de HNC Charlene Cowell, donde incluyó una mesa de arte y artesanía donde todos invitados tuvieron la oportunidad de hacer su propio juguete de avión de espuma. Lo cual fue muy divertido. Una presentación informativa y educativa de Takeda presentada por Patricia Espinosa Thompson y Yinell Núñez las educadores bilingües de salud de Takeda. También hubo una mesa de comida que incluía nachos, pequeñas picaduras de pizza, y galletas eran parte de las delicias. También se han establecido dispensadores de soda. Tres familias asistieron al evento y aprendieron sobre el manejo del dolor y los tipos de dolor y cómo lidiar con ellos, especialmente con respecto a las personas que viven con hemofilia presentando por Takeda. Disfrutaron de la deliciosa comida y bebidas. Hicieron arte y un avión juguete de espuma que los niños disfrutaron. El último elemento fueron las “power cards” proveídas por HNC a todas las familias que asistieron para ir y disfrutar en los juegos de arcade de Dave and Buster’s. En general, la experiencia fue muy maravilloso y educativo y delicioso. Hemofilia de Carolina del Norte siempre va más allá para proporcionar a sus miembros las mejores y más educativas actividades.

Retiro de la Unión Latina

13 y 14 de Julio del 2019
Winston-Salem, Carolina del Norte

El Segundo Retiro de la Unión Latina se llevara a efecto el 13 y 14 de Julio, en el Hawthorne Inn & Conference Center en Winston-Salem. Durante ese fin de semana tendremos un programa enteramente en Español, que incluirá educación, red social y diversión. Las acomodaciones serán distribuidas el Sábado por la noche, juntamente con almuerzo y cena para ese día, así como también desayuno y almuerzo para el día Domingo. Hemofilia de Carolina del Norte (HNC, por sus siglas en Ingles), proveerá tarjetas para gasolina, para facilitar la asistencia de los miembros al Retiro. Si usted necesitase acomodaciones especiales, por favor contacte la oficina de HNC, para coordinar la asistencia requerida.

Queremos animar a los miembros del HNC de habla Hispana a participar de este evento. El retiro brindara la oportunidad de conocer a otros miembros del HNC también de habla Hispana, en un ambiente favorable y de soporte. La fecha para inscribirse ya ha caducado, pero si esta interesado en participar, no dude en contactar HNC en events@hemophilia-nc.org o envie un texto a Gillian Schultz, Gerente del Programa, al (919) 272-6000 para averiguar si aun hay espacio disponible.
SOAR Program Update

The Hemophilia of North Carolina (HNC) SOAR Program provides education, resources, and support for women and girls with bleeding disorders. Those involved with SOAR also work to raise awareness and advocate for better diagnosis and treatment through educational opportunities and advocacy initiatives throughout the year. A SOAR track was held at this year’s Adult Retreat, from May 31-June 2 in Greensboro. Topics included the new Multidisciplinary Women & Girls Clinic at UNC, Intimacy, and Managing Stress.

The Women’s Advocacy Coalition (WAC) continues to raise awareness through the #DontBlush campaign on social media. Please help HNC by sharing every Thursday. Members will also exhibit at the North Carolina Nurse’s Conference this September and the North Carolina School Nurse’s Conference in December. WAC has also connected with the Girl Scouts to raise awareness with girls in the Charlotte area.

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.

JOIN IN HNC’S SOCIAL MEDIA CAMPAIGN #DONTBLUSH

to raise awareness about women and girls with bleeding disorders.

Contact the HNC office for copies of images to post on your own social media accounts or follow HemophiliaNC on Facebook, Instagram or Twitter to share #DONTBLUSH posts.

HNC SOAR Educational Dinner

March 25, 2019
Raleigh, NC

SOAR members gathered at Mia Francesca at North Hills in Raleigh for the Hello Talk! Women, Let’s Talk About Hemophilia presented by Takeda Clinical Educator, Betsy Koval. Although the program specifically focused on the area of women with hemophilia, women having a variety of bleeding disorders were able to participate in the conversation about the obstacles and challenges that women with bleeding disorders face. The program touched on a variety of topics that included the science of how hemophilia is inherited, the difficulty women have with proper or timely diagnosis of their bleeding disorder, and the symptoms of bleeding disorders that are unique to women. Hemophilia of North Carolina (HNC) would like to thank Takeda for providing this opportunity for women in the community to gather, learn, and share with one another.
ATTENTION KIDS AND TEENS!

JNC GETTIN’ IN THE GAME Applications Will be Accepted From

July 1 Through July 26

November 8-10, 2019
Phoenix, AZ

Hemophilia of North Carolina (HNC) is very excited to once again have the opportunity to send two representatives from North Carolina to CSL Behring’s 18th Annual Gettin’ in the Game® Junior National Championships (JNC). This special annual event will take place in Phoenix, Arizona, from November 8-10, 2019. Applications are available to NC children who have a bleeding disorder and who will be between the ages of 7 and 18 by November 8, 2019.

Throughout the weekend, educational sessions will be available for parents and caregivers to learn more about relevant topics within the bleeding disorders community. Chapter participants will learn the fundamentals of baseball, golf, or swimming, proper stretching techniques, and the importance of physical fitness and healthy lifestyles.

CSL Behring will provide travel arrangements and cover travel costs, including airfare, hotel, scheduled meals, and transportation while in the host city for each competitor and one accompanying adult (please note: family will be responsible for their transportation to and from their hometown airport).

Complete Information and an application form will be available for download from the HNC website on July 1. Applications must be submitted to HNC by Friday, July 26, 2019, to be considered. Preference may be given to first-time applicants. Otherwise, participants will be selected on a first-come-first-served basis.
HNC Continues to Meet with Hematology Centers Around the State

Continuing its effort to meet with medical and service providers at hematology centers and Hemophilia Treatment Centers (HTC) throughout North Carolina, Hemophilia of North Carolina’s (HNC) staff paid a visit to Duke University Medical Center’s Hemostasis and Thrombosis Center.

The ultimate goal of this initiative is to build and strengthen partnerships between HNC and the providers that our members see at these centers. These meetings have become an opportunity for HNC staff to acquaint the centers with the many HNC programs and services while also gaining a better understanding of the changing needs of the community from the perspective of each center’s team of providers. It is through this partnership that HNC hopes to be able to better ensure that programs and services remain relevant and well received, and also help HNC to continue its outreach to people with bleeding disorders around the state who are not familiar with the organization’s programs and services.

HNC has its final meeting with the HTC at St. Jude Affiliate Clinic at Novant Health Hemby Children’s Hospital Hematology & Oncology Clinic during the production time of this newsletter.

Hospital Cup Lunch

May 29, 2019
Charlotte, NC

With the Charlotte Family Festival & Walk over, Hemophilia of North Carolina (HNC) appreciates the support of all the donors who helped to make it a success. One celebration held each year is the Hospital Cup Lunch, to acknowledge the support of the Hemophilia Treatment Center (HTC) that raised the most money for the event. This year’s competition was tight, but in the end, the Hemophilia Treatment Center of Levine Cancer Institute and Levine Children’s Hospital came out on top! On May 29, HNC provided lunch and presented the plaque to go on the Hospital Cup trophy that was awarded at the Festival & Walk. The efforts of the staff at the HTC of Levine Cancer Institute and Levine Children’s Hospital, and all of our hematology centers, are hugely appreciated by HNC and the community that it supports!

Unión Latina goes to Dave & Busters

May 4, 2019
Cary, NC

By: Joseppe Vilchis, HNC member

Hemophilia of North Carolina (HNC) had an educational event for the members of the Latin Union Group at Dave & Buster’s. Three families attended the event. Executive Director of HNC, Charlene Cowell, set up an arts and crafts table where everyone made their own foam toy plane which was very fun and the kids enjoyed. There was delicious food and drinks including nachos, small pizza bites, and cookies, as well as soda. Patricia Espinosa Thomson and Yinell Nunez, Bilingual Health Educators from Takeda presented an informative and educational presentation. Families learned about pain management, types of pain, and how to deal with it, especially as people living with hemophilia. At the end, everyone received “power cards” provided by HNC for all the families to enjoy in the Dave and Buster’s arcade. Overall, the experience was wonderful, educational, and delicious. Hemophilia of North Carolina always goes above and beyond to provide their members with the best and most educational activities.
NOW! Conference
May 17-19, 2019
Phoenix, AZ
By: Ashley Lorfils, HNC Member

National Outreach von Willebrand (NOW!) is a national educational conference for individuals and families who are living with this chronic disorder.

This year we attended the NOW! Conference in Arizona that is hosted by the Arizona Hemophilia Association (AHA) by a grant provided by CSL Behring. I had first learned of this event from a CSL Behring representative at the HNC Family Retreat this past fall. This conference is all about von Willebrand disease (VWD) and we were so excited to find out about such an event. They had several keynote speakers. The first was Dr. Ronesh Sinha who talked about The Science of Stress and has a blog that I’ve listed below. Secondly, there was Dr. Robert Montgomery who went over What is VWD and Why Do I Bleed. Lastly, there was Steve Maguire who had a great session on joy. In addition to the keynote speakers, there was a variety of breakout sessions that ranged from dental care, women’s health, kids, and fun lifestyle sessions. Steve Maguire had one breakout session called Living Your Best Life and the room was packed, overflowing into the hallway. All the sessions were engaging, informative and we always left with more then what we came in knowing.

AHA also did a great job at providing fun and interactive child care during the adult sessions. My kids don’t always enjoy going to child care during these types of events but they couldn’t stop talking about how much fun they had. There was a magician, reptile touch and feel, and game truck, plus the resorts Coyote Camp and River Ranch. During our evenings we spent time in the pool and playing mini golf.

It was great to meet other families and hear their stories about how VWD affected them. During the medical professional panel questions time, it was nice to hear other people ask questions that I may not have even thought of but was glad to now know the answer. I would highly recommend this conference to anyone with VWD personally or in their family. We hope to be able to go back in a few years.

Dr. Sinha’s Blog: culturalhealthsolutions.com/blog/

HNC Adult Retreat
May 30–June 2, 2019
Greensboro, NC

This was the inaugural year for Hemophilia of North Carolina’s (HNC) newly reformatted Adult Retreat, combining the original Adult Retreat format with the SOAR and Men’s Retreat format to form one bigger, all-inclusive, two-night Adult Retreat. For the first year, it seemed fitting to hold the event in the center of the state, so approximately 60 of HNC’s adult community members gathered in Greensboro for a weekend of education and networking with fellow community members.

With severe storms throughout the area, attendees cautiously made their way to the Embassy Suites Greensboro Airport Hotel on Friday evening to check in and enjoy the opening night reception. All guests arrived safely, received their schedules for the weekend, and had a chance to mingle and relax before the sessions began on Saturday morning. Combining general sessions for all adults as well as separate tracks for men and women, there was a great variety of topics for everyone to learn from and share experiences. The first session, Sharing Your Story: Advocacy in the Bleeding Disorders Community, was presented by Betsy Koval of Takeda, and gave participants the tools they need to develop and tell their story in a way that they can communicate and advocate for themselves and others. In the next session, From the Physical to the Emotional: Emotional Aspects of Living with a Bleeding Disorder, Mary Ann Massolio of CSL Behring facilitated...
HNC Adult Retreat

continued from previous page

an open discussion about the physical and emotional aspects of living with a bleeding disorder.

The afternoon provided three breakout session tracks. For Men and Blood Brotherhood members, there were sessions on But I Can’t Bring Home the Bacon! Coping with Male Role Expectations presented by Dave Robinson from Hemophilia Federation of America (HFA), and Show Me Where it Hurts: Pain, Anxiety, & Depression presented by Laurel Pennick, SSW, LCSW, of the National Hemophilia Foundation (NHF). Women and HNC SOAR members were privileged to hear a presentation about the new UNC Women & Girls Clinic by Drs. Alice Ma & Yasmina Abajas of the UNC Chapel Hill Hemophilia Treatment Center followed by a session called Intimacy and Living with a Bleeding Disorder by Mary Ann Massolio of CSL Behring. Finally, for men and women who are parents, caregivers, and spouses, two sessions were presented including Adversity, Strength, and Resilience by Linda Pollhammer of Pfizer Hemophilia, and The Power of Empowerment from Tanya Stephenson of Sanofi Genzyme.

It was a full day of education mixed with chances to meet and greet fellow HNC members and visit with vendors, so participants were ready for some free time to visit some of the local attractions or just rest and relax at the hotel. Later that evening, some attendees participated in the optional evening activity, a minor league baseball game at the Greensboro Grasshoppers. It was a great night to be outside and enjoy the atmosphere of the stadium. The Grasshoppers won, and after the game, spectators were treated to an exciting fireworks display. Attendees who did not opt to attend the game enjoyed dinner at the hotel. Regardless of whether someone stayed for the hotel dinner or attended the game, members from both groups were able to continue to get to know one another and strengthen their relationships with other community members.

Day two started with two general sessions about topics that are ever changing and important to everyone. Emerging Trends in the Insurance Landscape, presented by Kimberly Ramseur of HFA, helped members understand what’s happening in insurance today and the path it took to get there. Understanding Gene Therapy Research and its Potential Application to Hemophilia, from Laureen Temple of Spark Therapeutics, offered attendees a glimpse at the history of gene therapy, how research has made a lot of progress in applying this type of therapy to hemophilia, and the promise of gene therapy being used for other inherited bleeding disorders. Finally, after another opportunity to visit with vendors, the last sessions of the day were a Men’s Rap Session directed by Steven Humes, HNC Board Member, and a women’s session called Managing Stress & Improving Wellness with Laurel Pennick of NHF.

Overall, the weekend was a success with a lot of positive feedback from adults who attended. Hotel accommodations and meals at the Adult Retreat are provided to all attendees at no cost to members. HNC hopes to continue growing this newly remodeled Adult Retreat in 2020!
2019 Friends of HNC

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2019. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

General Donations
Gay Boggess
Daisy Bratton
Michael & Mary Cavanagh
Lori Conger
Irene Cowell
W. Allen & Sue Heafner
William Katz
Daryl Steinbraker

Charlene Cowell’s Facebook Fundraiser for the George D. McCoy Scholarship Fund
Debbi Adamkin
Daisy Bratton
Cheri Clark
Reid Coleman
Sue Cowell
Daniel Cox
Michael Craciunoiu
Manisha Dass
Karyn Davis
Jama Fleming
Frannie Haynes
Tommy Heindl
Steven Humes
Maya Joanne
UH Kamala
Susan Lake
Jennifer Newman
Rich Pezzillo
W. Ellie Peters
Katherine Register
Jennifer Slepin
Tanya Stephenson
Paul & Emily Wilson

Bleeding Disorders Awareness Month
Tim & Madz Igelman
(The Bamboo Cookhouse Pop Up Fundraiser)

In Honor of Charles Register
John & Patricia Bartlett

In Memory of Charles Register
John & Patricia Bartlett

In Memory of Bill Goldston
Penni Tharp

In Memory of Jeffery Neal
The Cowell Family
Karyn Davis

In Memory of Ralph Wayne Ward
Kelly & Shirley Gilbreath

We gratefully acknowledge the individuals who generously donated to HNC during the past quarter of 2019. We extend a sincere thank you to our supporters, some of who have contributed several times during this period.

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HOPE Program Update

Hemophilia of North Carolina’s (HNC) HOPE Program is for families who have a child ages 12 or under with a bleeding disorder. Educational and support opportunities are geared towards families who have children in this age range. This summer, HNC will offer three programs to help prepare families to go back to school: on July 25 in Greenville and in August in Charlotte and Raleigh. Also be on the lookout for information and registration for the Family Retreat, returning to the Great Wolf Lodge in Concord. In addition to educational events, HNC rolled out Community Connections Groups in different areas of the state for anyone affected by bleeding disorders including Asheville and the Wilmington area. You can read more about the Community Connections on the front page of this edition of The Concentrate. Other areas with groups being formed include Lexington, Mocksville, Sanford, and Charlotte. HNC also offers a Parent Mentoring Program to provide more directed support to those families looking to connect with someone else in the community and oversees a private Facebook Group for the HOPE Program.

If you have ideas for events in your area, are looking for information about a particular topic, want to know more about the Mentoring Program or for any other information about the HOPE Program, please contact Gillian Schultz, HNC Program Manager, at gillian.schultz@hemophilia-nc.org, by calling or texting Gillian directly at (919) 272-6000, or by calling the HNC office at (800) 990-5557. You may also check the HNC webpage, your email, Facebook, Twitter, and Instagram pages for updates about upcoming programs and events.

Blood Brotherhood Program Update

Are you a man with a bleeding disorder? Did you know that Hemophilia of North Carolina (HNC) has a program just for you? The HNC Blood Brotherhood Program provides men with a bleeding disorder the opportunity to connect and socialize with other affected men.

From May 31-June 2, Blood Brotherhood members got together at the Adult Retreat, where a men’s track provided them opportunities to learn from each other, share experiences, and of course have some fun with other guys with bleeding disorders. Coming up next is the HNC Blood Brotherhood Retreat, from July 26-28 at the Trinity Center in Pine Knoll Shores. This annual event provides the opportunity to get together in a casual and relaxing environment with more details provided in a separate article of this newsletter. For other upcoming events this year, stay tuned to the HNC website and Facebook page, and be on the lookout for email announcements.

HNC’s Blood Brotherhood Program is an extension of the Hemophilia Federation of America (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.hemophiliefed.org to register. If you have questions about the HNC Blood Brotherhood Program, contact Gillian Schultz, HNC Program Manager at gillian.schultz@hemophilia-nc.org or call the HNC office at (800) 990-5557.

Unión Latina Program Update

The Unión Latina Program of Hemophilia of North Carolina’s (HNC) continues to support the needs of the Spanish speaking population across North Carolina. An educational program was held on May 4 at Dave & Buster’s in Cary, which you can read about in this newsletter. Upcoming events include the Latin Union Retreat, from July 13-14 in Winston-Salem, August 24 in Asheville, October 20 in Concord, and December 7 at the HNC Holiday Celebration in Durham.

The Unión Latina Program is meant to support and educate Latino individuals and families in North Carolina who are affected by bleeding disorders. Programming is provided in Spanish and is possible thanks to a grant from Takeda. For more information, visit the HNC website.
IN MEMORY OF...
Jeffery H. Neal

Jeff was a longtime member of Hemophilia of North Carolina (HNC) and a familiar face at Blood Brotherhood events through the years. Fellow Blood Brothers will remember how he mastered the grill at retreats. And he even brought out his cooking talents for the entire community to enjoy at an HNC event in the Morrisville area a few years back. A regular attendee at many HNC events and retreats, Jeff will be missed by many.

Obituary for Jeffrey H. Neal:
Coats: Jeffrey H. Neal, 61, died Wednesday, May 22, 2019 at SECU Jim and Betsy Bryan of UNC Healthcare. He was born in Alamance Co, the son of the late James Neal and the late Phyllis Rogers. He was also predeceased by his brother, Timmy Neal.

Mr. Neal is survived by his wife, Sharon Neal; daughters, Brandy LeQuire, Christy Timmons, Jennifer Stackhouse; son, Bryan Neal Chadwick; sister, Mary Chadwick; grandchildren, Will LeQuire, Caleb LeQuire, Justin LeQuire; and great grandson, Oliver LeQuire.

No services are planned.

In lieu of flowers, memorial donations can be made to the Hemophilia of North Carolina, 260 Town Hall Dr., Suite A, Morrisville, NC 27560 or online Hemophilia-nc.org.

The family is being assisted by Clements Funeral & Cremation Services, Inc. in Durham. Online condolences may be sent to www.clementsfuneralservice.com.

CONGRATULATIONS TO THE CLASS OF 2019!

Hemophilia of North Carolina (HNC) would like to congratulate all of this year’s graduates.

Whether you’re moving up to middle or high school, or moving on to your first job, college, or beyond, HNC wants to applaud you on a job well done!
Where Does Your Factor Come From?

By: Laurie Kelley
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Publication: PEN 5.19; Column:YOU, Sponsored by Takeda

You may know the brand name of the factor concentrate your child or other loved one uses to treat bleeds. And you may have chosen the brand with the help of your hematologist. But where do get your factor? Who provides it? Is your current brand the best way to meet your personal needs? Do you have choice of provider?

Pharmaceutical companies develop and manufacture factor. Then they sell the factor to a licensed pharmacy—a factor provider. You can’t buy factor directly from the manufacturer, just as you can’t buy a car directly from General Motors, or diapers from Kimberly-Clark. And you can’t get factor from your local drug store. Your hematologist supplies a prescription to a factor provider, who delivers it to you. Who are factor providers?

HOSPITAL PHARMACIES
You want a factor provider that can meet your personal needs; this usually means being cost-effective and speedy, and supplying factor in the correct assay sizes with all the ancillaries (such as needles and syringes) you require. Unless you are a member of a health maintenance organization (HMO) and are required to buy factor from the hospital pharmacy, or your hospital runs a 340B program (see p. 18), obtaining your factor through a hospital pharmacy is usually not a good option. Why not? Hospital pharmacies are the least cost-effective factor provider, and often mark up the cost of factor several hundred percent to cover the high overhead costs of running the hospital. Also, hospital pharmacies are not set up for home delivery and unlike specialty pharmacies, do not offer any additional services, such as a home nurse. Factor is already very expensive without the hospital markup! You’ll want a long-term solution, with a factor provider that ships to your home.

SPECIALTY PHARMACIES
Specialty pharmacies are one of the chief factor providers in the US. If your insurance payer approves a specialty pharmacy based on your physician’s prescription, you make a phone call, order your factor, and receive the order at your home within 24 to 48 hours, along with all necessary ancillaries and supplies. Reimbursement specialists handle your insurance paperwork. Specialty pharmacies stock most brands of factor, and usually can provide a size or assay that closely mirrors what you need for your child’s infusions. Some specialty pharmacies will send a nurse to your home to perform or assist in the infusion process. There are many specialty pharmacies and home care companies that service hemophilia, and some are devoted only to hemophilia.

YOUR HTC
Did you know your hemophilia treatment center might sell factor? There are about 140 HTCs in America as of this writing, and over 100 participate in the 340B program; all are licensed distributors of factor. So you also have the option—if your payer permits—to purchase factor from your HTC. Why and when would you consider buying from your HTC? Federally funded HTCs can take advantage of the federal Public Health Service (PHS) Act known as the 340B Drug Pricing Program. The PHS Act allows certain federally funded entities and public hospitals to purchase prescription outpatient drugs (including factor) at steeply discounted prices. So federally funded HTCs can buy factor from pharmaceutical companies at rock-bottom prices, and then sell it to you and make a profit.

In theory, 340B pricing is beneficial. It offers competition to help keep prices down, reduces costs for the government, and generates funds for the HTC to use for staff positions or overhead—which is truly needed. But not every eligible HTC uses the 340B program. And even when an HTC does offer factor through 340B, not all the HTC’s hemophilia consumers take advantage of this. Why? Sometimes, 340B pricing doesn’t guarantee lower prices to the consumer: some HTCs charge the same price per unit as specialty pharmacies. And some consumers simply prefer the personal relationship they have with their specialty pharmacy reps.

PBM PHARMACIES
Pharmacy benefit managers (PBMs) are powerful, multi-billion-dollar companies hired by insurance companies to manage the insurance benefits and prescription drug plans of private-sector entities, such as employers and labor unions. PBMs help determine the formulary—a limited list of preferred drugs that the payer will reimburse. PBMs also negotiate and manage contracts with pharmaceutical companies to buy the drugs needed by plan beneficiaries like you. The main function of a PBM is to keep prescription drug costs low for the insurance company.

PBMs are able to make high-volume drug purchases to receive substantial discounts from pharmaceutical companies. With their vast resources and negotiating skills, PBMs such as Express Scripts and CVS Health now serve most of the hemophilia patients in the US. Some PBMs have started their own specialty pharmacies to sell factor; and because they have a direct line to the payer, these PBMs are able to switch families from the factor provider of their choice to the PBM’s specialty pharmacy. They have incredible power over pricing, product availability, and your payer.

Continued next page
Where Does Your Factor Come From?

Based on this, can you even choose a factor provider? Unfortunately, your healthcare payer—insurance company or government program—often chooses for you. Find out if your insurance company reimburses for specialty pharmacy services. Then, learn which companies are in-network for you. Your choices might be limited, because for the payer, working with a single factor provider is one way to lower costs. More and more often, choice is being restricted. You may face a struggle when choosing a preferred factor provider.

If you can choose, use this list of questions to ask your factor provider to make sure your personal needs are met:

• Which brands of factor concentrate do you provide?
• How much product will you provide at one time?
• How are products delivered to me?
• Do you ship during emergencies?
• Do you supply the assay size I need as a single dose?
• How much will I pay per unit of product?
• Do you (the HTC) offer 340B pricing?
• Are you recognized as an in-network provider by my insurance company?
• What are your hours of operation?
• Are a pharmacist and registered nurse available 24/7?
• Can I use your regular HTC services even if I choose to use a specialty pharmacy as my factor provider?
• Do you supply ancillaries: needles, syringes, and bandages?
• Do you provide needle disposal containers?
• Do you contract with local home nursing services?
• Is home nursing service included in the cost of product or billed separately?

Even though choice is being limited, you are not limited! Learn all you can about who supplies your factor, and continue to safeguard your needs. Ask questions, and get the answers that will help you make effective decisions.

WANT TO KNOW MORE ABOUT RESOURCES IN NORTH CAROLINA?

Visit the Resources section of the Hemophilia of North Carolina (HNC) website which includes webpages that provide information to help navigate the various resources in NC and nationwide.

The Recently Diagnosed page provides a basic guide for people with bleeding disorders including information about nonprofits that serve the community, Hemophilia Treatment Centers (HTC), a glossary of terms, pharmaceutical corporations and their products, home care companies providing service in NC, and the 340B Program available through certain NC HTCs.

Need more information? The HNC website Resources section also has pages on topics related to Emergency Resources, Treatment Centers, Travel Services, Health Insurance, and Other Resources.
HNC Advocacy Committee Updates

It has been a busy year for the Hemophilia of North Carolina (HNC) Advocacy Committee. In addition to the monthly conference calls, committee members have participated in a variety of initiatives. Some of the highlights include:

- NC Rare Disease Day – HNC partnered with the National Organization for Rare Disorders (NORD) in February to advocate for people with rare diseases, including bleeding disorders, amongst NC legislators.
- HNC sat on a panel at a Syneos Health Rare Disease Day event in February.
- On February 27, HNC participated in the NC Medicaid Expansion Advocacy Day with more than 200 other advocates.
- HNC met with the NC Department of Health and Human Services (DHHS) and the Governor’s Offices separately to discuss Medicaid Expansion.
- HNC partnered with 12 other organizations to send personalized letters to all NC Senators and Representatives to express support for expanded healthcare coverage for North Carolinians.
- March: Bleeding Disorders Awareness Month – HNC advocates received proclamations designating March as Bleeding Disorders Awareness Month from major cities (Raleigh, Greensboro, and Charlotte) as well as one from Governor Cooper.
- Fourteen NC advocates participated in the National Hemophilia Foundation Washington Days and visited with their elected officials.
- HNC attended the Preferred Drug List review panel meeting in May to ensure that if hematologic products were discussed, HNC would be able to alert the community of any changes.

HNC advocates are continuing to push for access to healthcare in North Carolina, including Medicaid Expansion. HNC is also watching the transition of Medicaid Managed Care to ensure that any changes that may affect the rare disorder community will be communicated effectively to those that are accessing Medicaid services. Additionally, HNC continues to look for ways to infuse advocacy into programming. It’s one way that HNC hopes to inspire members of all ages to participate in the important work of advocating for the bleeding disorders community today and tomorrow!

If you’re interested in learning more or getting involved in the advocacy efforts, please call or email Charlene Cowell, HNC Executive Director, at info@hemophilia-nc.org or (800) 990-5557.
Hemophilia of North Carolina
2019 Calendar of Events Highlights

June 29-July 2, 2019  HNC/HSC Teen Retreat – Rock Hill, SC
July 13-14, 2019    Union Latina Retreat – Winston Salem, NC
July 25, 2019       Educational Dinner, Greenville, NC
July 26-28, 2019    Blood Brotherhood Retreat – Pine Knoll Shores, NC
August 3, 2019      Raleigh Festival Team Captain Meeting – Morrisville, NC
August 17, 2019     Family Day Out – Clemmons, NC
August 24, 2019     Union Latina Event – Asheville, NC
August 30, 2019     Educational Dinner – Asheville, NC
September 7-8, 2019 Family Retreat – Concord, NC
October 12, 2019    Raleigh Family Festival & Walk for Bleeding Disorders – Morrisville, NC
October 20, 2019    Union Latina Event – Concord, NC
November 2, 2019    Screening of “Bombardier Blood” – Morrisville, NC
December 7, 2019    Holiday Celebration – Durham, NC

Talk to your doctor to see if ADYNOVATE may be right for you.

For more information, please visit www.ADYNOVATE.com

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START YOUR WALK TEAM TODAY!

FAMILY FESTIVAL 2019
& Walk for Bleeding Disorders

Check-in begins at 9:00am
Opening Announcements begin at 9:45am
followed by the Official Walk Start

Saturday, October 12, 2019
Lake Crabtree County Park
1400 Aviation Parkway
Morrisville, NC

Join Hemophilia of North Carolina (HNC) for the annual Family Festival and Walk, a fundraiser dedicated to preventing the complications of bleeding disorders.

For more information please visit: www.hemophilia-nc.org/festival
or contact: Gillian Schultz, HNC Program Manager at festival@hemophilia-nc.org
or call (800) 990-5557.