

THE CONCENTRATE

THE OFFICIAL NEWSLETTER FOR HEMOPHILIA OF NORTH CAROLINA

FALL 2019

Do You Like to Travel? Here's a Chance to Win a Fabulous Trip and Support HNC!



Hemophilia of North Carolina (HNC) is announcing an exciting vacation raffle fundraiser and is asking members around the state to participate. Whether you buy or sell tickets, members who participate will make a big impact on helping to sustain HNC's programs and services for members around the state.

Each \$25 raffle ticket will give the ticket holder a chance to select ONE of these three wonderful vacations, each valued between \$2,500-\$3,000. With only 500 tickets available, the odds are good that the ticket you buy or sell will be the winner!!

- A New York Broadway Show and Dinner Package
- The New Orleans Jazz and Dinner Experience
- World Traveler Package to one of these five great locations: Tuscany (Italy), Bali (Indonesia), Whistler (Canada), Athens (Greece) or Paris (France)

Tickets will go on sale during the Raleigh Festival & Walk on October 12 and will be available through December 31, 2019, or until the 500th ticket is sold. Why not make HNC Vacation Raffle tickets a part of your holiday giving this year?

Stay tuned for more information about how to buy or sell tickets, details about each vacation package, and the drawing event scheduled to take place in early January at a location in the Raleigh area (as well as live streamed on Facebook).

ACT NOW to Continue Home Delivery of *The Concentrate* Newsletter



Do you enjoy receiving this newsletter delivered directly to your home, or would you prefer reading this newsletter online?

By informing Hemophilia of North Carolina (HNC) of your preference, you can help HNC conserve valuable resources by only providing home delivery to those

who select it!

Contact the HNC office to OPT IN to home delivery of *The Concentrate* by December 1 if you want to continue receiving your copy of *The Concentrate* delivered by mail to your home address. Only members who OPT IN to

Continued page 3

Save The Date

NHF Annual Meeting

October 3-5, 2019
Anaheim, CA

Raleigh Family Festival & Walk

October 12, 2019
Morrisville, NC

Educational Dinner

October 17, 2019
Charlotte, NC

Evento de la Unión Latina

October 20, 2019
Huntersville, NC

Screening of *Bombardier Blood*

November 2, 2019
Morrisville, NC

Factor VII Support Group

November 2, 2019
Morrisville, NC

Women's Event

November 7, 2019
Charlotte, NC

Educational Dinner

November 14, 2019
Durham, NC

NOW VWD Conference

November 15-17, 2019
Phoenix, AZ

Holiday Celebration & Evento de la Unión Latina

December 7, 2019
Durham, NC

Annual Meeting

March 7-8, 2020
Raleigh, NC

Charlotte Family Festival & Walk

April 18, 2020
Charlotte, NC



Hemophilia of North Carolina

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

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www.hemophilia-nc.org

In this Edition:

UPCOMING EVENTS	Page 3
RECENT EVENTS	Page 5
SUPLEMENTO DE LA UNIÓN LATINA	Page 9
SOAR SUPPLEMENT	Page 10
OUR YOUNG VOICES	Page 11

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 (Collect)
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.uneedpsi.org

World Federation of Hemophilia

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

VISION STATEMENT

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

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



ACT NOW to Continue Home Delivery of *The Concentrate* Newsletter continued from page 1

receiving this newsletter by mail before December 1, 2019, will continue to receive *The Concentrate* by mail in 2020. If you don't OPT IN you will receive a link to read the newsletter online through downloadable version of *The Concentrate* on the HNC website.

To OPT IN, send your first and last name, and street address by email to info@hemophilia-nc.org, by phone (800) 990-5557, or text to (919) 271-4171. If you're not receiving emails from HNC about programs and events in your area, please contact the HNC office so you don't miss out on HNC news and information.

Raleigh Festival & Walk: Supporting the Bleeding Disorders Community in NC!

October 12, 2019

Morrisville, NC

Taking place on October 12 at Lake Crabtree Park in Morrisville, the 2019 Family Festival & Walk for Bleeding Disorders has a lot in store for you and your family! Great food, music, games, crafts, and more will be on hand for all to enjoy. This is Hemophilia of North Carolina's (HNC) biggest event of the year. It's a day of family-oriented fun that builds and strengthens the community of people affected by bleeding disorders in North Carolina while also raising critical funds for HNC's programs and services.

HNC members can give back to the community by registering, starting or joining a team, fundraising, volunteering, and more. It's a fun way to show your support to HNC and community members throughout the state, so please plan to participate and make 2019 the biggest event yet! Visit the HNC website to register as a participant or volunteer, form your walk team, and start fundraising today!



Save the Date! Bombardier Blood

November 2, 2019

Morrisville, NC

Hemophilia of North Carolina (HNC) is thrilled to be showing a special screening of the documentary *Bombardier Blood* on November 2 at the Park West Stone Theatre in Morrisville. This movie documents Chris Bombardier's climb to the top of Mount Everest. Chris Bombardier has severe hemophilia B, but that didn't stop him from reaching for his dreams and successfully climbing the seven summits! In addition to climbing the tallest mountains on each continent, he used his experience as an opportunity to raise funds for Save One Life, an international organization that helps people with bleeding disorders across the globe. In 2017, he partnered with filmmaker James Patrick Lynch and Believe Limited to document his journey. Join HNC and Laurie Kelley, founder and President of Save One Life, for this memorable experience.



Chris Bombardier taking final steps to summit

2019 Holiday Celebration Comes to Durham

December 7, 2019

Durham, NC

Hemophilia of North Carolina (HNC) will be holding its annual Holiday Celebration at the Durham Hilton near Duke University in Durham, NC. HNC members and their immediate families are invited to celebrate the close of another successful year with the entire HNC family.

Community members of all ages are welcome to join fellow HNC members for an afternoon of food, fun, an inspirational presentation, and a visit from Santa with a gift for all children in attendance!

In addition, HNC is planning an optional visit to the nearby Durham Museum of Life & Science, so members who attend can enjoy a full day of fun in the Durham area.

More information about this event, including details and information on how to register, will be available on the HNC website by mid-October.

HNC Annual Meeting: Save the Date!

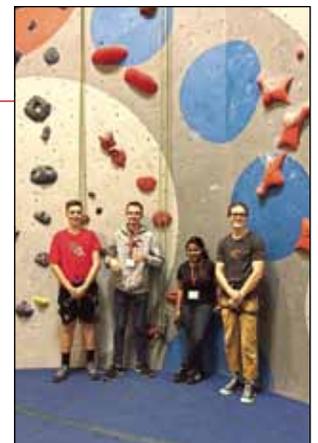
March 7-8, 2020

Raleigh, NC

Save the date for the Hemophilia of North Carolina (HNC) Annual Meeting taking place during the weekend of March 7-8, 2020, at the Hilton Raleigh North Hills, in Raleigh, NC. Stay tuned to the HNC website in early 2020 for details.

The Annual Meeting is HNC's largest educational event of the year, with members gathering from across the state. There will be sessions for everyone that will be chosen based upon the diverse needs of the community and on feedback from past years' Annual Meetings. If there is a topic that you want to learn more about, please contact the HNC office by emailing events@hemophilia-nc.org. In addition to sessions for adults, there will be children's programs, teen activities, and daycare for children under 18. The Annual Meeting also provides the opportunity to vote on the HNC Board of Directors, learn about what HNC is doing in the community, and find out about HNC's financial standing during the Business Meeting.

Be on the lookout in early 2020 for more information and registration.



There's something for everyone at the HNC Annual Meeting. Last year's teen track included rock climbing.

HNC Visits CSL Behring's Plasma Center

June 26, 2019
Charlotte, NC

On June 26, Hemophilia of North Carolina (HNC) Program Manager, Gillian Schultz, and HNC member Cary Shaw were invited to visit the CSL Plasma Center in North Charlotte. They had the opportunity to share their stories with Councilwoman Jennifer Steep from Gastonia and learn more about the plasma donation process. Following a presentation where Cary and Gillian both spoke, they toured the facility and saw how the plasma is collected and stored before being sent to another facility where the plasma is used to make products, including factor.

Inspired by the Teens

June 29-July 2, 2019
Rock Hill, SC

What do 34 teens, 10 chaperones, two facilitators, and two bleeding disorder organizations have in common? They had an awesome time at the Hemophilia of North Carolina (HNC)/ Hemophilia of South Carolina (HSC) Teen Retreat! On June 29– July 2, the “Carolina Crew” (coined by teens years ago) headed to Camp Canaan in Rock Hill for four days and three nights. The HNC/HSC Teen Retreat is an amazing opportunity for any teen in the community to learn, grow, and connect with others. The partnership between the two organizations allows future leaders to cross state borders and create lasting friendships.

Teens just want to have fun! Fortunately, GutMonkey has a way of infusing fun into any program they facilitate. HNC/HSC were happy to see a familiar GutMonkey face, Haelynne Barron. Haelynne used games and reflection activities to help discuss the important topic of change. Change is constant and especially as someone begins to transition from youth to adulthood, it can be overwhelming. Haelynne helped the teens uncover some of those fears as well as aspirations for the future. The program allowed teens to face these uncertainties, realize they aren't alone, and to begin thinking about how they can better control the changes happening

in their lives. In addition, Sarah Shinkman

from Hemophilia Federation of America led a “transitioning to adulthood” session on the first night to help set the stage. This session offered teens the chance to figure out the real costs of adulthood. Having them guess the costs of every day expenses was quite entertaining to both the teens and the chaperones!

It wouldn't be a Teen Retreat without s'mores! In addition to free time, teens had no excuse that they were bored with all of the activities offered. This included the high ropes course, kayaks, zip line, evening laser tag, arts & crafts, gaga ball, swimming, movies, and more. Ryan Griffith, HNC/HSC member and owner of Marble Slab Creamery, and his son came out and brought ice cream sundaes to help re-energize the teens after all the excitement of the day.

This event wouldn't happen without HNC's partnership with HSC, fabulous chaperones and facilitators, Camp Canaan staff, and of course our rockstar teens! It is truly inspiring to see our youth grow into independent, confident adults that are ready to make their mark on the community!



Retiro de la Unión Latina/Latin Union Retreat

13-14 de julio, 2018/July 13-14, 2019
Winston-Salem, NC

Hemophilia of North Carolina (HNC) held its 2nd Annual Unión Latina (Latin Union) Retreat in July at the Hawthorne Inn & Conference Center in Winston-Salem, NC. Eight families gathered for a weekend of programming and connecting with others in the community with all sessions taking place in Spanish. Attendees were able to learn through a variety of educational sessions in their native language, providing members an enhanced setting to gain a better understanding of the presentations, ask questions, and more easily participate in group discussions.

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Unión Latina members participate one of the retreat activities

Retiro de la Unión Latina / Latin Union Retreat

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Unión Latina members participate one of the retreat activities

children participated in a separate children's track with childcare provided by Preferred Childcare. The children did arts and crafts, played games, had a surprise visit from Twist the Balloon Man, watched movies, and participated in a Program called *Let's ROCK Out!* by Kaleideum.

On Saturday night, after participating in sessions and some free time to enjoy the pool or area activities, the families all gathered together for dinner and Family Game Night which included a rousing game of Lotería, a spinning top game called Pirinola, and an exciting game of La Bruja!

Everyone was grateful for the educational opportunities provided at the Unión Latina Retreat, and just as importantly attendees appreciated the ability to connect with one another and learn from each other.

Sessions included *Hemophilia, the Female Connection* by Abigail Plumley of Novo Nordisk, *Independence & Management* by Jose Fernando & Guadelupe Torres of National Hemophilia Foundation, *Understanding Health Care in the US* by Anahi Venzor Strader, MD, and Dana C. Nora, MPH, of the Hispanic League, *Understanding von Willebrand Disease* by Patricia Espinosa-Thomson of Takeda, *Infusion Support for Caregivers with Hemophilia* by Daysi Fardales of Pfizer, and a *Challenges & Advocacy Roundtable* led by Joseppe Vilchis, HNC member. The



Joseppe Vilchis, HNC Member, leads a discussion on *Challenges & Advocacy*

Blood Brothers at the Beach

July 26-28, 2019

Pine Knoll Shores, NC

The Hemophilia of North Carolina (HNC) Blood Brothers got to enjoy the Annual Blood Brotherhood Retreat from July 26-28 in Pine Knoll Shores, NC. The Trinity Center served as a great location for the guys to enjoy a weekend at the beach filled with time to connect and share with fellow adult men with bleeding disorders. The event kicked off with an evening campfire and s'mores as men from across the state were able to get to know one another in a relaxed setting. The retreat focused in on social support and the importance of friendships within the bleeding disorders community. The guys shared stories of the impact these friendships can have throughout the weekend during several roundtable discussions.

In addition to some fun in the sun at the beach and an optional evening mini golf game, the attendees enjoyed an educational presentation on the advocacy efforts of HNC and how to get involved with state and national advocacy as it relates to bleeding disorders. The guys shared stories of advocacy on a personal and legislative level, and also discussed the new changes to North Carolina's Medicaid program.



Blood brothers enjoy mini golf and time on the beach during the Blood Brotherhood Retreat

If you missed the retreat stay tuned to the HNC website and Facebook page for future Blood Brotherhood meetings and gatherings. Also, adult men are encouraged to use the private online forum to connect with Blood Brothers nationwide and in between gatherings. The forum can be found at www.hemophiliafed.org.

Another Great Year at HNC's Family Day Out

August 17, 2019
Clemmons, NC

Hemophilia of North Carolina (HNC) members gathered for a day of fun in the sun at the 4th Annual HNC Family Day Out at Tanglewood Park in Clemmons, NC. With 17 families in attendance, members had a chance to get to know one another or catch up with families they don't get to see very often. Everyone enjoyed the games, crafts, costumed characters, and a wonderful picnic lunch at the picnic shelter before heading over to the park's Aquatic Center to cool down and have fun in the lazy river or variety of pools and water slides.

While everyone was enjoying their picnic lunch, Picnic Sponsor representatives had an opportunity to address the group. Then, Gillian Schultz, HNC

Program Manager, took some time to review upcoming HNC programs and events, including the HNC Family Festival scheduled to take place in Raleigh on October 12. It was another great year at the Family Day Out!



Educational Dinners Across the State

June 20, 2019
Kinston, NC

July 25, 2019
Greenville, NC

August 20, 2019
Morrisville, NC

August 22, 2019
Charlotte, NC

August 30, 2019
Asheville, NC

Hemophilia of North Carolina (HNC) traveled across the state this summer to provide a variety of educational opportunities in several North Carolina cities. HNC would like to thank its industry partners for making all of these educational opportunities possible.

Kinston, NC:

On June 20, HNC partnered with Takeda to bring the "Hello Talk!" *Understanding von Willebrand Disease* to members in the Kinston area. Betsy Koval, Takeda Clinical Educator, provided a hands-on program to help explain the symptoms and various types of von Willebrand disease (VWD). VWD is the most common bleeding disorder, but not the most well-known or easily



HNC members participate in activities to learn more about von Willebrand disease

diagnosed. As families gathered and enjoyed dinner at Chef and the Farmer, they were engaged in an interesting presentation about VWD that was understandable to attendees of all ages. HNC would like to thank Takeda for bringing this valuable program to its members.

Greenville, NC:

HNC members headed to Greenville on July 25 to enjoy dinner at Villedge Wood Fire Kitchen and HOPE Educational Program called *Back to School: 504 Plans in Your School*, presented by Ann Lowish, a registered nurse who has been involved in the bleeding disorders community since 1980. Members in attendance learned and discussed many of the steps necessary to prepare for heading back to school with a bleeding disorder and how to implement a

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Educational Dinners Across the State continued from previous page



HNC members enjoy dinner at P.F. Chang's in Charlotte as they discuss how to plan for back to school

504 Plan for students of all ages. HNC would like to thank CSL Behring and Realo Specialty Care Pharmacy for making this program possible.

Morrisville, NC:

The educational program on August 20, *Setting Educational Expectations*, led by Tanya Stephenson, Sanofi-Genzyme CoRe Manager, helped families understand the benefits of being proactive with their child's school. Attendees participated in an interactive discussion and presentation while enjoying dinner at Travinia Italian Kitchen. Thanks to Sanofi-Genzyme for this educational opportunity for HNC members in the Morrisville area.

Charlotte, NC:

HNC continued to provide information as families and children were preparing to go back to school in the Charlotte area on August 22, with the educational program, *Setting Educational Expectations*, led by Tanya Stephenson, Sanofi-Genzyme CoRe Manager. The evening focused on what you need to know about sending a child to school with a bleeding disorder, including a discussion about IHPs, 504 plans and IEPs. Everyone left feeling a little more comfortable knowing about what to talk to with teachers and nurses. Thank you to Sanofi-Genzyme for this educational opportunity.

Asheville, NC:

HNC traveled west to Asheville on August 30 for an educational dinner, *Living with a Bleeding Disorder*. Families gathered around the table at the Cantina at Historic Biltmore Village for a conversation about growing up with a bleeding disorder. Jecorei Lyons with Drugco Health shared his story of diagnosis and how he learned to manage his bleeding disorder. Families talked about the benefits of camp and community. Thank you to CSL Behring and Drugco Health for sponsoring this program.

If there is a topic that you would like to hear about in your area, please contact the HNC office at (800) 990-5557 or events@hemophilia-nc.org.



Kids enjoy dessert at the Asheville dinner on August 30

Unión Latina Event in Asheville

August 24, 2019
Asheville, NC

It was a cool summer day in Asheville as almost 25 members of HNC's Unión Latina Program gathered for an educational presentation and visit to the Western North Carolina Nature Center. Patricia Espinosa-Thomson, Takeda Bilingual Clinical Educator, presented *Resilience: Growing Through Life's Changes*. Families learned about what it means to be resilient, and why that's important when living with a bleeding disorder. The presentation concluded with some physical activities and the marshmallow tower challenge, where they had ten minutes to build the tallest tower out of spaghetti, with a marshmallow on the top. It was a fun competition for everyone! Following the program, families had the opportunity to visit the Western North Carolina Nature Center, which included exhibits of plants and animals native to the Appalachian Mountains. Thank you to Takeda for sponsoring the Unión Latina Program.



Members building their spaghetti towers at the Unión Latina Event

Actualidad del Programa Unión Latina

El Programa Unión Latina (Latin Union) de Hemofilia de Carolina del Norte (HNC) por sus siglas en inglés, continúa apoyando las necesidades de la población de habla hispana a través de Carolina del Norte. El Retiro de Unión Latina se sostuvo en Julio 13-14 en Winston-Salem y conectó a cerca de 40 miembros de habla hispana. En agosto 24, HNC organizó un Programa Unión Latina con 25 asistentes en el Centro de Naturaleza Occidental de Carolina del Norte (Western North Carolina Nature Center) en Asheville. Reserve el día 20 de octubre para un evento en el área

de Huntersville y también el 7 de diciembre en el HNC Holiday Celebration en Durham.

El Programa Unión Latina está dedicado a apoyar y educar a individuos y familias Latinas en Carolina del Norte quienes son afectadas por desórdenes sanguíneos. La Programación es provista en Español y es posible gracias a una subvención de Takeda. Para más información, visite la página de HNC.

Retiro de la Unión Latina

13-14 de julio, 2019
Winston-Salem, NC

Hemofilia de Carolina del Norte (HNC) por sus siglas en inglés, sostuvo su 2do Retiro de Unión Latina en Julio en el Hawthorne Inn & Conference Center en Winston-Salem, NC. Ocho familias se reunieron para un fin de semana de programas y conexión con otros en la comunidad, sosteniendo todas las sesiones en español. Los asistentes pudieron aprender a través de una variedad de sesiones educacionales en sus idiomas nativos, proporcionando a los miembros con un escenario avanzado para conseguir un mejor entendimiento de las presentaciones, hacer preguntas y facilitarles las discusiones en grupo.



Gracias a todos los miembros de Unión Latina por unirse a HNC en el retiro.

Las Sesiones incluyeron a *Hemofilia, la Conexión Femenina*, por Abigail Plumley de Novo Nordisk, *Independencia y Manejo* por Jose Fernando & Guadalupe Torres de La Fundación Nacional de Hemofilia, *Comprendiendo el Cuidado de la Salud en los Estados Unidos* por Anahi Venzor Strader, MD, y Dana C. Nora, MPH, de La Liga Hispana, *Comprendiendo el mal de von Willebrand* por Patricia Espinosa-Thomson de Takeda, *Apoyo de Infusión para los que cuidan pacientes con Hemofilia* por Daysi Fardales de Pfizer, y *Mesa Redonda acerca de Retos y Soporte Activo* dirigido por Joseppe Vilchis, miembro de HNC. Los niños participaron en un curso separado con cuidado infantil proveído por Preferred Childcare. Los niños trabajaron en arte y artesanía, jugaron juegos, tuvieron una visita sorpresa de Twist the Balloon Man, vieron películas y participaron en un programa llamado Let's ROCK Out! por Kaleideum.

El sábado por la noche, después de participar en sesiones y de tener algún tiempo libre para disfrutar de la piscina y áreas de recreación, las familias se reunieron para cenar y participar en la Noche del Juego que incluyó un juego de Lotería, uno de rueda llamado Pirinola y un excitante juego de La Bruja.

Todo el mundo estuvo agradecido por las oportunidades de educación proveídas en el Retiro de Unión Latina e igualmente importante, los asistentes apreciaron la habilidad de conectarse y aprender de cada uno.

Fotografías – por favor use fotos en ambos, Sección de reportes de eventos recientes y Suplemento de la Unión Latina ya que hay espacio disponible.

Evento de Unión Latina en el Oeste

Agosto 24, 2019
Asheville, NC

Fue un fresco día de verano en Asheville cuando cerca de 25 miembros del Programa Unión Latina (HNC) se reunieron para una presentación educacional y visita al Centro de Naturaleza Occidental de Carolina del Norte. Patricia Espinosa-Thomson, Educadora del Takeda Bilingual Clinical, presentó *Resilience: Growing Through Life's Changes (Resistencia: Creciendo a través de los Cambios de la Vida)*. Familias aprendieron acerca de lo que representa tener resistencia y por qué es importante cuando se vive con un desorden sanguíneo. La presentación concluyó con algunas actividades físicas y el reto de la torre de malvaviscos, donde tuvieron diez minutos para construir la torre más alta hecha de espaguetis, con malvaviscos encima. ¡Fue una competencia divertida para todos! Siguiendo con el programa, las familias tuvieron la oportunidad de visitar el Centro de Naturaleza Occidental de Carolina del Norte, lo que incluyó exhibiciones de plantas y animales nativos de las Montañas Apalachina. Gracias a Takeda por patrocinar el Programa Unión Latina.

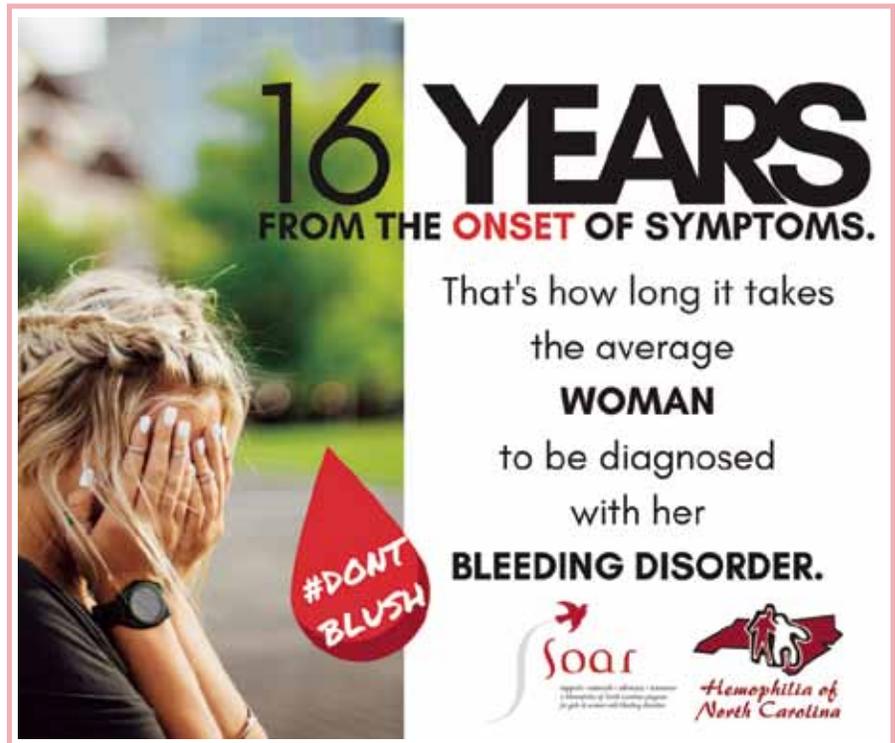
SOAR Program Update

The Hemophilia of North Carolina (HNC) SOAR Program provides education, resources, and support for women and girls with bleeding disorders. One of the many goals of SOAR is to raise awareness and advocate for quicker and more accurate diagnosis of a bleeding disorder among women and girls. This year, HNC will be exhibiting at the North Carolina Nurse's Association (NCNA) Conference in September in Winston-Salem and at the North Carolina School Nurse's Association (NCSNA) Conference in December, in Greensboro, to raise awareness especially about women and girls with bleeding disorders. HNC continues with the #DontBlush campaign to raise awareness that women and girls do have bleeding disorders among the general public. Don't forget to like and share #DontBlush posts on Facebook and Instagram!

Save the date for a women's pottery night on November 7 in Charlotte. Whether you plan on creating a piece of pottery for yourself, or even as a gift with the upcoming holidays, the night will provide the opportunity to connect with other women in the community. This event is open to all women in the community, including those who do not have a bleeding disorder.

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.



16 YEARS
FROM THE **ONSET** OF SYMPTOMS.

That's how long it takes
the average
WOMAN
to be diagnosed
with her
BLEEDING DISORDER.

#DONT
BLUSH

SOAR
Hemophilia of North Carolina

Our Young Voices

Fall 2019

Teens in Action at the 2019 HNC/HSC Teen Retreat



Community Connections Across the State

Hemophilia of North Carolina's (HNC) Community Connections program continues to grow. Community Connections are casual get-togethers around the state led by HNC members who are committed to giving back to the bleeding disorders community. They provide the opportunity for connection among adults and children so that no one has to feel alone living with a bleeding disorder. Over the past several months, HNC has held Community Connections events at Jordan Lake in Apex, Wilmington, and Winston-Salem. For more information about the Community Connections groups and how to join or start a group in your part of the state, contact Gillian Schultz, HNC Program Manager, at events@hemophilia-nc.org or call/text (919) 272-6000.

Community Connections at Jordan Lake (led by HNC Member, Troy Schoolcraft):

It was a beautiful day at Jordan Lake. Families had a great time networking, getting their kids together, and talking about some of the struggles that they have all experienced with hemophilia. We highly encourage anybody to come out the next time.

Community Connections in Wilmington (led by HNC Member, Amanda Harris):

Five adults and five children came out to enjoy an unlimited pizza buffet and arcade games at Cicis Pizza in Wilmington. Everyone had a great time and can't wait to do it again.



The need for connection and community is primal, as fundamental as the need for air, water, and food.

Dean Ornish

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Family Retreat

September 7-8, 2019
Concord, NC

The Hemophilia of North Carolina (HNC) Family Retreat is one of the most anticipated events of the year, and this year's retreat was no different. On Saturday morning, 30 families from across the state who have children twelve and under diagnosed with a bleeding disorder gathered for a memorable and impactful weekend at the Great Wolf Lodge.



The weekend started with an orientation session and icebreaker. Following lunch, the children and adults separated into different tracks to learn among their peers and get to know one another. The first session for adults, *Allowing Your Child to Soar*, presented by Dr. Jeffrey Karst from the Hemophilia Federation of America (HFA), walked parents through the steps of teaching their children to become independent adolescents and eventually adults. Following this session, HNC brought back *Bleeding Disorders Mingle*, which was better than ever! Over the course of an hour, families had the opportunity to meet and talk about different experiences and scenarios they may have had while raising a child with a bleeding disorder.



Meanwhile, the children participated in a variety of activities geared towards their particular age. Childcare was provided by NannysPlus childcare agency. Daycare was provided for children under four. Children ages 4-7 participated in *My Story of Resilience*, led by Kimberly Ramseur from the HFA, where through coloring and conversations, they learned more about their bleeding disorders. Children ages 8-12 learned about bleeding disorders in the session, *My Factor My Body*, led by Betsy Koval, clinical educator for Takeda. All the children had the opportunity to take ownership of their bleeding disorder in a fun way by participating in the Ted E Bear Clinic led by Judy Igelman, HNC member.

Following Saturday's sessions, families dispersed into the waterpark at the Great Wolf Lodge for lots of fun on the waterslides, wave pool, splash pad, water basketball, lily pad crossings, and more. It was great to see everyone having fun at the waterpark with one other after a day of connecting with new and old friends.



Sunday featured additional programs for adults and children. *What About Self-Infusion?* provided an overview of self-infusion, including techniques and best practices to begin learning, and then hands-on experience with simulated infusions using Baycuffs with a demonstration of an infusion from one brave, 8 year old HNC member. At the same time, the Parent Roundtable provided parents the opportunity to talk about topics important to them, especially as self-infusion isn't for the entire community. *How to Communicate With Your Child's School*, led by Dr. Michael Guerrero with Novo Nordisk, detailed the difference between 504 plans and IEPs, who is eligible for what plan, and important considerations to make when talking with teachers. The final session of the day, *Advocacy: Where We Make the Difference*, led by Tony Mitchell from CSL Behring and Charlene Cowell, HNC Executive Director, explained why advocacy is so important and ways that everyone can be involved. Sunday's children's track allowed kids to enjoy a round of miniature golf and the conclusion of the Ted E Bear Clinic.



HNC would like to thank its Program Partner, HFA, along with the event sponsors: Bayer Healthcare, CSL Behring, Genentech, Novo Nordisk, Pfizer Hemophilia, Sanofi-Genzyme, and Takeda who helped to make this event possible.





- Help
- Opportunity
- Partnership
- Empowerment

HOPE Program Update

It's hard to believe that it is already fall! Hemophilia of North Carolina's (HNC) HOPE Program has had an active year with many opportunities for families to learn and connect with each other. In the last few months, HNC has held a number of educational dinners to help families prepare for sending their children back to school with a bleeding disorder. If you need more information to share with school personnel, please contact the HNC office for a variety of available resources. The popular Family Retreat took place on September 7-8 at the Great Wolf Lodge in Concord, where families truly had the opportunity to make new connections and develop a support system. The Community Connections program is beginning to grow, with events having taken place in Apex, Wilmington, and Winston-Salem. In addition to the events,

HNC offers a Parent Mentoring Program and oversees a closed Facebook Group.

HNC's HOPE Program is designed to support families who have children twelve and under diagnosed with a bleeding disorder. 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

Blood Brotherhood Program Update

Are you an adult 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.

The Blood Brotherhood program has enjoyed several programs focusing around educational opportunities including advocacy, changes to the state's Medicaid program, and ultrasound for the diagnosis of bleeding events and joint damage. Hopefully you can find time to attend a Blood Brotherhood gathering near you but in the meantime, stay tuned to the HNC website and Facebook page, and be on the lookout for future events.

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.hemophiliated.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 (Latin Union) Program of Hemophilia of North Carolina (HNC) continues to support the needs of the Spanish speaking population across North Carolina. The Unión Latina Retreat was held on July 13-14 in Winston-Salem and connected nearly 40 Spanish speaking members. On August 24, HNC hosted a Unión Latina Program with 25 attendees at the Western North Carolina Nature Center in Asheville. Save the date for an event

on October 20 in Huntersville area and also on 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.



HNC Visits the St. Jude HTC

June 12, 2019
Charlotte, NC

Hemophilia of North Carolina (HNC) completed its visits to seven hematology centers in North Carolina including all five Hemophilia Treatment Centers (HTCs), with a visit to the St. Jude Affiliate Clinic at Novant Health Hemby Children’s Hospital. Charlene, Gillian, and Karyn were able to meet with the staff at St. Jude’s to discuss what HNC is doing in the community, to learn more about their initiatives, and to find out how we can support each other to benefit the patients and members of HNC. HNC appreciates the opportunity to work with the treatment centers across North Carolina and looks forward to partnership opportunities in the months and years to come.



St. Jude and HNC staff

2019 SECC STATEWIDE CAMPAIGN KICK-OFF!

August 2, 2019
Raleigh, NC



Karyn and Phil ready to introduce state employees to HNC

Hemophilia of North Carolina (HNC) was proud to be chosen to participate in this year’s Charity Fair on August 2 to kick-off the 2019 State Employees Combined Campaign (SECC)! Dozens of SECC charities were in attendance in Downtown Raleigh’s Bicentennial Mall, a walkway from the State Capitol to the Legislative Building between the NC Museum of History and the NC Museum of Natural Sciences. Hundreds of state employees gathered during an extended lunch break to meet representatives of charitable organizations throughout NC and select one as the designated charity for the SECC workplace giving program.



Charities from around the state gather at The Bicentennial Mall in Raleigh

HNC was represented by Board Vice President, Phil Poovey, and Manager of Operations, Karyn Davis. It was an excellent opportunity to meet with state employees, discuss the work HNC does throughout the state, and ask for their support.

Are you a state employee and interested in making HNC your designated charity? North Carolina state employees can opt to make contributions to an approved charity 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.

WORKPLACE GIVING

Does your employer offer an employee giving program?

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 HNC 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.

Diplomat / McCoy Scholarship Winners Shower HNC with Gratitude

By: Kathy Register, HNC Board Member

On May 12 of this year, 11 volunteers gathered in our Morrisville office from 9AM to 5PM to read scholarship applications. Thank you Amy, Charlie, Gail, Judy, Kathy, Lenore, Marvin, Phil, Richard, Sushant, and Teme. Scholarship applications came from across the United States and beyond, including one each from Bethpage, Tennessee and Old Bethpage, New York!

For many years Hemophilia of North Carolina (HNC) had a modest scholarship program with limited funding and scope. In 2009, BioRx, a specialty pharmacy that served the bleeding disorders community, provided \$8,000 that expanded our program to include promising students around the country. Diplomat Pharmacy later acquired BioRx and several other specialty pharmacies, and HNC's scholarship administration partnership continued, now with Diplomat Specialty Infusion Group. This year we had \$12,000 to distribute in awards ranging from \$500 to \$3,000. To be eligible, applicants must be seeking higher education and either be diagnosed with a bleeding disorder, a caregiver of a person diagnosed with a bleeding disorder, or have a sibling or parent in the same household diagnosed with a bleeding disorder.

The George D. McCoy HNC Scholarship is new this year and is funded and administered exclusively by HNC. It was established by the family and friends of George D. McCoy, a founding member of HNC, its past president, advocacy chair, and universally beloved mentor to so many in North Carolina with bleeding disorders. The annual \$1,000 award is designated for someone with severe hemophilia A. This year we were pleased to select Brian Duval, of Golden Valley Minnesota, as the inaugural recipient. We know George would be pleased.

This year we had 93 applications, each one scrutinized by at least two readers and then by a third in the case of a close call. Winners, both men and women, ranged in age from 17 to 53. Perhaps even more keenly than in years past, the award decisions were agonizing—so accomplished were the majority of applicants. Our reading committee members are so caring and dedicated that our process spilled beyond reading day. We had to compile and re-compile our metrics and comments for days via email and telephone, in order to award these scholarships as fairly and even-handedly as we could. Thanks to Charlie for being “scholarship central”. There were 15 winners in all, with awards ranging from \$500 to \$1250.

After award letters were mailed, HNC started receiving email after email from grateful winners. For us readers, this softened considerably the days-long worry of getting it right.

Brian Duval wrote: “This scholarship will benefit me by allowing me to afford higher education and allowing me to pursue my goal of becoming a healthcare lobbyist! In college, I plan on majoring in business with a minor in political science, being a member of the honors program, and continuing my advocacy efforts with the Hemophilia Foundation of Nebraska. The generosity of everybody who contributed ... to this scholarship means the world to me.”

To see more of our winners and their photographs, visit: hemophilia-nc.org/scholarship-winners



Brian Duval

2019 SCHOLARSHIP WINNERS

Brian Duval

Golden Valley, Minnesota
2019 Recipient of the
George D. McCoy
Hemophilia of North Carolina
Education Scholarship

2019 Recipients of the
Diplomat Specialty Infusion Group
Hemophilia of North Carolina
Education Scholarship

Griffin Alexander

Naples, Florida

Jack Brogan

Houston, Texas

Athena Brummett

High Point, North Carolina

Justin Horbacz

Ocean Township, New Jersey

Jibin Johns

League City, Texas

Hunter Johnson

Longmont, Colorado

Colton Ku

Durham, North Carolina

Daniel Liedl

Morgantown, West Virginia

Luke Luckey

Ann Arbor, Michigan

Riley Mills

Hickory, North Carolina

Zachary Oatley

North Canton, Ohio

Tori Robbins

Manahawkin, New Jersey

Lily Tignor

Bethpage, Tennessee

Julia Tsvyakh

Old Bethpage, New York

HNC Advocacy Committee Updates

When will North Carolina approve a budget? How is Medicaid Managed Care impacted by the budget delay? Will Medicaid Expansion happen in the state? These are a few of the many questions that the Hemophilia of North Carolina (HNC) Advocacy Committee has been looking at as we enter the month of September.

The NC budget has been a hot topic for most residents as its delayed approval as of the writing of this article on September 9, 2019, affects most operations and activities of the state. The biggest point of contention that stands in the way of an approved budget is Medicaid Expansion. Governor Roy Cooper has been adamant that NC needs to expand Medicaid as one of only 14 states that have yet to do so. The budget from the legislature does not include plans for expansion. The two sides have yet to discuss any ideas to compromise. In the meantime, piecemealed funding bills for budget items are being approved one-by-one.

One funding bill that Governor Cooper vetoed was for Medicaid Managed Care (MMC). As announced in earlier HNC communications, NC is going to see a major overhaul of the Medicaid Program. These changes were set to roll out in phases, with the first phase starting in November. Due to the lack of funding, the NC Department of Health and Human Services has announced that they are pushing back this roll out until February, at which time all NC Medicaid recipients will be switched over to the new MMC. As of now, all Medicaid recipients will need to enroll in MMC by December 13.

Two other bills that HNC advocates have been watching are SB 86: NC Small Business Healthcare Act and SB 432: Birth Center & Pharm Benefits Mgr. Licensure. SB 86 would allow small businesses, trade associations, and others to take advantage of association health care plans (AHPs), which are cheaper than Affordable Care Act (ACA) plans. The bill has already passed but may be delayed until a federal appellate court reviews an earlier decision that struck down a 2018 federal regulation that expanded the use of AHPs. A major concern is whether health care coverage will uphold the same protections that ACA plans do.

SB 432 is still being considered by the NC Legislature. HNC is supportive of the bill's ban on the use of Accumulator Adjuster Programs (AAP). AAPs "are programs Pharmacy Benefit Managers (PBMs) provide, mostly to large self-insured employers, which is applied to patients who use drug co-pay cards and other forms of manufacturer co-pay assistance. Under an AAP, a PBM accepts co-pay assistance for out-of-pocket costs associated with

a prescribed drug but then doesn't credit that amount toward the patient's overall deductible. This means that the PBM will draw down the full value of the co-pay card and still require the patient to pay co-pays (for additional medication fills, doctor's visits, etc.) up to the yearly out-of-pocket maximum. The manufacturer assistance will not apply toward satisfying the yearly maximum."¹ AAPs have already impacted the bleeding disorders community, as well as others, and HNC believes that North Carolina should join other states in protecting patients from these practices.

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.

¹ <https://www.hemophiliefed.org/our-role-and-programs/assisting-and-advocating/policy-priorities/accumulator-adjustor-programs/>

BIG CHANGES COMING TO MEDICAID

Without an approved North Carolina state budget, managed care for Medicaid enrollees has been pushed back to February 1 for all NC counties. If you are on NC Medicaid, you will need to take action by December 13 in order to be eligible.

Hemophilia of North Carolina (HNC) will continue to bring you email updates and alerts as new information is made available.

If you are not receiving emails from HNC, please register your email address by calling the HNC office at (800) 990-5557 or emailing info@hemophilia-nc.org.

The Chapter Staff Organization



CSO members from around the country

The Chapter Staff Organization (CSO), which is run by local bleeding disorders non-profits, organized and hosted a first-of-its kind two-day event in St. Louis, MO. Charlene Cowell, Executive Director of Hemophilia of North Carolina, was proud to join this meeting of thought leaders and executive directors from 34 organizations to discuss sustainability and collaboration within the bleeding disorders community long-term.

Thank you to Jordan Bazinsky, New England Hemophilia Association community member, for helping to lead and facilitate this important dialogue and discussion.

Alone we can do so little; together we can do so much.

Helen Keller

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

- Richard Atwood
- Daisy Eberle Bratton
- Mark & Jo Anne Buckley
- Rich Cea
- Irene Cowell
- Sue and W. Allen Heafner
- Allen & Linda Kurtz
- Phillip Poovey
- Brent White

Thank You

In Honor of the Register Family

Drs. David Howell & Sara Miller

In Honor of Stan and Tink Shelton

Susan Sydes

In Honor of Charlie Stotz

The Chaves Family

For the George D. McCoy Scholarship

Ahmed Al Badri

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Hemophilia of North Carolina 2019 Calendar of Events Highlights



October 12, 2019	Raleigh Family Festival & Walk for Bleeding Disorders – Morrisville, NC
October 17, 2019	Educational Dinner – Charlotte, NC
October 20, 2019	Union Latina Event – Concord, NC
November 2, 2019	Screening of “Bombardier Blood” – Morrisville, NC
November 2, 2019	Factor VII Support Group – Morrisville, NC
November 7, 2019	Women’s Event – Charlotte, NC
November 14, 2019	Educational Dinner – Durham, NC
December 7, 2019	Holiday Celebration & Evento de la Union Latina – Durham, NC
March 7-8, 2020	Annual Meeting – Raleigh, NC
April 18, 2020	Charlotte Family Festival & Walk – Charlotte, NC



IN THIS TOGETHER

Saturday, 7:18 pm

Checking out a music festival
with his girlfriend

Marc, hemophilia A

Not an actual patient

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

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bleedingdisorders.com



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**START YOUR WALK
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**save the
date**
Saturday, October 12, 2019

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

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**.

www.hemophilia-nc.org/festival