Come Out and Celebrate the 5th Annual HNC Family Festival & Walk in Charlotte

April 27, 2019
Charlotte, NC

The Hemophilia of North Carolina (HNC) Family Festival & Walk for Bleeding Disorders is just around the corner. Taking place once again in Uptown Charlotte, the 5th Annual Festival & Walk is expected to be a fun time for all! Can you believe it’s been 5 years since the Walk expanded to include Charlotte? Join HNC on April 27 to celebrate together!

As you have helped HNC to meet or exceed the fundraising goal, it is time to come out and celebrate!

Walkers enjoy the scenery of Uptown Charlotte

Educational Scholarships Available: Deadlines Approaching

Members of the bleeding disorders community are fortunate to have many scholarship opportunities available to them. Hemophilia of North Carolina (HNC) offers two scholarship programs.

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

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

Save The Date
HFA Symposium
April 4-7
San Diego, CA

World Hemophilia Day Celebration
April 16
Charlotte, NC

World Hemophilia Day
April 17

Family Festival & Walk for Bleeding Disorders
April 27
Charlotte, NC

NOW VWD Conference
May 17-19
Phoenix, AZ

Adult Retreat
May 31 - June 2
Greensboro, NC

NHF Inhibitor Summit
June 6-9
Indianapolis, IN

CHES Inhibitor Camp
June 21-24
Lakewood, PA

NHF Inhibitor Summit
June 27-30
Seattle, WA

HNC/HSC Teen Retreat
June 29 - July 2
Rock Hill, SC

Blood Brotherhood Retreat
July 26-28
Pine Knoll Shores, NC

NHF Inhibitor Summit
August 1-4
Boston, MA

Family Day Out
August 17
Clemmons, NC

Family Retreat
September 7-8
Concord, NC
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.

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.
Your Action Needed NOW: Keep Receiving The Concentrate by Mail

Help Hemophilia of North Carolina (HNC) conserve valuable resources! Do you enjoy receiving this newsletter delivered directly to your home, or would you prefer reading this newsletter online? Contact the HNC office to **OPT IN** to home delivery of *The Concentrate*.

If you want to continue to receive your copy of *The Concentrate* delivered by mail to your home address, please let us know! Only members who **OPT IN** to 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 view a 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.

Meet HNC’s Newest Board Members

Hemophilia of North Carolina (HNC) held the election for its Board of Directors at the Annual Meeting on March 2 in Charlotte and would like to welcome newly elected Board members Phil Poovey and Sushant Patil. HNC is also appreciative of Matt Igelman, who will be serving another two-year term, and Kelly Cribbs, who was accepted by the membership as HNC’s next president. At the same time, on behalf of all members, HNC would like to acknowledge those board members who have completed their terms of service and will be leaving their positions on June 30, 2019. It’s with great appreciation that HNC says thank you to Amy Shair Miller, Reid Coleman, and Steve Peretti for the time and commitment they’ve given to HNC and the members of this community.

*Sushant Patil, PhD – Morrisville*

Professionally, Sushant works as a Bioinformatics Scientist at UNC-Chapel Hill. Besides his research-focused academic career, he desires to be a problem-solver in real-world settings. He has been a good leader, mentor and organizer. Motivation, planning, management, and seasoned communication are some of his attributes. He likes working with teams in multi-cultural environments and aspires to be a positive catalyst for Hemophilia of North Carolina.

*Phillip Poovey — Raleigh*

Phil is originally from Hickory, NC but has lived in Raleigh since 1975. He graduated from UNC-Chapel Hill in 1964, with some additional graduate work in counseling. He worked for 30 years with the NC Division of Vocational Rehabilitation as a counselor, program specialist and was director of Human Resources. Retired since 1998, he has been active in the Glen Forest Homeowners Club as board member and past president. His deceased husband of 43 years, George D. McCoy, was active in establishing HNC in the 1970's and a $1,000 scholarship in his name will be awarded to a person with hemophilia for postsecondary training in the spring of 2019. Phil was honored as HNC’s 2018 Volunteer of the Year.
March Was Bleeding Disorders Awareness Month!

Hemophilia of North Carolina (HNC) members from around the state helped to spread the word and raise awareness for bleeding disorders throughout the month of March. With social media posts about bleeding disorders, participation in the National Hemophilia Foundation (NHF) Red Tie Campaign, and by requesting proclamations from North Carolina's city and state leaders, thousands of people were reached because of your efforts.

Thank you to HNC members for working with their city and state leaders to get proclamations declaring March as Bleeding Disorders Awareness Month for the state of North Carolina! We thank our state and local government leaders for their support! If you want to get a proclamation in your city for next March, please contact the HNC office to find out how.

HNC wants to give a big shout-out to The Bamboo Cookhouse for donating a portion of their proceeds for the month of March. The Bamboo Cookhouse, usually a food truck that travels the state, had the opportunity to spend March in a brick and mortar location in a popular part of Durham. Owners, Tim and Madz Igelman, have a special connection to this community. Tim's brother, Matt, lives with severe hemophilia and is on HNC's board of directors. In addition to serving delicious food, they helped to educate thousands of people about bleeding disorders!

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

Join Us for World Hemophilia Day

April 16-17, 2019
Charlotte, NC

April 17, 2019, will mark the 29th World Hemophilia Day, and the World Federation of Hemophilia (WFH) has themed this year's day as Reaching Out: The First Step to Care. You can follow and participate in WFH's 2019 campaign by visiting www.wfh.org/en/whd, where you will find links to a variety of activities, games, and social media images. World Hemophilia Day will also help to illustrate the importance of the WFH Humanitarian Aid Program.

On the local level, Hemophilia of North Carolina (HNC), along with Hemophilia of South Carolina (HSC), will be commemorating this day of building awareness about bleeding disorders around the world by partnering with Sanofi Genzyme for an event in Charlotte, NC, on April 16. On April 17, HNC will be lighting up the Wells Fargo Duke Energy Center in Charlotte red to raise awareness for hemophilia and other inherited bleeding disorders, and to honor our history and the progress within our community. You can view photos of buildings around the world lit up red by visiting the WFH website.

No matter where you are on April 17, you can do your part to help spread awareness by wearing red, posting on social media, and telling those you meet that you're wearing red for bleeding disorders.

Come Out and Celebrate the 5th Annual HNC Family Festival & Walk in Charlotte

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goal each year, this year's Festival & Walk fundraising goal has been increased to $70,000 and HNC needs YOU to help raise that amount. Registration is open on the HNC website along with tips and tricks to help make fundraising as easy as possible.

As in past years, the main event area for the Charlotte Family Festival is in the heart of Uptown Charlotte, on Mint Street between BB&T Ballpark and Romare Bearden Park. The morning of fun and entertainment will include music, performances, children's activities, prizes, food, and of course a walk around Bank of America Stadium and BB&T Ballpark.

It's not too late to start a team, register as an individual, and sign up to volunteer. Plan to bring your family, friends, coworkers, and 4-legged friends with you on April 27. The Festival's success depends on the support of Walk teams, individual fundraisers, and sponsors in order to reach our fundraising goals! All of the money raised stays right here in North Carolina to benefit HNC members across the state. Your enthusiasm and support will help HNC to continue to offer programs and services to the state's bleeding disorders community.
Big Changes for the 2019 HNC Adult Retreat
May 31-June 2, 2019
Greensboro, NC

Save the date for the 2019 Hemophilia of North Carolina (HNC) Adult Retreat, from May 31-June 2. There are some big changes happening to the Adult Retreat this year! The retreat will be merging three past events, the Adult Retreat, SOAR Retreat, and Men’s Retreat, into one bigger event with the hope of a larger turnout and opportunity for more networking between members.

Don’t worry, in addition to the general sessions that the Adult Retreat is known for, there will also be separate tracks for men and for the SOAR Program. HNC is looking forward to having a variety of programs and speakers, including Dr. Ma and Dr. Abajas from the UNC Chapel Hill Hemophilia Treatment Center for the SOAR track, programs from the Hemophilia Federation of America and National Hemophilia Foundation for general sessions and men’s track, and other sessions to be announced soon.

Information and registration will be available soon on the HNC website, or you can contact the HNC office at (800) 990-5557.

Teen Retreat: Join the Carolina Crew in June!
June 29-July 2, 2019
Rock Hill, SC

Who: Teens, ages 13-18, who have a bleeding disorder or are the sibling or child of a person with a bleeding disorder. Teens will be allowed to bring one friend or family member with them as long as that person is also a teen.

What: Hemophilia of North Carolina (HNC), in partnership with Hemophilia of South Carolina (HSC), is providing this fun, educational, and interactive weekend designed especially for teens in the community. If you’ve never been to one of the HNC/HSC Teen Retreats, please check out the HNC Facebook page for photos. Gut Monkey will also return to lead teens in their Leading Edge program. Find out more about the Leading Edge Program at www.gutmonkey.com.

Where: Teens will head back to Camp Canaan in Rock Hill, SC to enjoy a great weekend of fun and educational programming.

When: The Teen Retreat will take place from June 29 through July 2, 2019.

Why: The Teen Retreat is a great opportunity to make new friends, share laughs, challenge yourself, and prepare for your future.

How: Forms for registration will be available soon on the HNC website, so be on the lookout. HNC will provide busing from the East Carolina University Hemophilia Treatment Center in Greenville and the HNC office in Morrisville.
Talking about Financial Aid for College: An Educational Dinner

December 11, 2018
Charlotte, NC

While many people were busy shopping for holiday gifts, 15 Hemophilia of North Carolina (HNC) members gathered at Maggiano’s Little Italy in Charlotte for an educational dinner, Navigating Financial Aid, facilitated by Tanya Stephenson, Sanofi Genzyme CoRe Manager. Attendees learned about the Free Application for Federal Student Aid (FAFSA), important things to keep in mind when completing the application, and different resources that are available to help people pay for the cost of attending college.

Following the presentation, HNC Program Manager, Gillian Schultz, provided information about the scholarships that HNC offers including the George D. McCoy Education Scholarship and the Diplomat Specialty Infusion Group/Hemophilia of North Carolina Education Scholarships, as well as other scholarship opportunities that are available to people affected by bleeding disorders. Some scholarships available are for individuals diagnosed with a bleeding disorder, while others are also available for members of the same household.

After an informative discussion, good meal, and time to catch up and talk about plans for the holidays, everyone left with some new information that will help them as they prepare to apply for college. For more information about the HNC Scholarships along with other scholarship opportunities, see page 1 of this newsletter or visit the HNC website at www.hemophilia-nc.org/scholarships.
Ultrasound: Blood Brotherhood Event

December 15, 2018
Hickory, NC

By: Matthew Igelman, HNC Blood Brother

Getting together at WOOD Pizza in Hickory, NC, for lunch and the educational program Ultrasound: What it Looks Like in There, by Jennifer Newman, MSPT, from the UNC-Chapel Hill Hemophilia Treatment Center, was a great way to wrap up 2018. We got to learn about Musculoskeletal Ultrasound hands on! The gathering was a unique opportunity to use new cutting-edge portable ultrasound technology thanks to Jen Newman. She explained the benefits ultrasound can bring in the diagnosis and care of bleeding disorders. Guys that attended, most utilizing this ultrasound technology for the first time, were amazed at how useful the technology can be for bleeding disorders.

We can’t wait to see more Blood Brothers at events in 2019.

Charlotte Festival & Walk: Team Captain Meeting

January 19, 2019
Matthews, NC

On January 19, five team captains or potential team captains met for a working lunch to learn more about the Charlotte Family Festival & Walk for Bleeding Disorders. An overview of the Festival & Walk, directions on how to register, and helpful tips were provided to help team captains with their fundraising efforts. The meeting concluded with a brainstorming session on possible individual fundraising ideas including selling homemade crafts, a lemonade stand, providing donors with a small trinket of thanks, hosting a spaghetti dinner, posting on social media, asking medical providers, selling magnets, bake sales, and approaching restaurants about spirit nights to fundraise for Hemophilia of North Carolina.

HNC Casino Night – Everyone was a winner!

January 26, 2019
Durham, NC

The 12th Annual “Hearts for Hemophilia” Casino Night event took place at the Durham Convention Center in the heart of Durham’s city center. It was a lively night of entertainment with wonderful food, casino games, and exciting live and silent auctions.

Each guest started out with $10,000 in “fun money” to play casino games including blackjack, craps, Texas hold’em poker, and roulette. At the end of the night, winners could trade in their winnings for raffle tickets to win some fabulous prizes.

The silent auction was filled with some extraordinary prizes that went to the highest bidder including: getaways to Charlotte, the Omni Hotel Richmond with rafting on the James River, and a Bluegreen Resort weekend in Myrtle Beach, sports memorabilia, art by Dan Campbell and Lewis Wilson, tickets to CATS at Durham Performing Arts Center, wine tasting at Total Wine & More, artisan pieces including handblown glass and handmade jewelry, a comedy package with tickets to Raleigh Improv.

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HNC Casino Night — Everyone was a winner!  

and Goodnights Comedy Club, tickets for area attractions including Marbles Kids Museum, the NC Zoo, and the Great Raleigh Trolley, themed gift baskets, and gift cards to many area restaurants.

When it came time for the live auction the event’s auctioneer, Kandyce Ellis (NCAL 10202), stole the show with her warm personality and energetic style. The live auction featured some amazing prizes including a Carolina Panthers Lithograph Signed Football, a Clemson University Football signed by Head Coach Dabo Swinney and Defensive Coordinator Brent Venables, and a Deluxe Durham Stay-cation including a one-night stay and dinner for two at 21C Museum Hotel and Counting House Restaurant with cinema passes to Durham’s historic Carolina Theatre, but it was Kandyce’s ability to get the crowd involved that made the auction such a success. As always, the most meaningful part of the live auction was the opportunity for those in attendance to make a bid to contribute to the Hemophilia of North Carolina (HNC) Emergency Financial Assistance Program. This is an important part of HNC’s mission to support the bleeding disorders community, so every dollar donated during this part of the auction goes directly to helping families obtain MedicAlert IDs and managing financial emergencies.

Win or lose, everyone present helped HNC raise more than $22,500 with all proceeds helping HNC continue its mission of improving the quality of life for those affected by a bleeding disorder and move closer to fulfilling the vision for all persons affected by bleeding disorders to achieve their full potential without barriers or limitations.

The HNC Board of Directors would like to acknowledge the hard work and effort that made this event possible, especially the Casino Night Committee Members, Ryan Griffith, Diane Johnston, and Xaviette Pointer-Kincy. In addition, thank you to the entire list of sponsors, donors, and individuals who came out to support Casino Night and Hemophilia of North Carolina.
HNC Meets with Hematology Centers Around North Carolina

As part of Hemophilia of North Carolina’s (HNC) effort to strengthen partnerships between HNC and North Carolina’s hematology centers and Hemophilia Treatment Centers (HTC), HNC staff has been traveling the state to meet with each center’s staff and medical providers. These meetings have become an opportunity for HNC to acquaint the centers with its programs and services while gathering information about the changing needs of the community from those who are seeing patients with bleeding disorders on a routine basis.

These meetings have been beneficial to both HNC and the centers they’ve been visiting. HTCs and hematology centers will now have a better understanding of how HNC programs and services can be a benefit to their patient populations. In addition, HNC staff has been communicating their need for HTCs to support HNC by helping to inform patients about what they can gain from membership to HNC, including educational and support opportunities as well as special events, advocacy, scholarships, and more. It is through this partnership, that HNC hopes to be able to better ensure that programs and services remain relevant and well received by both existing and new members moving into the future.

Since November of 2018, meetings have taken place with Mission Hospital’s pediatric hematology center in Asheville, and the Hemophilia Treatment Centers at East Carolina University, University of North Carolina – Chapel Hill, Levine Cancer Center and Levine Children’s Hospital, and Wake Forest University. HNC is finalizing meeting dates with the remaining centers as of the time of this newsletter’s publication.

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Infusion Support: HOPE Educational Dinner
February 21, 2019
Greensboro, NC

Managing infusions for hemophilia or von Willebrand disease can be tricky. From helping your child to adjust to the regular sticks, to dealing with developmental changes and learning to self-infuse, it is no small feat administering factor. On Thursday, February 21, as part of Hemophilia of North Carolina’s (HNC) HOPE Program for families, HNC was pleased to offer an educational presentation, *Infusion Support for Caregivers of Patients with Hemophilia*, facilitated by Jeffery McFall, Pfizer Patient Affairs Liaison. It was a full house at Mark’s Restaurant as families got to know each other. In addition to the tips and tricks presented, families shared their own experiences with managing infusions and the challenges that they sometimes face. Following a delicious dinner, presentation, and lively conversation, families left with some new ideas about how to help their child. Thank you to Pfizer Hemophilia for partnering on this event.

Transition to High School: An Educational Dinner
February 22, 2019
Jacksonville, NC

Regardless of your age, whether you’re starting at a new school or job, transitions can be complicated. At the recent educational dinner, *Transition to High School*, participants were offered great insight into the necessary steps to making school transitions go more smoothly.

Families gathered at Golden Corral in Jacksonville, NC, and enjoyed an all-you-can-eat buffet dinner before the presentation began. Participants ranged from a student already in high school who was recently diagnosed with a bleeding disorder, to a middle school student with a bleeding disorder who will be moving up to high school soon. Shelby Smoak, Ph.D., gave an informative presentation that included an overview of 504 plans and an open discussion about collaboration with medical providers, teachers, school administrators, and others in order to develop a plan that is right for the individual student. Families at the dinner shared their own experiences to help one another as they work their way through the various processes involved with transitioning.

Thank you to CSL Behring and BioMatrix Specialty Pharmacy for partnering with HNC on this event.

46th HNC Annual Meeting: Moving the Community Forward
March 2, 2019
Charlotte, NC

Hemophilia of North Carolina (HNC) members from across the state gathered in Charlotte on March 2 at the Sheraton Charlotte Airport Hotel for the Annual Meeting. This year’s theme, *Moving the Community Forward*, highlighted where the bleeding disorders community has been and the bright future ahead.

As everyone checked in at the registration desk on Saturday morning, attendees were able to grab some breakfast and meet with the sponsors before heading into the day’s sessions. Attendees who had never been to an Annual Meeting before were welcomed with the First Time Attendees Session which highlighted what to expect for the day. Then, Dr. Steven Pipe led the first session of the day, *Shifting Paradigms of Treatment for Hemophilia*. The session reviewed factor replacement therapy and the development of long-acting factor products, as well as how methods of treatment are changing from factor replacement to other treatments including bispecific monoclonal antibody therapy, treatments in clinical trials that target anti-thrombin, and gene therapy trials.

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Noticias del Programa de la Unión Latina

El Programa de la Unión Latina de Carolina del Norte (HNC, por su sigla en Inglés) está optimista de tener un gran año 2019! El cual comenzó con una sesión educacional, Resistencia: Superando los Cambios de la Vida, durante la reunión anual el pasado 2 de Marzo.

Otros próximos eventos de la Unión Latina para el 2019 están programados para el 4 de Mayo en Raleigh, el 14 de Septiembre en Concord, y el 7 de Diciembre para la celebración de fin de año del HNC, cuya localidad será anunciando pronto.

HNC espera con gran expectativa el Segundo Retiro de la Unión Latina, el evento será aún mas grande este 2019. La fecha será anunciada prontamente, así es que este atento.

La Unión Latina es un programa diseñado por HNC para dar soporte y asistir a individuos de origen latino y sus familias en Carolina del Norte, quienes han sido afectados por enfermedades hemorrágicas. Los eventos en Español, de un día de duración que se llevan a cabo durante el año, son posibles gracias a Takeda. Para mayor información, por favor visitar el sitio web de HNC.

Les Invitamos a Celebrar el 5to Festival de la Familia y Caminata del HNC en Charlotte

27 de Abril del 2019
Charlotte, Carolina del Norte

Hemofilia de Carolina del Norte (HNC por sus siglas en Inglés) y su Festival de la Familia y Caminata están prontos a celebrarse. Este se llevara a cabo nuevamente en Uptown Charlotte. Este 5to Festival y Caminata prometen ser todo un suceso y mucha diversión para todos! Parece increíble que ya han transcurrido 5 años desde que la Caminata se extendió para incluir Charlotte! Acompañen a HNC el 27 de Abril, para celebrar juntos!

Cada año ustedes han contribuido a HNC a lograr o superar las metas de reunión de fondos. Este año la meta de fondos a reunir ha aumentado a $70,000. HNC les necesita para lograr reunir esa cantidad. La inscripción esta abierta en la pagina web del HNC, así como ideas y datos para que la reunión de fondos sea posible y de una manera fácil.

Como en años anteriores, el evento mas importante de esta área para el Festival Familiar de Charlotte se encuentra en el corazón de Charlotte, en la calle Mint, entre BB&T Ballpark y Romate Bearden Park.

Esa mañana promete ser de mucha entretención y diversión e incluirá música, presentaciones, actividades para los niños, premios, comida y por supuesto un paseo alrededor del Bank of America Stadium and BB&T Ballpark.

Todavía es tiempo para organizar un equipo, inscribir a una persona y a anotarse como voluntario. Planeé traer a toda la familia, a sus amigos, colegas e incluso a su amigo de cuatro patas favorito el 27 de Abril. El éxito del Festival depende del apoyo de los equipos que participen en la caminata, de los individuos que consiguen fondos, y de los auspiciadores, que hacen un gran esfuerzo para lograr nuestra meta. Todo el dinero que se logre reunir, quedará aquí en Carolina del Norte para beneficio de todos los miembros de HNC, en el estado. De su entusiasmo y soporte dependerá que HNC continúe con los programas y servicios para aquellos que sufren de enfermedades hemorrágicas en Carolina del Norte.
SOAR Program Update

Hemophilia of North Carolina (HNC) continues to raise awareness and advocate for women with bleeding disorders. The HNC SOAR Program provides education, resources, and support for women and girls with bleeding disorders and works to raise awareness and advocate for better diagnosis and treatment through educational opportunities and advocacy initiatives throughout the year.

In 2019, there will be one big change to the SOAR Program. Instead of a standalone SOAR Retreat, there will be a SOAR track at the HNC Adult Retreat from May 31-June 2. Please save the date and join HNC at the Adult Retreat!

To help raise awareness about women and girls with bleeding disorders, The HNC Women’s Advocacy Coalition started the #DontBlush campaign. Almost every Thursday, HNC posts a fact about females with bleeding disorders on its Instagram and Facebook pages. Help HNC to raise awareness and spread the word by sharing these facts on your social media accounts. In January and February of 2019, posts with #DontBlush reached over 4,000 individuals on Facebook alone, so please help HNC make a difference in the life of a woman or girl suffering with an undiagnosed bleeding disorder by participating in this awareness campaign.

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.
Kids & Teens at the HNC Annual Meeting

Kids and teens had a great time with the variety of programming available at this year’s Annual Meeting (see full article on page 10). Here are some highlights. Please plan to attend next year’s Annual Meeting in the Raleigh area in March 2020.
After lunch, HNC showed the documentary, Bad Blood: A Cautionary Tale, which documented the tragedy of the hepatitis and HIV crises in the 1970s and 1980s. It is through remembering the past, the struggles of those who fought for safe factor and a safe blood supply, that we remember the importance of advocacy and why the bleeding disorders community continues to be a watchdog now and into the future.

The HNC Annual Business Meeting was an opportunity for members to hear about HNC’s financial health and also to vote for nominees of the 2019-2021 term of the HNC Board Directors. Everyone who was on the ballot was elected or re-elected to the HNC Board (see page 3 for more information).

In addition to the general sessions, there were breakout sessions held in the morning and the afternoon. Morning sessions highlighted different bleeding disorders. Virginia Kraus from Grifols presented Overview of Von Willebrand Disease, Maria Herrera from the National Hemophilia Foundation (NHF) presented Factor Function: How Half Life Affects You, which reviewed how knowing the half-life of your treatment is important for managing hemophilia. Charlene Cowell, HNC, led a roundtable conversation about the needs of the rare bleeding disorders community, including those with rare factor deficiencies and platelet disorders. Yinell Nunez from Takeda led the Unión Latina session, Resilience, Growing Through Life’s Changes. The afternoon featured breakout sessions for HNC Programs including the Blood Brotherhood, HOPE, and SOAR, as well as a session for partners and spouses. Jennifer Newman, Physical Therapist at the UNC Chapel-Hill Hemophilia Treatment Center (HTC), used ultrasound to show men with bleeding disorders inside their joints, and how ultrasound can be used to manage a bleeding disorder for the Blood Brotherhood Session. Dr. Bryant, from the HTC at the St. Jude Affiliate Clinic at Novant Health Hemby Children’s Hospital led the HOPE session, Managing Transitions, which focused on the importance of teaching children to become independent at different stages of childhood and adolescence. Cheri Clark, led the SOAR session, How to Advocate for Women with Bleeding Disorders, where she shared her story of not being diagnosed until she was 40 years old, and how important it is for women to work with their healthcare providers to receive a diagnosis. Cathy Tiggs, from NHF led a session Relationships and Intimacy for partners and spouses.

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Finally, the HNC staff presented *Your Impact in the Bleeding Disorders Community* to show how every member helps to guide the path that HNC takes in the future. Whether through participation in events and programs, advocacy, volunteering, or fundraising, every HNC member has a role in what HNC can do in the future.

In addition to the adult programming, the Annual Meeting provided an opportunity for HNC’s younger members to learn and participate in fun programs throughout the day. Teens learned about being advocates in a session about advocacy, led by Kimberly Ramseur, HNC Advocacy Chair, and sponsored by the Hemophilia Federation of America (HFA). They also had the opportunity to learn about joint health and using ultrasound to see inside their joints in a session led by Jennifer Newman, PT at the UNC HTC. The afternoon offered a trip to the Inner Peaks Indoor Climbing Center where teens had the opportunity to participate in rock climbing in a safe and fun indoor environment. Children from ages 4-12 participated in a variety of programs throughout the day including *Junior Scientist* or *My Amazing Blood*, led by Leslie Oygar from Accredo. In the *Junior Scientist* program, children learned about DNA and extracted DNA from strawberries. Children who participated in *My Amazing Blood* learned about the properties of blood and made slime to represent their own blood. The children also participated in a Magic Show, led by Twist the Balloon-Man, and created art projects with Abrakadoodle. Amazing Gaming on Wheels was at the meeting in the morning, which provided the kids some fun and friendly gaming opportunities. Daycare was provided for the youngest attendees. All the children’s nannies were provided through Nannys Plus.

A final thank you to HFA, NHF, sponsors, volunteers, and members who contributed and helped make HNC’s 46th Annual Meeting a success. Stay tuned for the date of next year’s Annual Meeting, which will be in March 2020 in the Raleigh area.

The hemophilia treatments of today were once the dreams of yesterday. Proof that when SCIENCE AND THE COMMUNITY come together, great things happen.
Volunteer and Special Guest Dinner
March 1, 2019
Charlotte, NC

As has been the tradition, the Hemophilia of North Carolina (HNC) Volunteer and Special Guest Dinner took place the evening before the Annual Meeting. This year’s dinner in appreciation of HNC’s volunteers, special guests, and supporters took place at the Sheraton Charlotte Airport Hotel. This was an opportunity to come together and celebrate those who help make it possible for HNC to continue to provide programs and services to the bleeding disorders community in North Carolina. Those who attended were honored to be able to listen to an engaging presentation by Dr. Steven Pipe, Pediatric Medical Director, Hemophilia and Coagulation Disorders Program; Director, Special Coagulation Laboratory at the University of Michigan.

Dr. Pipe’s presentation about the bright future of treatment for bleeding disorders was an inspiration to those who dedicate their time, talent, and resources to bettering the lives of those affected by bleeding disorders.

HNC is grateful to all of the volunteers and supporters who made its programs and services a success in 2018!

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
Barbara & Marlin Hargett
W. Allen & Sue Heafner
Julia Jessop
Cathy Hinson Jones
Carolyn Brandon Nuscher Kriesten
Linda & Allen Kurtz
Genise Lee
Della McDowell
Ronald & Christina Roberts
John Sakakeeny

In Honor of Bob Conger
Natalie Branton

In Memory of Derek Lee Brown
Thomas & Jane Brown

In Memory of Paul H. Everhart
Michael Everhart

In Memory of Warren Jewett
Dr. & Mrs. Gilbert White

In Honor of Caleb Price
Robert & Patsy Houston

In Memory of George D. McCoy
Phillip Poovey
Paul & Emily Wilson

In Memory of David Paul Vess
Carolyn Bailey

In Honor of Charles Register
John & Patricia Bartlett
Betty & John Leydon
Bryant Stolp
Penni Tharp

In Memory of George D. McCoy
Phillip Poovey
Paul & Emily Wilson

In Memory of W arren Jewett
Dr. & Mrs. Gilbert White

Thank You
HOPE Program Update

Hemophilia of North Carolina’s (HNC) HOPE Program is for families who have a child 12 or under with a bleeding disorder. Educational opportunities are geared towards families who have children in this age range and may include information about daycare and school, 504 plans and IEPs, child development, infusion support, transitions, and more. HNC can also offer resources to assist families with these topics. On February 21, HNC held a HOPE Educational Dinner in Greensboro, Infusion Support for Caregivers of Patients with Hemophilia, which you can read more about in this edition of the newsletter.

In addition to educational events, HNC is working hard to provide other types of support, including the Mentoring Program and HOPE Facebook group. HNC is also beginning to roll out Community Groups in different areas of the state including Asheville, Southport, Sanford, Lexington, and Mocksville. Community Groups will provide informal opportunities – including playdates, park outings, and more – to get together with other members of the bleeding disorders community. Please stay tuned to your email and the HNC Facebook page for more information about this opportunity.

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. You can reach her 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

Calling all men with a bleeding disorder! The Blood Brotherhood program at Hemophilia of North Carolina (HNC) is a great way to connect with other men throughout the year. The Blood Brotherhood held its first gathering at the HNC Annual Meeting in Charlotte on March 2. During the break-out session in the afternoon, Jennifer Newman, Physical Therapist from the UNC-Chapel Hill Hemophilia Treatment Center, presented a hands-on demonstration in her program Using Musculoskeletal Ultrasound in the Care of Bleeding Disorders. It was also a great time to socialize with the fellow blood brothers.

Stay tuned to the HNC website for more gatherings of the Blood Brotherhood in 2019 as they become scheduled and be sure to save the date for the Blood Brotherhood Retreat on July 26-28 in Pine Knoll Shores, NC.

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

Unión Latina Program Update

Hemophilia of North Carolina’s (HNC) Unión Latina Program is looking forward to a great 2019! The year started with an educational session, Resilience: Growing Through Life’s Changes at the Annual Meeting on March 2. Other Unión Latina dates for 2019 include May 4 in Raleigh, July 21 in Asheville, September 14 in Concord, and December 7 at the HNC Holiday Celebration, location to be announced soon. HNC is also looking forward to the second Annual Unión Latina Retreat, to be held this summer. Following a very successful first Unión Latina Retreat in 2018, HNC is looking forward to the opportunity to grow the event in 2019. The date will be announced very soon, so be on the lookout.

The Unión Latina is an HNC Program designed to support and educate Latino individuals and families in North Carolina who are affected by bleeding disorders. Programming for one-day events throughout the year are provided in Spanish and made possible thanks to a grant from Takeda. For more information, visit the HNC website.
Remembering Michael Riddick

By: Jeff Harper
Raleigh, NC

The hemophilia-inhibitor community lost a special friend with the passing of Mike Riddick on February 27, 2019, at the age of 40.

Mike was born in Plymouth, NC on February 10, 1978, attended St Augustine College, and re-located to Raleigh in 2006. He was employed by HRF, Inc. responsible for inventory control and donor travel arrangements.

He attended many hemophilia/inhibitor events where he developed lasting friendships and was known for his “Magnetic” personality. He was eager to help others, including individuals and their parents affected by hemophilia-inhibitors by sharing his own life experiences. In recent years he spent personal time with an affected younger individual sharing his knowledge and helping instill confidence.

Mike enjoyed traveling and politics. He spent his free time researching geo-political topics covering a broad range of history.

He leaves behind a large loving family, many friends, and co-workers.

We will miss our friend Mike.

More Hemophilia Literature for Younger Readers

By: Richard J. Atwood

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Here are more books about hemophilia for younger readers. In the August issue of PEN, we surveyed books with fictional main and supporting characters who happen to have hemophilia. Other literary genres, such as biography, time-travel fantasy, as well as some unexpected references, also include hemophilia. Something for everyone.

Follow your curiosity by exploring different genres of literature for younger readers. I suggest the following books for your enjoyment and learning.

**BIOGRAPHY**

*The Uncanny* (Sterling, 1998)
Peter Hepplewhite and Neil Tonge

The Unexplained series of children’s books for young adults includes this story of how Rasputin, or the Mad Monk, used his powers to heal a joint bleed that Alexei Romanov, son of the Russian tsar, experienced because of his hemophilia in 1907. The text teases the reader, but doesn’t supply enough information on the full story of Rasputin.

*Blood Red Snow White: A Novel of the Russian Revolution* (Orion, 2007)

Marcus Sedgwick

Though this children’s biography is based on documented facts, it could also be considered a spy novel. In 1913, Arthur Ransome, a writer of children’s books, leaves his family behind in England to become a newspaper correspondent in St. Petersburg. There he learns of Alexei, who has hemophilia, and of Rasputin with his healing powers. Ransome marries the private secretary of Leon Trotsky (1879–1940; a leader of the Russian Communist Party after the 1917 Bolshevik Revolution), becomes a British agent, and returns to England in 1942 to write more children’s books.

*Germ Stories* (University Science, 2008)

Arthur Kornberg

These 10 profiles of germs are written for young readers as poetry, with catchy rhymes accompanied by dynamic illustrations and photographs. The story of HIV mentions the fictional Bill, a second grader with hemophilia. The references to hemophilia and AIDS seem dated, but readers may not notice.

*Patrick’s Wish* (Second Story, 2010)

Karen Mitchell with Rebecca Upjohn

In this biography for young readers, with accompanying family photographs, Lyanne tells the story of her older brother, Patrick Fortin (1978–2001), who had hemophilia and AIDS in Canada. Patrick’s wish was a cure for AIDS, and before her brother died, Lyanne promised to tell Patrick’s story.


Nelson Price

This young adult biography summarizes the accomplishments of Ryan White (1971–1990), who became a national celebrity because he had both hemophilia and HIV. Ryan wanted to continue attending school in Indiana even with serious medical conditions. Taking advantage of all the publicity, Ryan became a spokesperson for AIDS education. Unfortunately, while hemophilia was controlled, AIDS was deadly. This book helps us remember Ryan.
More Hemophilia Literature for Younger Readers

continued from previous page

**TIME-TRAVEL FANTASY**

Travel through the space-time continuum is a popular topic for young readers.

**The Curse of the Romanovs** (Margaret K. McElderry, 2007)
Staton Kabin
Alexei Nikolaevich Romanov, 12-year-old son of the Russian tsar, has hemophilia. He uses visualization techniques taught by Rasputin to save his own life by escaping Russia in 1918. Alexei travels through time and space to New York City in 2010. There he meets Varda Ethel Rosenberg, his 15-year-old distant cousin whose father with hemophilia died of AIDS. Varda saves Alexei by traveling back to St. Petersburg in 1918. Ages 12 and up.

**Secrets of the Survivors** (Xlibris, 2008)
Mark L. Eastburn
This young adult fantasy novel, written by an author with von Willebrand disease, tells the story of 10-year-old Alex Hidalgo and his younger sister Katherine, from Philadelphia. The siblings are contacted by survivors of an intelligent ancient reptilian civilization from 65 million years ago. In their struggle to save planet Earth, Alex and his sister enlist three other classmates, one of whom has hemophilia.

**The Queen Must Die: Chronicles of the Tempus** (Atlantic, 2010)
K.A.S. Quinn
The author admits that she “tinkered” with the facts in this children’s novel, part of a trilogy that involves travel through time and space. Katie Berger-Jones falls asleep in New York City while reading the letters of Queen Victoria’s daughters, and then wakes up in Buckingham Palace in London, 1851. There Katie meets Prince Leopold, who has hemophilia, before she struggles to return home on the same day she left. Leopold was actually born in 1853.

**What’s Up with Louis? Medikidz Explain Hemophilia** (Medikidz, 2011)
Dr. Kim Chilman-Blair and Shawn deLoache
This storybook comic features five Medikidz who live on the planet Mediland. When Louis, on Earth, is mocked by his friends for having hemophilia, the Medikidz teleport him to their planet. Once he discovers his potential, Louis returns to Earth knowing how to properly treat his hemophilia.

**Risked** (Simon & Schuster, 2013)
Margaret Peterson Haddix
This science fiction novel tells the story of 13-year-old Jonah Sizemore and his younger sister Katherine, from Ohio, who help rescue 36 famous missing children from the past. These missing children, now using aliases, include Anastasia Romanova and Alexei Romanov, who has hemophilia. With the aid of a time-travel device, the children attempt to alter history by traveling back to Russia in 1918. Ages 8–12.

**HEMOPHILIA IN UNEXPECTED PLACES**

Authors of fiction for young readers may refer to hemophilia in unexpected ways.

**Tiger Eyes** (Bradbury, 1981)
Judy Blume
This young adult novel follows 15-year-old Davey Wexler when she moves with her family to Las Alamos, New Mexico. At her new school, Davey views a film on hemophilia, but she already knows about hemophilia because she read Nicholas and Alexandra in eighth grade.

**Fallen Angels** (Scholastic, 1988)
Walter Dean Myers
In this young adult novel, Richard Perry graduates from high school in Harlem, New York, and enlists in the army in 1967. Richard declines a bonding ritual of mixing blood with other black soldiers by claiming to have hemophilia. Another soldier notes that hemophilia is a medical deferment from military service.

**Billy’s Boy** (Wildcat, 1997)
Patricia Nell Warren
Included in a series on gay family life, John William Heden is age 12 in 1989. He moves with his single, lesbian mother to Malibu, California. Searching for his father, supposedly a gay Olympic track medalist who donated his sperm before he died, John William meets Michael, who is conducting research at UCLA on inherited blood diseases like hemophilia.

**Summertime Blues** (Oxford University, 2001)
Julia Clarke
In this coming-of-age novel for young adults, 17-year-old Alexander Harling, from London, responds to a rude comment about his mother. Alexander beats up the guilty classmate, who bleeds so much that Alexander thinks the boy is hemophilic and needs a transfusion.

**The Healing Time of Hickeys** (Polestar/Raincoast, 2003)
Karen Rivers
In this teen novel written as a diary, Haley Andromeda Harmony is a 16-year-old Canadian high school senior in 2002. Because she’s a hypochondriac, Haley searches internet sites for a definition of hemophilia. When she skins her knuckles, Haley then believes she is bleeding to death due to her supposed hemophilia.

**Birthmarked** (Roaring Brook, 2010)
Caragh M. O’Brien
As part of a fiction trilogy for young readers, this novel follows 16-year-old Gaia Stone, who lives in a divided country and trains as a midwife in the year 2409. Gaia learns about the health problems of dying children and infertile mothers due to inbreeding in the privileged city. The biggest concern is an increasing number of children with hemophilia. Sadly, hemophilia is not cured in the future.

**The Truth About Celia Frost** (Usborne, 2011)
Paula Rawsthorne
In this young adult thriller, 14-year-old Celia Frost is born with a rare blood-clotting disorder for which there is no treatment—or so her overprotective mother claims. When a classmate cuts Celia, she goes to the local hospital. Her mother refuses to allow any blood tests. After arguing with her mother, Celia learns the truth: her mother abducted her from a research laboratory, where as a child, Celia had been experimentally injected with live viruses. To prevent the spreading of the viruses, her mother employed what is now called Munchausen Syndrome by proxy, imposing a fake medical diagnosis on a child. Meanwhile, the research doctor tries to capture his escaped research subject, putting Celia’s life in danger. You can find hemophilia included in a wide variety of literary genres. Literature meant for younger readers can be enjoyed by all ages, including adults. Find something you and your child like, pick up a book, and read.

1. Unfortunately, the author never uses the label Munchausen Syndrome by proxy (MSBP), or ever attempts to fully explain the fictional mother’s psychiatric condition.
   In this rare condition, parents fabricate the physical symptoms in the child, producing a chronic fictitious disorder, most often without the child’s awareness or willingness.
   For hematology MSBP, this usually involves parents forcing their child to ingest an anticoagulant to induce bleeding symptoms.
Hemophilia of North Carolina (HNC) was honored to be able to partner with the National Organization for Rare Disorders (NORD) and their NC Rare Action Network (NC RAN) to host the NC Rare Disease Day at the North Carolina Legislature. What has been known in the past as HNC Legislative Day is a two-part event that takes place each year and is scheduled around the North Carolina Legislative Session dates.

The first part of the event is a training dinner that takes place the evening before meeting with legislators. This year’s dinner took place at the Tobacco Road Sports Cafe in Raleigh. Members of several NC rare disease organizations came together for a night of training. The evening started off with introductions, followed by presentations to go over what to expect during legislative meetings, best practices for meeting with legislators, and the main talking points for advocates to discuss with their representatives. There was also plenty of time for practice and role-playing, so participants could take their time and gain confidence before their meetings the next day.

Nathan Schaefer from the National the Hemophilia Foundation (NHF) provided a lot of great information to members about what to expect during their meetings along with a list of things to do and what not to do, and staff from HNC along with Kathleen Henry, Ambassador of NC RAN, introduced the main talking point of the day: Medicaid Expansion. While the overreaching goal of the day is to continue to build relationships between HNC members and their legislative representatives, one goal of this year’s event was to help legislators understand why Medicaid Expansion is important to people with rare diseases.

The next morning, 38 rare disease constituents and supporters gathered at a booth on the Halifax Mall in Raleigh. Advocates broke into small groups, and visited 33 different legislative offices to spread awareness about people with bleeding disorders and other rare diseases, and to tell legislators why Medicaid expansion is important. In addition, several legislators and their staff members stopped by the booth for free coffee and lunch, and to learn more about people with rare diseases and medical conditions in North Carolina.

HNC encourages everyone to become an advocate and go to Raleigh for HNC’s next Legislative Day or NC Rare Disease Day. If Raleigh is too far, you can be an advocate in your own neighborhood by visiting your legislator’s local office and telling your story. If you’re not sure how to contact your legislator, please call the HNC office for assistance.

To join HNC’s advocacy efforts, we encourage you to be proactive and participate on our monthly advocacy committee calls. You may also register for the advocacy committee email list for continuing updates about advocacy initiatives by emailing info@hemophilia-nc.org or calling the HNC office at (800) 990-5557 to get involved!
Q & A with HNC’s New Advocacy Chair, Kimberly Ramseur

Hemophilia of North Carolina (HNC) would like to take this opportunity to welcome its new Advocacy Chair, Kimberly Ramseur, and thank outgoing Advocacy Chair, Matthew Igelman, for his dedicated service to the position these past years. Read below for a brief introduction to Kimberly.

What is your hometown? Gastonia
What is your current city? Gastonia
What inspires you to advocate for the bleeding disorders community?

People often ask me, why or how I became an advocate for those living with bleeding disorders. I like to believe advocacy chose me.

When I was younger, my mother told me about the story of her older brother who passed away when he was 8 years old; he had hemophilia. At the time, I didn’t really understand what that meant or the significance it would have on my family. I didn’t know of any other relatives with the bleeding disorder, it was as if it randomly appeared and then somehow went away. Years later, it resurfaced when a close relative was diagnosed at birth. I recall the bruises, the swollen joints, visits to the doctor, and the weary faces that were noticeably, but not purposefully visible. What I don’t recall, were the opportunities to connect with other families or access to vital information impacting bleeding disorders, i.e., health insurance, access to care. I honestly don’t know if my relatives even knew such programs or entities existed. Caring for a loved one with any disorder can be overwhelming at times; living with a disorder brings about its own challenges—so having a voice and letting your voice be heard can be difficult, not to mention trying to manage day-to-day activities.

Years ago, I heard someone say in reference to advocacy, “If you’re not present at the table, you’re the first to get cut.” The quote has stuck with me ever since. It’s simple, yet so true. Bleeding disorders are often so rare, that if you don’t make it part of the discussion people will forget they exist and will offer little to no protections when most needed. My mission is to make sure that never happens. We may be small, but we are powerful. I not only believe that to be true, but I’ve seen it. I see the fight in everyone from those living with bleeding disorders to their caregivers. I see my nephews and I see my sister and brother-in-law and our entire family, near and far, come together as one; united through blood, advocates by choice. We come from a long history of trailblazing advocates. They started the fight, passed the torch and now it’s up to us keep it going for future generations.

Any additional comments?

I’m delighted to be amongst such an amazing group of people at HNC and I look forward to building and advocating with you!

We’re Rare and We Matter

Did you know that February 28 was Rare Disease Day? Well, for much of the community, every day is rare disease day. But on February 28, individuals and organizations around the world come together to raise awareness of the 7,000 rare diseases. In the United States, the National Institutes of Health estimates that there are 25-30 million people living with rare disorders. Hemophilia of North Carolina (HNC) partnered with the National Organization for Rare Disorders and their NC Rare Action Network for a Rare Disease Day 2019, which can be found on page 20.

Charlene Cowell, HNC Executive Director, also had an opportunity to present at a Rare Disease Day event at Syneos Health. Other presenters included NC Representative Becky Carney; Moke Sharma, Head of Development Operations, Alexion Pharmaceuticals; Peter J. Pitts, President and Co-founder, Center for Medicine in the Public Interest and Former FDA Associate Commissioner for External Relations; Tara J. Britt, Associate Chair, NC Rare Disease Network/Advisory Council and Development Officer, UNC Medicine; Leslie Nelson-Bernier, President, Medical Foundation of NC & Associate Dean for Development, UNC School of Medicine;
NC Medicaid Expansion Advocacy Day
February 27, 2019
Raleigh, NC

On February 27, North Carolinians from the mountains to the sea joined together to advocate for Medicaid Expansion. With over 200 people in attendance, and organizations like Hemophilia of North Carolina (HNC) represented, advocates began their day hearing from a variety of speakers about the importance of expanding Medicaid. Speakers included Representative Verla Insko and the North Carolina (NC) Department of Health and Human Services Secretary, Dr. Mandy Cohen. There was a special message from NC Governor Roy Cooper, expressing his support for this important issue. Attendees also had a chance to hear powerful stories from a panel of individuals that have either personally suffered or had family members suffer as a result of the healthcare gap caused by the lack of expansion in NC’s Medicaid Program. After empowering attendees to share their stories, it was time to do just that. It must have been a sight to see as these hundreds of advocates walked down the street towards the legislative building to meet with their representatives and senators to share why Medicaid Expansion is important to them.

Educational Scholarships Available: Deadlines Approaching
continued from page one

an applicant pursuing education in a health related field. The application deadline is May 1. Contact the HNC office or visit the HNC website for an application or if you need more information.

In addition to the HNC Education Scholarships members can find more scholarship opportunities using the resources listed below (see the HNC website for more information). Also, students’ high school guidance counselors or college financial aid officers can be excellent resources to assist members with finding monies for continuing education.

• Beth Carew Memorial Scholarship from Colburn Keenan Foundation: visit www.colkeen.org/?page_id=123
• Hemophilia Federation of America website Programs & Services: visit www.hemophiliafed.org/programs/educational-scholarships
• LA Kelley Communications, Inc.: visit www.kelleycom.com/scholarships
• National Hemophilia Foundation website Community Resources: visit www.hemophilia.org/Community-Resources/Scholarships
Hemophilia of North Carolina
2019 Calendar of Events Highlights

April 4-7, 2019
HFA Symposium – San Diego, CA

April 16, 2019
World Hemophilia Day Celebration - Charlotte, NC

April 27, 2019
Charlotte Family Festival & Walk for Bleeding Disorders – Charlotte, NC

May 31-June 2, 2019
Adult Retreat – Greensboro, NC

June 29-July 2, 2019
HNC/HSC Teen Retreat – Rock Hill, SC

July 26-28, 2019
Blood Brotherhood Retreat – Pine Knoll Shores, NC

August 17, 2019
Family Day Out – Clemmons, NC

September 7-8, 2019
Family Retreat – Concord, NC

October 3-5, 2019
NHF Annual Meeting – Anaheim, CA

October 12, 2019
Raleigh Family Festival & Walk for Bleeding Disorders – Morrisville, NC

December 7, 2019
Holiday Celebration – Location TBD, NC

Stay empowered by the possibilities.

References:
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.